



National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia

# Draft Administration and Technical Report

Draft Guideline for public consultation Consultation period: 18 July 2022 – 29 August 2022 Have your say at <u>autismcrc.com.au/supporting-children</u>

# Guideline Development Group

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**Suggested citation:** Trembath, D., Varcin, K., Waddington, H., Sulek, R., Pillar, S., Allen, G., Annear, K., Eapen, V., Feary, J., Goodall, E., Pilbeam, T., Rose, F., Sadka, N., Silove, N., Whitehouse, A. (2022). *National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia: Draft Guideline for public consultation*. Autism CRC. Brisbane.

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# Acknowledgements

The Guideline Development Group warmly acknowledges the following people who have contributed to the development of Guideline.

# Children, families, and community

We warmly acknowledge and thank the children, families, and members of the autistic and autism communities who have so generously shared their experiences, insights, views, and expertise to inform the development the Guideline. This includes participation in the original studies included in the systematic reviews undertaken as part of the development, participating in the community consultation activities, and providing feedback on the Draft Guideline.

### **Research** assistants

We warmly acknowledge and thank the research assistants who contributed their expertise to coding the information that was collected through the community consultation process. The team included Briohny Dempsey (Telethon Kids Institute), Georgina Earl (Telethon Kids Institute), Libby Groves (Griffith University), Emma Hinze (Griffith University), and Rachelle Wicks (Griffith University).

## **Reference Group**

We warmly acknowledge and thank the members of the Reference Group, each of whom represented an organisation that is relevant to supporting the learning, participation, and wellbeing of autistic children and their families. The names of all members of the Reference Group, and their organisations they represented are presented in Chapter 2.

### Further assistance

We warmly acknowledge and thank the following people who contributed their expertise to the development of the Guideline. The following people provided advice in relation to the community consultation activities: A/Prof Jenny Cartmel (Griffith University), Dr Marilyn Casley (Griffith University), and Prof Sharynne McLeod (Charles Sturt University) who provided advice in relation to the children and young people consultation activities, A/Prof Zachary Munn who provided advice in relation to GRADE methodology, and Dr Kiah Evans and Dr Bahareh Afsharnejad who provided AGREE-II ratings on a draft of the Guideline. The following people contributed to the preparation of community consultation activities: Dr Emmah Baque (Griffith University), Dr James Best (Junction Street Family Practice), Kelly Clark (Centre for Social Impact, University of Western Australia), Georgia Davies (Victoria University of Wellington), Rhiannon Latham (Queensland Department of Education), Antonina Loncarevic (CliniKids, Telethon Kids Institute), Meghan McAnany (Griffith University), Claire Perrozzi (CliniKids, Telethon Kids Institute), Amanda Porter (personal contribution) Shaun Ruigrok (personal contribution), and Carla Wallace-Watkin (Victoria University of Wellington). The following people at Autism CRC contributed to sharing information with the community about the Guideline development process, hosting online activities (e.g., webinars), and preparing the documents (graphic design, copyediting): Cally Jackson, Jason Kotzur, Darcy Maguire, and Sally Vidler.



# 1. Introduction

This chapter outlines the purpose and contents of this report.

### 1.1 Purpose of this report

The purpose of this report is to outline the administrative aspects of the Guideline development process and a detailed summary of the methodology. This report is currently in draft form to support public consultation on the Draft Guideline and will be updated with further information regarding the final stages of the Guideline development process.

### 1.2 Overview of information presented

This report comprised the following chapters:

- 1. Acknowledgements
- 2. Introduction
- 3. **Project Administration.** This chapter provides a summary of the Guideline questions, the people involved in its development, project governance, and the Public Consultation process.
- 4. **Research Methodology.** This chapter provides a summary of the systematic process used to move from Guideline questions to the collection and synthesis of evidence from a variety of sources, through to the formulation of recommendations and the production of the Guideline and associated documents.
- 5. **Scoping Review of Existing Guidelines.** This chapter presents the aims, method, and results of this systematic review of previously published guidelines from around the world.
- 6. Umbrella Review: Effects of Non-pharmacological Supports on Child and Family Outcomes. This chapter presents the aims, method, and results of this umbrella review (review of reviews) to examine the effects of a variety of non-pharmacological supports.
- 7. Systematic Review of Individual and Family Experiences of Accessing Services. This chapter presents the study aims, method, and results of this systematic review to examine the experiences of autistic children and families accessing supports in Australia.
- 8. **Community Consultation: Online Survey.** This chapter presents the aims, method, and results of this study seeking the views of all members of the autistic and autism communities.
- 9. **Community Consultation: Focus Groups.** This chapter presents the study aims, method, and results of this study seeking the views and experiences of autistic adults and parents of autistic children.



- 10. **Community Consultation: Delphi Study.** This chapter presents the study aims, method, and results of this study seeking the views of practitioners.
- 11. **Community Consultation: Brief Online Survey.** This chapter presents the study aims, method, and results of this study seeking the views of autistic children, young people, and adults.
- 12. **Community Consultation: Parent Reflection.** This chapter presents the study aims, method, and results of this study seeking parents' reflections on the experiences of their autistic children.
- 13. **Community Consultation: Expression Through Artwork.** This chapter presents the study aims and methods that was designed to the seek the views of autistic children, young people, and adults.

# 2. Project Administration

## 2.1 Chapter overview

This chapter provides a summary of how the Guideline development project was administered. It begins with a statement of the purpose of the Guideline, scope, and target users to provide context for readers, drawing on the same information presented in the Draft Guideline document. This chapter also includes a summary of the people involved in the Guideline development process, project governance, and the process for obtaining feedback on the Draft Guideline through the Public Consultation process.

## 2.2 Guideline objectives

The specific objectives were to develop a Guideline that:

- 1. Describes an evidence-based practice framework for providing supports to autistic children aged 12 years or younger and their families.
- 2. Contains sufficient flexibility to apply to all children regardless of their age, gender, communication or intellectual capacity, cultural or language background, or where they live in Australia.
- 3. Is feasible for clinical practitioners to implement across the full breadth of clinical or community settings in Australia.
- 4. Meets the needs and expectations of children and families receiving the supports.



# 2.3 Guideline scope

The scope of the Guideline was determined prior to the commencement of the research and community consultation activities. The scope of the Guideline is provided in Table 2.1.

Table 2.1. The scope of the Guideline

Aspect	In scope	Out of scope	
Recipients of supports	Children aged 12 years or younger with an autism diagnosis and their family members.	Children and families not meeting this criteria.	
		Pharmacological therapies and other biological-based therapies.	
	Focused on directly supporting the learning, participation, and wellbeing of autistic children, including through addressing environmental and contextual barriers.	Focused on broader aspects of family functioning, including parental mental health.	
Delivered within a clinical or community setting.		Specifically designed for delivery in a medical, primary school, or high school settings.	
Outcomes targeted by supports	Learning, participation, and wellbeing.	Outcomes related to conditions that co- occur with autism (e.g., sleep, gastrointestinal function, mental health).	

## 2.4 Guideline target users

The primary target users of this Guideline are practitioners working in Australia who are involved in the planning, selection, delivery and/or monitoring of supports for autistic children and their families.

Secondary target users of this Guideline include the following groups:

- Autistic children and their families can use this Guideline to understand an evidencebased practice framework for accessing and receiving supports.
- Service providers can use this Guideline to align resource allocation with an evidence-based practice framework.
- Australian training providers, including peak bodies and tertiary education institutions, can use this Guideline to tailor clinical and educational resources, courses and qualifications to ensure practitioners achieve the learning outcomes required for the planning, selection, delivery and monitoring of supports.
- Governmental bodies can use this Guideline to make evidence-based policy decisions regarding funding and provision of supports, based on consensus-based recommendations that are relevant to the Australian autistic and autism communities.



# 2.5 Guideline funding

Autism CRC funded the development of the Guideline and its publication. Andrew Whitehouse (Telethon Kids Institute, University of Western Australia) and David Trembath (Griffith University, Telethon Kids Institute) were appointed Co-chairs of the Guideline Development Group (GDG), and their respective institutions received funding from Autism CRC to support this work. Andrew Whitehouse's and David Trembath's contributions were in-kind, with funding used to employ research fellows/assistants to support the work, to support community consultation activities, and honorariums for the Guideline Development Group and Reference Group members.

## 2.6 Process for ensuring editorial independence from funders

The GDG had complete editorial independence from Autism CRC in developing the Guideline, with each entity having clearly defined roles and responsibilities. In chronological order, the mechanisms to ensure editorial independence included:

**Conceptualisation:** Members of the GDG (Rhylee Sulek, David Trembath, Kandice Varcin, Hannah Waddington, Andrew Whitehouse) initially proposed the development of a guideline as one of the recommendations arising from a research review of evidence for the effects of non-pharmacological supports for autistic children and their families. This research was commissioned by the National Disability Insurance Agency and supported by Autism CRC (Whitehouse et al., 2020).

**Commissioning:** Autism CRC invited Andrew Whitehouse and David Trembath to submit a proposal for the development of a guideline, which was ultimately approved by the Autism CRC board. Andrew Whitehouse and David Trembath consulted with Autism CRC regarding aims, scope, and representation, but retained complete independence in all aspects of the proposal.

**Funding agreements:** Autism CRC engaged University of Western Australia/Telethon Kids and Griffith University via formal funding agreements. The funding agreement stipulated that each party would ensure that research was conducted in accordance with the Australian Code for the Responsible Conduct of Research (National Health and Medical Research Council [NHMRC], 2018), which highlights the importance of honesty, rigor, and transparency: all of which rely on editorial independence.

**Conduct:** The GDG were responsible for all aspects of project design and delivery. Autism CRC involvement was limited to (a) receiving updates on progress towards agreed project milestones in accordance with the funding agreements and (b) facilitating the community consultation through sharing information (e.g., overview of activities, invitations to participate) via the Autism CRC website and database, and via social media. The GDG were responsible for drafting the information that Autism CRC shared with the community. All research activities were approved by the Griffith University Human Research Ethics Committee and implemented using Griffith University research infrastructure (e.g., Microsoft Teams for focus groups, REDCap for online surveys). Autism CRC was not involved in evidence synthesis nor formulation or refinement of the recommendations.



**External consultation:** The GDG were responsible for all consultation regarding the contents of the Guideline, including liaising with and incorporating feedback from the Reference Group.

**Draft Guideline:** The GDG were responsible for drafting the Guideline. Autism CRC had access to a copy of the Draft Guideline as it was developed to assist with formatting and graphic design. Autism CRC had authority to make changes to the formatting (e.g., organisation branding) and phrasing (e.g., in order to prepare plain language summaries in consultation with the GDG and to improve accessibility) but did not have authority to make changes to the meaning of any statement or recommendation in the Guideline.

**Draft Guideline public consultation:** Autism CRC will promote the consultation, but the GDG, using Griffith University infrastructure, will be responsible for all other aspects of consultation including receiving and responding to feedback.

**Guideline finalisation:** The GDG will be responsible for any further changes to the Guideline. Autism CRC's role will be limited to production (e.g., copy editing, formatting).

**Dissemination:** Autism CRC will announce and promote the Guideline. The GDG will contribute to dissemination activities but will maintain editorial independence in relation to the nature of those activities (e.g., content of presentations).

# 2.7 Guideline Development Group

The Guideline Development Group was established in accordance with the National Health and Medical Research Council (NHMRC, 2011) requirements to lead the research and community consultation process.

### **Terms of Reference**

The Terms of Reference are presented in Appendix 2.1 and include the following information about the project:

- Background.
- Purpose of the Guideline Development Group.
- Anticipated timeline.
- Membership of the Guideline Development Group.
- Appointment of Chair.
- Responsibilities of Project Team Members.
- Meetings.
- Code of conduct for the Project Team.
- Reporting.

The Terms of Reference were signed by each GDG member ahead of the first meeting. Meetings were held monthly from November 2021 to June 2022 (and will continue monthly until September 2022).



### Recruitment

The members of the GDG were identified and appointed via a three-stage process.

- 1. In the first stage, the Co-chairs identified a range of perspectives that were critical to the development of this Guideline which focuses on autistic children's learning, participation, and wellbeing, as well as the wellbeing of their families. These perspectives included lived expertise (autistic people and parents), professional expertise (medical and allied health), expertise in working alongside Aboriginal and Torres Strait Islander communities, and expertise in human ethics. The Co-chairs also identified research expertise that would be relevant, including in relation to codesigned research, systematic reviews, community consultation, and Guideline development.
- 2. In the second stage, the Co-chairs identified people who had knowledge, skills, and experience relevant to each of these required perspectives, and distributed invitations via email. Consideration was given to ensuring diversity within the GDG. The email included an introduction to the project and Terms of Reference. The Co-chairs made themselves available to meet with invitees to discuss the Terms of Reference.
- 3. In the third stage, the invitees returned the signed Terms of Reference to confirm their role within the GDG.

#### Members

The members of the GDG, including name, position, affiliation, role, and expertise are presented in Table 2.2.

Name	Position, affiliation, role, and expertise
Prof Andrew Whitehouse (Co-chair)	Andrew Whitehouse is a Speech Pathologist and Angela Wright Bennett Professor of Autism at the Telethon Kids Institute and the University of Western Australia. Andrew is also the Director of CliniKids, a clinical research centre of excellence for autistic children, and is Autism CRC's Research Strategy Director. He brings over 20 years' clinical research experience in working with autistic children and their families. He also brings experience in Guideline development, having chaired the development of the National Guideline for the Assessment and Diagnosis of Autism in Australia. Andrew was the Co-chair of the Guideline Development Group.
A/Prof David Trembath (Co-chair)	David Trembath is an Associate Professor in Speech Pathology at the Menzies Health Institute Queensland, Griffith University and Honorary Research Fellow at CliniKids, Telethon Kids Institute. He brings over 20 years' of clinical-research experience working with autistic children and their families. David was the Co-chair of the Guideline Development Group.

**Table 2.2.** Members of the Guideline Development Group.



Dr Kandice Varcin	Dr Kandice Varcin is a Research Fellow at the Menzies Health Institute Queensland, Griffith University. She is also a registered psychologist who brings experience and expertise in research focused on autism, early development and the evaluation of therapies and supports for young children and their families.		
Dr Hannah Waddington	Dr Hannah Waddington is a senior lecturer at Victoria University of Wellington and the Clinic Lead of the Victoria University of Wellington Autism clinic. She is also a practicing educational psychologist who brings experience in provision of early support to autistic children and their families.		
Dr Rhylee Sulek	Dr Rhylee Sulek is a Research Fellow within the School of Health Sciences and Social Work, Griffith University. She brings experience in working with young autistic children and their families when receiving early supports and therapies, and the inclusion of key stakeholders in the co-production of research.		
Ms Sarah Pillar	Sarah Pillar is the Integration Project Manager at CliniKids, Telethon Kids Institute. She has a professional background in Speech Pathology and brings experience in providing clinical services to autistic children and their families. Sarah is a PhD candidate through the University of Western Australia.		
Mr Gary Allen Gary Allen is the Senior Policy Officer Human Research Ethics and Research In Griffith University. Gary has worked in the human research ethics area since 19 with a number of research institutions, state and federal departments, private of and research ethics committees internationally. He also has a degree in education professional doctorate in social sciences. Gary brings extensive experience in the national and international governance of ethical conduct in research.			
Mx Katharine AnnearMx Katharine Annear is a founding member of the Autistic Self Advocacy Network Australia and New Zealand, a registered Developmental Educator, and Casual A at Flinders University. They bring lived experience as an Autistic person who also numerous Autistic family members, and are a passionate advocate for co-design research and public policy and the translation of research and policy into meaning practice for disabled people.			
Prof Valsamma Eapen	Professor Valsa Eapen is the Chair of Infant, Child and Adolescent Psychiatry at the University of New South Wales. An internationally-recognised child psychiatrist and researcher, Valsa's expertise combines extensive experience in childhood mental health and developmental disorders from a clinical and basic science research perspective.		
Ms Jessica FearyJess Feary is the Victoria and Tasmania Coordinator for Positive Partnerships. Sh background in occupational therapy and public health and brings over 15 years' experience working with neurodiverse people and their families in clinical, resear and educational settings.			
Dr Emma Goodall	Dr Emma Goodall is an autistic author, advocate, qualified meditation and mindfulness teacher and adjunct research fellow at the University of Southern Queensland. She is the Manager for Content & Research for Positive Partnerships and also runs Healthy Possibilities, a consultancy offering personal life coaching alongside autism specific continuing professional development for educators and families and NDIS services (many with a link to interoception). Emma speaks widely on the topic of interoception and the role mindful body awareness plays in emotional regulation.		



Ms Teresa Pilbeam	Teresa Pilbeam is a special education teacher, an advocate for informal family carers, and has worked alongside First Nations peoples across Australia. Teresa has 30 years' experience in special education, contributed to carer and disability reform for over 10 years, is an Independent Director on government and profit-for-purpose state and federal councils and boards, and has a lived experience of autism spectrum and complex disability. Teresa brings experience and expertise of governance, ways of working with Aboriginal and Torres Strait Islander Peoples, and an enthusiasm for enabling the voice of informal family carers to be heard in cross-sector conversations.				
Dr Felicity Rose	Felicity Rose is a Project Manager at Telethon Kids Institute. Her current project is to further implement the National Guideline for the Assessment and Diagnosis of Autism into clinical practice. She has a professional background in science and research and is also the parent of a young person on the autism spectrum.				
Dr Nancy Sadka	Dr Nancy Sadka is a Research Fellow at the Olga Tennison Autism Research Centre, La Trobe University. She works in the early identification and diagnosis of autism and is an advocate for families and children on the spectrum over the life span. She also is the mother of two autistic children and brings to the GDG over 25 years' of lived experience.				
Dr Natalie Silove	Dr Natalie Silove is a Clinical Associate Professor in the Discipline of Paediatrics and Child Health, University of Sydney and Senior Lecturer (Conjoint) at the School of Psychiatry (UNSW). She is also the Head of Child Development Services; Senior Staff Specialist, Child Development Unit at The Children's Hospital Westmead. She brings over 30 years' experience working with children and young adults with special needs, their families and schools.				

#### **Roles within the GDG**

All members of the GDG contributed to decision-making in relation to the design, development, and delivery of the Guideline and associated documents. This included reviewing materials, engaging in discussion at monthly GDG meetings, and endorsing the final versions of these documents.

Within the GDG, six members were responsible for developing and progressing the core research and development activities, including designing and completing systematic reviews, community consultation activities, and the Evidence to Decision (EtD) process (described in subsequent chapters): Sarah Pillar, Rhylee Sulek, David Trembath, Kandice Varcin, Hannah Waddington, and Andrew Whitehouse. Sarah Pillar, Rhylee Sulek, Kandice Varcin, and Hannah Waddington held salaried positions, while David Trembath and Andrew Whitehouse made substantial in-kind contributions. Each member contributed to all activities, while taking leadership of one or more activities. Specifically, Sarah Pillar led the systematic review of existing guidelines. Rhylee Sulek led the systematic review of child and family experiences, as well as community consultation involving the online survey and focus groups. Kandice Varcin led the Delphi survey of practitioners. Hannah Waddington led the systematic review of the effects of non-pharmacological supports on child and family outcomes.



### **Declaration of Interests**

The following process was adopted to ensure the declaration and management of any competing interests, in accordance with the NHMRC Guidelines for Guidelines (2016):

#### Develop a conflict-of-interest policy

The following information constitutes the conflict-of-interest policy used in the development of the Guideline.

#### Determining if an interest is a conflict of interest

Members of the GDG who were directly responsible for the design and conduct of research activities (Sarah Pillar, Rhylee Sulek, David Trembath, Kandice Varcin, Hannah Waddington, Andrew Whitehouse) each disclosed conflicts of interest using the International Committee of Medical Journal Editors (ICMJE) Disclosure of Potential Conflicts of Interests form (https://journals.sagepub.com/pb-assets/cmscontent/HPQ/coi\_disclosure.pdf) at the outset of the project, and these forms were made available to one another to review. No major conflicts of interest were identified. All members of the GDG were required to complete the same form prior to having input into the drafting of Guideline recommendations. GDG Co-chairs reviewed all forms and identified processes that would be put in place if required (e.g., self-abstaining or asking group member to abstain from one or more aspects of the guideline development process).

#### Appoint an independent chair

Autism CRC invited Andrew Whitehouse and David Trembath to act as Co-chairs based on their experience and demonstrated track record of co-designed and ethical research in related projects that included the development of the NHMRC endorsed National Guideline for the Assessment and Diagnosis of Autism in Australia (Andrew Whitehouse; Whitehouse et al., 2018) and the NDIA commissioned synthesis of evidence for non-pharmalogical supports for autistic children and their families (Andrew Whitehouse and David Trembath; Whitehouse et al., 2020). The Co-chairs have no financial interests relevant to the Guideline to declare, and all interests were declared in full to Autism CRC (and published online for the broader community) as part of the process of conducting and reporting the NDIA commissioned research.

#### Select development group candidates

As indicated above, members of the GDG were selected through a process that involved the Co-chairs first identifying perspectives and expertise that are critical to the development of the Guideline, and then inviting relevant people.

#### **Disclose interests throughout development**

All GDG and Reference Group members were required to declare any potential conflicts of interest that arise during the guideline development process by (a) updating their form and (b) notifying the Co-chairs at the start of the following meeting (standard agenda item). GDG members were advised to notify the Co-chairs of any changes in their declarations, prior to



providing feedback on any documents outside of GDG meetings (e.g., feedback on the Draft Guideline). The exceptions to this approach were members of the GDG directly involved in day-to-day work on the Guideline (Sarah Pillar, Rhylee Sulek, David Trembath, Kandice Varcin, Hannah Waddington, Andrew Whitehouse) who were required to notify this same group of any new disclosures as they arose and no later than the next weekly working group meeting.

#### Manage conflicts of interest

It was planned that conflicts arising would be managed according to recommendations in the NHMRC Guidelines for Guidelines (2016) including members recusing themselves and/or being excluded from aspects of the guideline development process, removing a member from the GDG should a serious breach in relation to disclosures occur, and refusing sponsorship where a conflict exists. All decisions were to have been discussed and documented within the GDG and published in the technical manual that accompanies the Guideline. It is noted that these actions have not been required during the development of the Draft Guideline.

#### Publish declarations of interest in the Guideline

The declarations of interests for all GDG members are provided in Appendix 2.2.

#### **Guideline Development Group meetings**

The GDG met via videoconference on a monthly basis from November 2021 to July 2022. Additional monthly meetings are scheduled for August and September 2022. Each meeting followed an agenda, focusing on (a) updates on Guideline activities and (b) discussion and decision-making within the GDG. Minutes of each meeting, along with a rolling record of actions arising and any supporting documents, were circulated between meetings.

The primary focus of each meeting was:

**November 2021:** Introduction of members, project overview, confirming processes for governance and communication, overview of methodology, and review of proposed timeline.

**December 2021:** Presentation and discussion of proposed methodology for community consultation.

**January 2022:** Progress report on systematic reviews and review of draft versions of the community consultation survey and Delphi survey.

**February 2022:** Progress report on systematic reviews, and review of new drafts of the online survey and Delphi survey.

**March 2022:** Progress report on systematic reviews, progress report on online survey and focus groups, and discussion of additional consultation activities (brief survey, expressions through art, reflection survey).

**April 2022:** An email update to GDG members providing a progress report on all research and community consultation activities.



**May 2022:** Presentation of the Evidence to Decision (EtD) process and discussion of draft Recommendations and Good Practice Points.

June 2022: Presentation and review of the Draft Guideline.

**July: 2022:** Presentation and discussion of the Draft Guideline Public Consultation process and draft Dissemination and Implementation Plan.

# 2.8 Reference Group

The Reference Group was established to support the work of the GDG, by providing insight and advice on matters relevant to their constituents. The Reference Group comprised representatives from organisations with members that play a critical role in supporting aspects of children's health, development, education, participation, and wellbeing, and/or supporting parents and families in raising autistic children; that represent Aboriginal and Torres Strait Islander Peoples and represent Culturally and Linguistically Diverse (CALD) communities; as well as from the key Government agency, the National Disability Insurance Agency.

### Terms of reference

The Terms of Reference are presented in Appendix 2.3 and include:

- Background (to the project).
- Purpose (of the Guideline Development Group).
- Anticipated timeline for the project.
- Membership of the Reference Group.
- Appointment of Chair.
- Responsibilities of Project Team Members.
- Meetings.
- Code of conduct for the Project Team.
- Reporting.

The Terms of Reference were signed by each Reference Group member ahead of the first of three meetings held during the Guideline development process in February, May and July 2022.

### Recruitment

The members of the Reference Group were identified and appointed via a three-stage process.

 In the first stage, the Co-chairs identified a range of critical aspects of children's health, development, education, participation, and wellbeing that are relevant to the Guideline, alongside aspects related to supporting parents and families in raising autistic children. The Co-chairs also identified the need for representation of



Aboriginal and Torres Strait Islander Peoples, representation of culturally and linguistically diverse communities, and representation from the key Government agency: the National Disability Insurance Agency.

- 2. In the second stage, the Co-chairs identified organisations, peak bodies, and agencies that are relevant to each of the aspects identified and sent an email invitation to a representative (typically CEO) of each organisation, peak body, or agency inviting their participation and requesting they nominate a representative to attend Reference Group meetings. The email included an introduction to the project and Terms of Reference. The Co-chairs made themselves available to meet with invitees to discuss the Terms of Reference.
- 3. In the third stage, the nominees returned the signed Terms of Reference to confirm their role within the Reference Group.

#### Members

The members of the Reference Group are presented in Table 2.3.

Stakeholder group	National peak body	Representative	Position
Autistic people	Autistic Self Advocacy Network – Australia and New Zealand	vork – Australia and meetings)	
Family members of autistic people	Autism Awareness Australia	Autism Awareness Australia Nicole Rogerson	
First Nations peoples	First Peoples Disability Network Australia	Jess Styles	Director, Programs
Culturally and linguistically diverse communities	Federation of EthnicDaniel CoaseCommunities' Council ofAustralia		Senior Advisor
Focusing on children's health	Neurodevelopmental and Behavioural Paediatrics Society of Australasia	Ashanthi Munasinghe	Member
Focusing on children's social-communication development	Speech Pathology Australia	Amy Fitzpatrick	Senior Advisor - Disability
Focusing on children's physical development	Australian Physiotherapy Association	Nicole Haynes	Member
Focusing on children's cognitive development	Australian Psychological Society	Tamara Cavenett	President



Focusing on children's sensory development	Occupational Therapy Australia	Karen Brown	Division Manager (ACT, NSW)
Representing service providers (peak body)	Australian Autism Alliance Frances Scodellaro		Member
Representing services (early childhood)	Relmagine Australia (formerly Early Childhood Intervention Australia)	Early Childhood	
Representing services (education)	Australian Association of Special Education	Patrick Kelly	President
Representing services (rural health)	National Rural Health Alliance	Gabrielle O'Kane	Chief Executive Officer
Representing researchers	Australasian Society for Autism Research	Jessica Paynter	Vice President
Representing policy advisors	Autism Advisory Group to the National disability Insurance Agency	Jim Mullan	Member
Government National Disability Insurance Agency		Sam Bennett	General Manager Policy, Advice and Research

### **Declared Interests**

The process for declaring interests and managing conflicts of interest was the same as outlined in relation to the GDG above. This included members completing declaration of interests forms which are presented in Appendix 2.4. Given that the Reference Group did not input into the formation of the draft Recommendations, some flexibility was given for members to complete their Declarations of Interest forms.

### **Reference Group Meetings**

The Reference Group met via videoconference on three occasions (February, May, and July 2022). Each meeting followed an agenda, focusing on (a) updates on Guideline activities and (b) discussion of these activities. Minutes of e ach meeting, along with a rolling record of actions arising and any supporting documents, were circulated between meetings.

The primary focus of each meeting was:

February 2022: Introduction of members, project overview, confirming processes for governance and communication, overview of methodology, and review of proposed timeline.



May 2022: Summary of progress towards the development of the Guideline, including research and community consultation activities, and review of upcoming stages of Guideline development.

July 2022: Summary of Draft Guideline documents, Draft Guideline Public Consultation process, and review of subsequent stages of Guideline development.

# 2.9 Other people who contributed to the Guideline development.

Table 2.4 presents the names, roles, expertise, and organisational affiliation of additional people who contributed to the Guideline development.

Name	Discipline/Expertise	Organisation	Role
Briohny Dempsey	Occupational therapy	Telethon Kids Institute	Research assistant
Georgina Earl	Neuroscience	Telethon Kids Institute	Research assistant
Libby Groves	Speech pathology	Griffith University	Research assistant
Emma Hinze	Psychology	Griffith University	Research assistant
Rachelle Wicks	Psychology	Griffith University	Research assistant
A/Prof Jenny Cartmel	Social work	Griffith University	Consulted on children and young people consultation
Dr Marilyn Casley	Social work	Griffith University	Consulted on children and young people consultation
Prof Sharynne McLeod	Speech pathology	Charles Sturt University	Consulted on children and young people consultation
Dr Emmah Baque	Physiotherapy	Griffith University	Piloted community consultation activities
Dr James Best	General Practitioner	Junction Street Family Practice	Piloted community consultation activities
Kelly Clark	Personal contribution	University of Western Australia	Piloted community consultation activities
Georgia Davies	Clinic manager	Victoria University of Wellington	Piloted community consultation activities
Rhiannon Latham Occupation therapy		Queensland Department of Education	Piloted community consultation activities

 Table 2.4 Additional contributors to the Guideline development.



Antonina Loncarevic	Clinical Psychology	Telethon Kids Institute	Piloted community consultation activities		
Meghan McAnany	Personal contribution	Griffith University	Piloted community consultation activities		
Claire Perrozzi	Speech Pathology	Telethon Kids Institute	Piloted community consultation activities		
Amanda Porter	Personal contribution	Personal contribution	Piloted community consultation activities		
Shaun Ruigrok Personal contribution Personal contribut		Personal contribution	Piloted community consultation activities		
Carla Wallace- Watkin	PhD student	Victoria University of Wellington	Piloted community consultation activities		
Cally Jackson	Marketing and Communications	Autism CRC	Community engagement regarding Guideline		
Jason Kotzur	Marketing and Communications	Autism CRC	Community engagement regarding Guideline		
Darcy Maguire	Marketing and Communications	Autism CRC	Community engagement regarding Guideline		
Sally VidlerMarketing and Communications		Autism CRC	Community engagement regarding Guideline		

# 2.10 Consumer representation

The following processes were used to ensure consumers (i.e., members of the autistic and autism communities) were involved in the development of the Guideline.

**Guideline Development Group:** Multiple people with lived expertise of autism were invited to be members of the GDG. One member is autistic, one member is autistic as well as a parent of autistic children, two members are parents of autistic children, and two members are second-degree relatives of autistic children.

**Reference Group:** Two organisations were specifically invited to join the Reference Group. The Autistic Self Advocacy Network – Australia and New Zealand is run by and represents autistic people. Autism Awareness Australia is run by and represents parents and other family members of autistic people.

**Community consultation activities:** A series of research studies were conducted as part of the Guideline development process to inform the recommendations. These were separate to the Public Consultation on the Draft Guideline and were used to gather evidence to inform the drafting of recommendations. The activities included:

• Focus groups for autistic people and parents of autistic children.



- An online community survey that was open to all members of the community including autistic people and family members.
- A brief survey, an expression through art activity, and a parent reflection activity that were designed specifically for autistic children and young people, as well as autistic people of all ages who communicate mainly in ways other than speech.

# 2.11 Involvement of Aboriginal and Torres Strait Islander Peoples and culturally and linguistically diverse communities

For a Guideline to serve the needs of all Australians, it is critical that the guideline development process gives particular consideration to issues related to Aboriginal and Torres Strait Islander Peoples and culturally and linguistically diverse communities. These considerations include recognising the enduring impact of historical injustices, discrimination, and marginalisation of Aboriginal and Torres Strait Islander Peoples; the importance of understanding and embracing culturally-bound understandings of child development, family, child-rearing practices, and disability; and the need to ensure that every Australian has access to culturally-responsive and appropriate health and education services, delivered by people with appropriate knowledge, skills, understanding, and experience. The GDG took the following steps to ensure the Guideline Recommendations were responsive to these and other considerations relevant to these peoples and communities:

- One member of the GDG (Teresa Pilbeam) was specifically appointed based on significant experience and expertise in working with Aboriginal and Torres Strait Islander Peoples and communities.
- The Reference Group included representatives from the peak organisation serving the health of Aboriginal and Torres Strait Islander Peoples, and the peak organisation representing Australians from culturally and linguistically diverse populations.
- National Aboriginal Community Controlled Health Organisation (NACCHO)
- Federation of Ethnic Communities' Council of Australia
- In consultation with Teresa Pilbeam (GDG member), the GDG:
- Ensured that 12 organisations that represent and/or work closely with Aboriginal and Torres Strait Islander Peoples received a direct invitation to participate in the community consultation process.
- Established with the National Aboriginal Community Controlled Health Organisation (NACCHO) an understanding that Autism CRC seeks to enter into a long-term partnership with Aboriginal and Torres Strait Islander communities, that will grow over time and support *proper way* collaboration and consultation. Short term agreed outcomes included consultation on the Guideline (as a member of the Reference Group), GDG member participation in a yarning circle in Darwin relating to service



provision within the National Disability Insurance Scheme, and consultation regarding key issues in the provision of supports to Aboriginal and Torres Strait Islander children who are autistic.

• Reviewed key documents to inform the development of the Guideline, including the AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research (2020).



# 3. Guideline Methodology

# 3.1 Introduction

This chapter presents an overview of the research methodology used to develop the Guideline, focusing on application of the GRADE (Grading of Recommendations, Assessment, Development and Evaluations) framework. The detailed methodology and findings of each of the research activities completed as part of the Guideline development process are presented in subsequent chapters.

# 3.2 NHMRC Guidelines for Guidelines

The Guideline development process adhered to the approach described in the *Guidelines for Guidelines* handbook (NHMRC, 2016). The phases of the development included *planning, developing*, and *reviewing* the Guideline. The final phases of *implementing* and *updating* the Guideline are discussed in Chapter 9. In adhering to the handbook, the Guideline Development Process also met the NHMRC Standards for Guidelines:

- Standard 1 Be relevant and useful for decision making
- Standard 2 Be transparent
- Standard 3 Be overseen by a guideline development group
- Standard 4 Identify and manage conflicts of interest
- Standard 5 Be focused on health and related outcomes
- Standard 6 Be evidence informed
- Standard 7 Make actionable recommendations
- Standard 8 Be up-to-date
- Standard 9 Be accessible

# 3.3 GRADE

GRADE provides a systematic approach for developing practice recommendations (Schünemann et al., 2013). The process involves (a) identifying clinical questions, (b) collecting relevant research evidence, (c) using the evidence to answer the clinical questions, and (d) in doing so formulate recommendations. In determining the strength of recommendations, the GDG must consider the certainty of evidence for the recommendation will affect, resource implications, impact on health inequities, acceptability to the people whom the recommendation will affect, and feasibility of implementation. These steps, as applied in this Guideline development process, are outlined below.



## 3.4 Guideline development process

### Step 1: Establishing the Guideline Development Group (GDG)

**Purpose:** The GDG was responsible for developing the guideline questions, gathering evidence through systematic reviews and community consultation, and using the evidence to formulate – and then grade the strength of - recommendations using an Evidence to Decision (EtD) process. The GDG will also be responsible for considering community feedback on the Draft Guideline during the consultation period (July 18 to August 29), making revisions if appropriate, and endorsing the final version for public release.

**Process:** The process for determining the roles, and people who ultimately filled those roles, is presented in Chapter 2. Briefly, it included three stages, the first of which was to identify relevant perspectives to inform the Guideline development process, to identify people who could contribute those perspectives, and then invite participation including agreement with the Terms of Reference.

**People involved:** A detailed description of the 15-member GDG is provided in Chapter 2. Briefly, among the group were autistic adults; parents and other family members of autistic individuals, including children and young adults with complex needs; people with expertise in working alongside Aboriginal and Torres Strait Islander communities; people with expertise in human ethics and research integrity; clinicians with experience in government and non-government sectors; and researchers with expertise in guideline development, including community consultation.

### **Step 2: Defining Guideline questions**

Purpose: Asking relevant questions is critical to the development of a useful Guideline.

**Process:** The GDG formulated a set of questions about key aspects of clinical practice that would be the focus of all research and consultation activities, and ultimately the recommendations. Within GRADE, questions are typically asked using a consistent format that specifies the *population* (P = population of interest), *intervention* (I = intervention/support that is being trialled), *comparison* (C = the alternative to the intervention/support), and *outcome* (O = the outcome of interest). Such questions should be relevant to the community. For instance, a question that seeks to answer whether one type of support for autistic children is more effective than another, could be framed as "In autistic children aged 0-12 years (population), is *Support A* (Intervention) more effective than *Support B* (Comparison), in increasing children's participation in daily activities (Outcome)?" To answer this question, there must be sufficient studies involving the specific population, types of supports, and outcome of interest to enable a meta-analysis to be completed, which involves quantitatively combining data from across studies. However, this situation is uncommon in relation to research involving autistic children and their families for several reasons including:

• Few or no studies available to answer questions that are most relevant to practice.



- Where studies are available, they vary in terms of the participant characteristics; nature, amount, and delivery of supports provided, and how outcomes of interest are measured.
- Where studies are available, they also vary in terms of methodological quality including the clear and complete reporting of data needed to complete metaanalyses.

The challenge with using the PICO format extends beyond consideration of whether empirical evidence is available to answer a particular question. Two broader challenges that were particularly relevant to this Guideline were as follows:

- Many questions parents and practitioners want answered do not align with the PICO format, such as "What are appropriate goals for supporting children and families?" and "How should goals be selected?" Conceivably, if there were two or more studies comparing the appropriateness of goals developed using two different methods, it would be possible to compare them to see which method was more appropriate. However, doing so would rely on there being two methods to compare, and then there being sufficient empirical evidence to compare them. At the same time, taking this approach would limit the answer to this question to consideration of just two methods, whereas consulting the autistic and autism communities is likely to yield far more diverse views and preferences in relation to what constitutes appropriate goals and how should they be selected.
- Related to the previous point, answering PICO questions relies on quantitative data. Yet, when it comes to understanding the views and experiences of autistic children, their families, and the broader autistic and autism communities, qualitative data are just as important. Therefore, questions need to be asked in a way that allows people to share a broad range of, at times differing, views and experiences.

Given these challenges and limitations with adopting the PICO format, the GDG elected to formulate questions in a way that would prioritise their relevance to everyday practice. Doing so was consistent with the NHMRC Standard 1 (Be relevant and useful for decision making) to ensure Standard 7 (Make actionable recommendations) could be achieved. For this same reason, the Recommendations included in the Guideline are consensus-based recommendations, drawing on evidence from the research literature, combined with evidence collected through detailed community consultation.

People involved: The questions were developed and endorsed by the GDG.

### **Step 3: Gathering evidence**

**Purpose:** For a Guideline to be relevant it must be evidence-based. For this Guideline, evidence-based meant being consistent with an *evidence-based practice* framework, that combines the best available research evidence, with evidence from professional practice, and the views and priorities of autistic children and their families. The purpose of gathering evidence was to ensure that recommendations could be formulated in a systematic way, consistent with GRADE, and reflecting multiple converging sources of evidence.



**Process:** The GDG designed a series of nine research projects to gather the best available evidence from existing research via three systematic reviews as well as six community consultation studies. Ethical approval for the consultation activities was procured through the Griffith University Human Research Ethics Committee (2021/843). The nine studies were:

- A scoping review of existing guidelines (presented in Chapter 4). This was a scoping review of previously published guidelines and similar best practice recommendations in Australia and overseas. Evidence was used, in combination with other sources, to identify a set of principles and practices that were then considered in the design of research activities. Note that evidence was not used to formulate recommendations, to avoid the risk of circular reasoning, whereby a recommendation in one guideline could be used to justify a recommendation in a later guideline.
- 2. An umbrella review of the effects of non-pharmacological supports on child and family outcomes (presented in Chapter 5). This was a systematic review of existing systematic reviews that examined these effects. The evidence was used to inform the formulation of recommendations, particularly in relation to Guideline questions about the selection and delivery of supports.
- 3. A systematic review of the experiences of autistic children and their families accessing supports in Australia (presented in Chapter 6). This was a systematic review of existing studies that examined the experiences of children and families accessing supports in community settings. The evidence was used to inform the formulation of recommendations, particularly in relation to the Guideline question about what guiding principles should be followed when providing supports to autistic children and their families.
- 4. An online survey designed to understand the experiences of the autistic and autism communities in accessing supports, and their views on best practice (presented in Chapter 7). This was open to all members of the autistic and autism communities. The evidence was used to inform the formulation of recommendations in response to all Guideline questions.
- 5. A series of focus groups designed to provide an opportunity for autistic adults and parents of autistic children to reflect on and discuss their views and experiences (presented in Chapter 8).
- A practitioner survey designed to identify areas of consensus for various aspects of clinical practice in supporting autistic children and their families. This followed a Delphi format, with two rounds conducted (presented in Chapter 9).
- 7. A brief online survey designed to understand the views of autistic children in accessing supports (presented in Chapter 10). This was designed to cater for all children, including those who communicate mainly in ways other than speech. The evidence was used to inform the formulation of recommendations in response to all Guideline questions.
- 8. A reflection activity in which parents were invited to observe and/or reflect on their autistic children's experiences of accessing supports (presented in Chapter 11). This was designed to cater for all children, including those who communicate mainly in



ways other than speech. The evidence was used to inform the formulation of recommendations in response to all Guideline questions.

9. A consultation activity involving the creation of art, which was designed to cater for autistic children, young people, and adults, including individuals who communicate mainly in ways other than speech (presented in Chapter 12).

The nine research and consultation activities were designed in such a way as to collect evidence from all key stakeholders, including autistic children and their families, as well as members of the broader autistic and autism communities. The sources of evidence (i.e., nine studies) the populations represented by each evidence source are summarised in Table 3.1.

Sources of evidence	Populations represented by each evidence source						
(i.e., research activities)	Autistic children	Autistic young people	Autistic adults	Parents	Family members	Practitioners	Other community members
Systematic review of existing guidelines	$\checkmark$	$\checkmark$		$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Systematic review of intervention effects	$\checkmark$	$\checkmark$		$\checkmark$	$\checkmark$		
Systematic reviews of child and family experiences	$\checkmark$			$\checkmark$	$\checkmark$		
Online community survey		$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Focus groups			$\checkmark$				
Delphi surveys							
Brief online survey	$\checkmark$	$\checkmark$	$\checkmark$			$\checkmark$	
Parent reflection	$\checkmark$	$\checkmark$	$\checkmark$				
Expression through art	$\checkmark$	$\checkmark$	$\checkmark$				

#### Table 3.1. Sources of evidence and populations represented.

**People involved:** The research activities were developed by the GDG. Jenny Cartmel (Griffith University), Marilyn Casley (Griffith University), and Sharynne McLeod (Charles Sturt University) provided expert input into the design of consultation activities for autistic children and young people. The following people contributed to the preparation of community consultation activities: Dr Emmah Baque (Griffith University), Dr James Best (Junction Street Family Practice), Kelly Clark (Centre for Social Impact, University of Western Australia), Georgia Davies (Victoria University of Wellington), Rhiannon Latham (Queensland Department of Education), Antonina Loncarevic (CliniKids, Telethon Kids Institute), Meghan McAnany (Griffith University), Claire Perrozzi (CliniKids, Telethon Kids Institute), Amanda Porter (personal contribution) Shaun Ruigrok (personal contribution), and Carla Wallace-Watkin (Victoria University of Wellington). The day-to-day work of gathering evidence was primarily undertaken by six members of the GDG (Sarah Pillar, Rhylee Sulek, David Trembath, Kandice Varcin, Hannah Waddington and Andrew Whitehouse). The coding and analysis of data was undertaken by these same six members of the GDG, with support for



qualitative data coding from five research assistants (Briohny Dempsey, Georgina Earl, Libby Groves, Emma Hinze, and Rachelle Wicks).

### Step 4: Moving from evidence to recommendations

As presented in the Draft Guideline, and reproduced here, an iterative process, built around an Evidence to Decision (EtD) framework, was used to move from evidence to recommendations (Alonso-Coello, Oxman et al., 2016; Alonso-Coello, Schünemann, et al., 2016). The process was led within the GDG by a *Draft Recommendations Working Group* (DRWG; Sarah Pillar, Rhylee Sulek, David Trembath, Kandice Varcin, Hannah Waddington, and Andrew Whitehouse), and is summarised here.

#### **Iteration 1: Practice statements**

The DRWG developed a set of practice statements relating to each of the Guideline questions. The statements took the same form as those used in Round 1 of the Delphi survey, where practitioner consensus on these statements had already been reached.

The DRWG then independently reviewed these statements against the following sources of evidence:

- Evidence emerging from the scoping review of existing Guidelines, the umbrella review of existing research evidence, and the systematic review of children's and families' experience of accessing supports.
- Other relevant research (e.g., neurodiversity-affirming practice, other international reviews of research evidence).
- Conceptual and ethical frameworks (e.g., AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research, 2020; International Classification of Functioning, Disability and Health, World Health Organisation, 2001).
- Regulations (e.g., National Disability Insurance Practice Standards Practice and Quality Indicators, 2021).
- Reports (e.g., Disability Royal Commission Interim Report, 2020).
- Conventions (e.g., United Nations Convention on the Rights of the Child, 1989).

During the independent review, each member made a list of suggested edits (additions, deletions, amendments) which were then raised and resolved at a meeting of the DRWG. The first iteration of the statements was shared with the broader GDG, discussed at the monthly meeting, and suggested edits documented.

#### Iteration 2: Draft recommendations

The DRWG incorporated the feedback from the broader GDG and revised the statements into a set of preliminary recommendations, supported by evidence tables. To do this, the DRWG members independently reviewed the statements against the complete set of evidence from the community Consultation process, which included the:

• Online community survey.



- Brief online survey.
- Focus groups.
- Parent reflections.
- Delphi survey Round 2.

Each member made a list of suggested edits (additions, deletions, amendments) which were then raised and resolved at a meeting of the DRWG. The DRWG also compiled evidence summary tables that were shared with the GDG, alongside the draft recommendations. The GDG provided feedback at the monthly meeting and via suggestions in shared documents, which were subsequently incorporated. Implicit in this process was the fact that not all evidence collected during the research activities converged in such a way as to warrant a recommendation or good practice point. For example, the Umbrella Review (Chapter 5) included collection of evidence regarding the impact of supports on children's autism characteristics, including efforts in some studies to reduce these. Although evidence of these effects was found, there were multiple converging sources of evidence indicating that attempts to reduce autism characteristics is not an appropriate goal (supports should focus on helping children acquire functional and individually meaningful skills), hence this evidence from the umbrella review does not feature in Recommendations or associated Good Practice Points. Accordingly, not all findings from the research activities presented in subsequent chapters feature in the evidence summaries that underpin the **Recommendations and Good Practice Points.** 

#### **Iteration 3: Strength of Recommendation judgments**

In the third iteration, the DRWG further revised the recommendation statements, with a focus on creating plain language wording to the extent possible. The DRWG also independently completed a review and judgement of each Recommendation against the seven criteria required within the GRADE Evidence to Decision (EtD) framework (Alonso-Coello, Oxman et al., 2016; Alonso-Coello, Schünemann, et al., 2016). The judgements related to certainty of evidence, benefits and risks, values and preferences, resource implications, equity considerations, acceptability, and feasibility. The judgements occurred over three rounds, with the first involving independent review, followed by two rounds of consensus review.

Based on the judgements, each Recommendation was then classified as either a 'strong' Recommendation or a 'conditional' Recommendation, as per the GRADE process and reflecting the confidence in the clarity of the balance between desirable and undesirable consequences. In the case of this Guideline, 'conditional' Recommendations indicated: uncertainty around alignment with values and preferences of children and families; a possible reduction in health equity; uncertainty around the acceptability of the Recommendation for practitioners; and/or a possible lack of feasibility in implementation. The classifications reflect the judgements of the GDG, based on the available evidence and other relevant considerations such as alignment with international conventions. The complete set of judgements is provided in the Supporting Evidence document.



#### **Iteration 4: Draft Guideline**

The DRWG prepared the Draft Guideline and shared it with the GDG, alongside the complete set of evidence summaries and Evidence to Decision (EtD) judgements. These documents were reviewed and then discussed by members at a meeting of the GDG. The GDG endorsed the documents, subject to further minor edits and formatting.

### Step 5: Community consultation on Draft Guideline

The GDG prepared the Draft Guideline and supporting documents (Summary of Evidence, Administration and Technical Report) for public consultation, which opened on 18<sup>th</sup> July 2022 and will close on 29<sup>th</sup> August 2022 (a 6 week period).

#### **Public consultation activities**

The following activities were undertaken ahead of the public consultation period:

- Autism CRC has maintained a webpage devoted the Guideline development, and this was updated to reflect the upcoming consultation period and invitation to participate.
- The GDG announced the upcoming public consultation period, via email distributed to people who had registered specifically for updates on the Guideline, as well as people who were on the Autism CRC communications database more broadly.
   Further announcements were made via Autism SRC social media, and then re-posted by GDG members.
- Autism CRC hosted a 1-hour free online community webinar, presented by the GDG Co-chairs, to share the purpose, rationale, scope, and methodology employed in developing the Draft Guideline as well as information on how to engage in the public consultation. All people who registered to attend the webinar were sent a link to the recording which was also posted on the Autism CRC website.
- A Co-chair of the Guideline Development Group emailed the office of the Director General, Chief Executive or Secretary of each state, territory and Commonwealth Health Department to prepare those offices for the publication of the Draft Guideline on 18<sup>th</sup> July 2022. These offices were then directly emailed the Draft Guideline on the 18<sup>th</sup> July 2022.

The following activities were undertaken during the public consultation period:

- The Autism CRC webpage was updated to include:
- A video explaining the public consultation process, and how people can participate.
- Direct links to the Draft Guideline, Summary of Evidence, and Administration and Technical Report.
- A link to participate in an online feedback survey, via REDCap hosted by Griffith University.
- Autism CRC announced the opening and closing of the public consultation period via email and social media.



• Autism CRC send reminders inviting participation throughout the public consultation period.

#### Feedback survey

Public consultation feedback was collected via the custom online survey, developed by the GDG and delivered via REDCap (Griffith University). The survey comprised three sections, commencing with participant information and consent, followed by an opportunity to provide general feedback on the guideline sections, and then the option to provide specific feedback on one or more Recommendations and associated Good Practice Points. Participants were able to choose the number of questions they answered and the level of detail provided. Furthermore, participants were able to choose whether to provide feedback as an individual, or on behalf of an organisation.

### **Step 6: Analysing Feedback and Review**

#### Analysing feedback from Public Consultation

All feedback will be (a) considered by the GDG, (b) shared with the NHMRC to support their evaluation of the Guideline, and (c) made publicly available at the time the Guideline is released

#### Independent review (AGREE-II)

The Draft Guideline will be reviewed by two independent researchers with experience with the Appraisal of Guidelines for Research & Evaluation Instrument (AGREE-II) checklist: Dr Bahareh Afsharnejad (Curtin University) and Dr Kiah Evans (University of Western Australia. The reviewers will provide their AGREE-II ratings to the Guideline Development Group, who will then discuss these ratings at a meeting with the Co-chairs.

#### **NHMRC** reviews

The NHMRC will coordinate two further rounds of independent evaluation, by seeking review from (a) Guideline methodological experts, and (b) content experts.

#### **Final revisions**

The GDG will use all information gathered from the analysis of the public consultation feedback and independent and NHMRC reviews to make revisions where appropriate. All changes will be documented and presented in summarised form in the final version of the Administration and Technical Report. The Guideline and all associated documents will be endorsed by the GDG prior to public release.

## 3.5 Recommendations and Good Practice Points

The Evidence to Decision (EtD) process resulted in a set of Recommendations and Good Practice Points, which were formulated and presented in a way that met the following requirements:



#### **Consensus-based Recommendations**

Using the GRADE methodology, recommendations may be described as *evidence-based* or *consensus-based*. Evidence-based recommendations are typically based on evidence derived from one or more systematic reviews containing meta-analyses of empirical data, that are relevant to one or more clinical questions presented using the PICO format. Consensus-based recommendations are typically based on sources of evidence, other than those described for evidence-based recommendations, such as through non-systematic reviews, evidence derived through consensus-based processes (e.g., Delphi studies), and qualitative data pertaining to relevant stakeholders' views and experiences.

For this Guideline, the GDG was unanimous in endorsing the formulation of consensusbased recommendations, for the following reasons explained in Section 3.4:

- The questions that are most relevant to professional practice rarely align with the PICO format.
- There is a lack of empirical evidence on which to make judgements, even if the PICO format was deemed appropriate.
- The GDG determined that it was critical to gather evidence from all relevant stakeholders across the autistic and autism communities, including autistic children, their families, and practitioners to ensure the Recommendations are relevant, acceptable, and feasible.

All Recommendations are clearly labelled as Consensus-Based Recommendations.

Recommendations are defined as "*Key elements of practice that must be followed for a practitioner to deliver evidence-based supports.*"

Good Practice Points were linked to specific Recommendations and defined as "Elements of practice that provide critical context to that Recommendation, such as how a Recommendation should be operationalised in clinical practice, or how it is applied to a specific population or under specific circumstances."

#### Language used in formulating Recommendations and Good Practice Points

In drafting the Recommendations and Good Practice Points, the GDG adhered to the following three requirements:

- 1. The wording must be in plain English, specific, unambiguous, employ consistent terminology, and accessible to parents and practitioners.
- 2. The wording must convey one or more specific actions that practitioners should take.
- 3. The wording must reflect the evidence on which the Recommendation or Good Practice Point, in terms of both strength and precision.



# 4. Scoping Review: Existing Guidelines

# 4.1 Background

Clinical practice guidelines relating to the provision of non-pharmacological supports for autistic children have been developed around the world. Existing international guidelines contain a variety of guiding principles and recommendations aligned to the international context in which they were developed. Understanding the breadth of principles and recommendations published within existing international guidelines supported the development process of the current Guideline.

Evidence was used, in combination with other sources, to identify a set of principles and practices that were then considered in the design of research activities. Note that evidence was not used to formulate recommendations, to avoid the risk of circular reasoning, whereby a recommendation in one guideline could be used to justify a recommendation in a later guideline

### 4.2 Aim

The aim of this scoping review was to explore and map key themes across the principles and recommendations published within existing international guidelines. Principles and recommendations were mapped according to a framework to support comparison across existing guidelines, and to ensure that a broad scope of existing considerations and themes relevant to a given area was able to be reviewed during the development of the current Guideline.

## 4.3 Research question

What are the principles and recommendations within existing international clinical guidelines for support provision for autistic children (0-12 years)?

## 4.4 Design

A systematic literature search and qualitative review using a framework approach (Gale et al., 2013) was selected as the most appropriate method for addressing the research aim and answering the research question.

## 4.5 Method

### Eligibility

Guidelines were included in the review if they met the following criteria:

- The clinical practice guideline's primary focus was autistic individuals.
- The clinical practice guideline included recommendations for children aged between 0 and 12 years. Clinical practice guidelines that made recommendations for older



individuals were included if the recommendations also included children between 0 and 12 years.

- The clinical practice guideline made recommendations primarily for nonpharmacological supports.
- The clinical practice guideline had been developed for use across more than one of the professional target user groups identified by the current guideline.
- The clinical practice guideline was linked with a state body/government authority and not solely the publication of a private company (e.g., health insurance company).
- The clinical practice guideline had full-text copies available in English.
- The clinical practice guideline was published since 2010.

Existing clinical practice guidelines were excluded if they met any of the following exclusion criteria:

- The clinical practice guideline did not include children under 12.
- The clinical practice guideline primary focus was to provide guidance related to the diagnosis of autism or use of pharmacological supports.
- The full-text was not available, or not available in English.
- The clinical practice guideline had been superseded by an updated version from the same jurisdiction.
- The clinical practice guideline was published prior to 2010.

### Literature search strategy

A literature search was conducted on the 17th of December using the following databases: Embase, PsycINFO, Education Resources Information Centre (ERIC), Medline, PubMed, CINAHL, Scopus, EBSCO Education Source, Web of Science Core Collection, Epistemonikos and Google Scholar. Variants and combinations of search terms relating to autism (Autis\* OR ASD\* OR Asperger\*) clinical support (interven\* OR therap\* OR treat\* OR manage\* OR support\* OR practice\*) and guidelines (guide\* OR "practice parameter") were used.

#### Filters: 2010-2022; Language: English

The reference lists of documents were scrutinised to identify additional relevant existing international guidelines not identified during the database searches.

### **Guideline selection**

All documents retrieved from the searches were imported into EndNote reference management software. Duplicates identified by the software were removed prior to screening. Titles and introduction, purpose and scope of the documents were screened against the inclusion/exclusion criteria by one reviewer (SP). Documents were excluded if



they met one or more exclusion criteria. Eligible existing guidelines were not reviewed for quality of development process.

### Data extraction and coding of included study data

One reviewer (SP) extracted key guideline details (including title, jurisdiction, year, stated purpose) for each of the included guidelines into a table (see Table 4.1). Included guidelines were imported into the NVivo Software Platform for coding of study results. A coding framework (Gale et al., 2013) was developed and used to code recommendations (see Table 4.2). The framework was developed by six members of the GDG (Sarah Pillar, Rhylee Sulek, David Trembath, Kandice Varcin, Hannah Waddington, and Andrew Whitehouse) based on consideration of:

- Evidence from the existing Guidelines, a previously conducted umbrella review of existing research evidence (Whitehouse et al., 2020).
- Other relevant research (e.g., neurodiversity-affirming practice, other international reviews of research evidence).
- Conceptual and ethical frameworks (e.g., AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research, 2020; International Classification of Functioning, Disability and Health, World Health Organisation, 2001).
- Regulations (e.g., National Disability Insurance Practice Standards Practice and Quality Indicators, 2021).
- Reports (e.g., Interim Report of Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 2020).
- Conventions (e.g., United Nations Convention on the Rights of Persons with Disabilities, 2006; United Nations Convention on the Rights of the Child, 1989).



# 4.6 Results

### **Guideline Characteristics**

A total of 14 guidelines were eligible for inclusion. Table 4.1 presents a summary of the included guidelines. The references for these Guidelines are provided in Appendix 4.1.

#### Table 4.1. Included guidelines.

	Title	Year	Jurisdiction	Stated Purpose
01	Management of autism in children and young people: A good clinical practice guideline	2014	Belgium	" provides recommendations based on current scientific evidence for treatment and support of children and adolescents with autism and their family."
02	Autism spectrum disorders in pre-school children: AMS-MOH clinical practice guidelines	2010	Singapore	" to assist practitioners who are involved in any of the following: surveillance, screening and early identification, referral for assessment, diagnosis and intervention of children with ASD."
03	Autism spectrum disorder: Evidence-based / evidence informed good practice for supports provided to preschool children, their families and carers	2016	Australia	" to assist with making decisions about the delivery of services to preschool children with autism, and their families and other carers."
04	Assessment, diagnosis and interventions for autism spectrum disorders: A national clinical guideline	2016	Scotland, UK	" provides recommendations based on current evidence for best practice in the assessment, diagnosis and interventions for children, young people, adults and older adults with ASD."
05	People with autism spectrum disorder: Identification, understanding, intervention	2019	Europe	" offers guidance on various key aspects from diagnosis to life-long support in view of promoting an evidence based and right-based approach to autism"
06	Clinical practice guideline on assessment and intervention services for young children with autism spectrum disorders (ASD): 2017 update report of recommendations.	2017	New York state, USA	" a tool to help assure that infants and young children with disabilities receive early intervention services consistent with their individual needs, resources, priorities, and the concerns of their families."



			1	
07	New Zealand autism spectrum disorder guideline	2016	New Zealand	" to provide guidance on autism spectrum disorder (ASD) in both children and adults in New Zealand."
08	Autism: the NICE guideline on the management and support of children and young people on the autism spectrum	2021	United Kingdom	" to advise on the management and support of children and young people on the autism spectrum."
09	Autism spectrum disorders: Guide to evidence-based interventions	2012	Missouri state, USA	" provides information and tools to support individuals with ASDs and their families and to assist healthcare professionals, educators, and other community-based service providers in making informed decisions about selection, implementation, and monitoring of ASD interventions."
10	National Clinical Guideline: The diagnosis and Management of Autism Spectrum Disorder	2019	Qatar	" to define the appropriate diagnosis and management of Autism Spectrum Disorder (ASD) in children and adults."
11	Clinical practice guidelines: management of autism spectrum disorder in children and adolescents	2014	Malaysia	" to be a guide for clinical practice, based on the best available evidence at the time of development."
12	Clinical practice guidelines for autism spectrum disorders	2019	India	Nil
13	Autism guidebook for Washington State: A resource for individuals, families and professionals	2016	Washington state, USA	" to serve as an informational tool to assist in the navigation of available treatments and services, and to understand the language and issues currently related to ASD."
14	Dubai clinical practice guidelines for autism spectrum disorder (ASD) in children and adolescents	2021	Dubai	"to address the gaps in the fragmented service, encourage evidence based practices and stop the non-evidence based and potentially harmful practices"



#### **Qualitative data**

Table 4.2 presents a summary of the codes, number of guidelines for which each code was relevant, and the number of references (i.e., separate quotes included in analysis).

Coding Framewor	k	Outcome	
Context	Question	Number of Guidelines	References
Principles	What guiding principles should be followed when providing supports to autistic children and their families?	12	246
Goal setting	What are appropriate goals for children and families?	14	246
	How should goals be selected?	11	77
Selection and planning	What types of supports might be relevant to children and families?	14	472
	How should these supports be selected?	14	383
	What skills and knowledge are required to plan supports?	13	134
Delivery	Who should deliver supports?	14	162
	In what settings should supports be delivered?	13	99
	In what formats/modes should supports be delivered	14	182
	In what amount should supports be delivered?	12	46
	What are the critical service interfaces for children and families?	8	16
Outcomes, quality, and safeguards	How should the effects of supports be monitored?	13	110
Sarcyualus	How can the risk of adverse effects be reduced?	12	32
	How should adverse effects be managed?	5	6
	How should the rights of children and families be protected?	11	87

 Table 4.2. Coding framework and summary of synthesis.



## 5. Umbrella Review: Effects of nonpharmacological supports on child and family outcomes

## 5.1 Background

A synthesis of existing research evidence is critical to the development of any guideline. This evidence can be used to inform the recommendations themselves and to help in determining the strength of those recommendations (NHMRC, 2016). This was an update of the umbrella review conducted as part of the Autism CRC project entitled *Supports for Autistic children: A Synthesis of Research Evidence* (Whitehouse et al., 2020). The process described here relates to the original update, for which the search was conducted in November, 2021. This update should be repeated at regular intervals to ensure that the umbrella review continues to contain the best available evidence.

## 5.2 Aim

The aims of this umbrella review were to synthesise data from existing systematic reviews regarding: (a) the effects of different non-pharmacological supports on a range of child and family outcomes, (b) any associations between the way in which a support was delivered (e.g., amount of support, the support setting) and the effects of those supports, and (c) any associations between child characteristics and the effects of those supports.

## 5.3 Research questions

This umbrella review aimed to answer the following research questions:

- Question 1: What non-pharmacological supports have been examined in SRs?
- Question 2: What effects do non-pharmacological supports have on child outcomes?
- Question 3: What effects do non-pharmacological supports have on family wellbeing?
- Question 4: What delivery characteristics influence the effects of supports, with a focus on the amount of support, setting, format, agent (person delivering the support), and mode?
- Question 5: What child characteristics influence the effects of supports, with a focus on child age, core autism characteristics, cognition, and communication skills?

### 5.4 Design

This project was an umbrella review, which involved systematically searching for, and selecting, relevant systematic reviews, then synthesising and presenting data from those reviews. The original and updated umbrella reviews were conducted in accordance with the procedures outlined in the Joanna Briggs Institute manual for evidence synthesis



(Aromataris et al., 2020) and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Page et al., 2021).

### 5.5 Method

The protocol for the original synthesis of research evidence was published on Open Science Framework on July 8th 2020 (https://osf.io/54vg8/).

#### Eligibility

Systematic reviews (SRs) were included in the umbrella review if they met all the following criteria:

- The SR was a meta-analysis or a narrative synthesis (an SR without a meta-analysis). A review was considered "systematic" if it: (1) included a clear statement of the purpose of the review; (2) described the search strategy (e.g., key search terms, multiple relevant databases, specification of search limits); (3) indicated the criteria used to select studies for inclusion; (4) presented all findings relevant to the main purpose of the SR, including those that did not favour the support; and (5) used a method of quality appraisal for each included study.
- The SR included autistic children. SRs that included children described as increased likelihood of autism were included if the SR also included autistic children. SRs that included autistic children and individuals with other developmental conditions were included if outcomes were reported separately for autistic children.
- The SR included children aged between 0 and 12 years. SRs that encompassed older individuals were included if outcomes were reported separately for children 18 years of age or younger.
- The SR reported on at least one non-pharmacological support that targeted the acquisition of developmental or educational skills.
- The SR provided the names of all included practices and categories of support.
- The SR included at least one RCT, quasi-RCT, and/or controlled clinical trial. SRs that included studies with other designs were included only if they also featured at least one RCT, quasi-RCT, and/or controlled clinical trial.
- There was no limit placed on comparison/control group.
- The SR reported summarised, quantitative data on the impact of the support on one or more of the umbrella review's main outcomes of interest. These outcomes, defined in Appendix 5.1 were:
  - Communication, including overall communication, social-communication, expressive language, and receptive language.
  - o Sensory development
  - Cognitive development
  - Social-emotional development



- o Motor development
- o Academic skills
- o School/learning readiness
- Daily activities and participation, including adaptive behaviour, play, and participation, and general outcomes.
- Overall autism characteristics and restricted and repetitive interests and behaviours [note: This terminology reflects diagnostic criteria and usage in most research in this area]
- General child outcomes.
- Family wellbeing and satisfaction: Specifically, parent knowledge and skills, social-emotional wellbeing, financial wellbeing and satisfaction, and child quality of life and satisfaction.
- Adverse child effects.
- The SR was published in a peer-reviewed journal or as a publicly available scientific report.
- The SR had full-text copies available in the English language.
- The final literature search was conducted in the last 10 years (2012-2021 in the case of the first update).
- SRs were excluded if they met any of the following exclusion criteria:
- The review did not meet the criteria to be considered "systematic".
- It was an umbrella review, rapid review, scoping review, or "review of reviews".
- SRs that report on supports with children with developmental conditions other than autism, or where outcomes for autistic children could not be extracted; and those that only included children described as increased likelihood of autism.
- The SR did not include children under 12 and/or included individuals over the age of 18 without separate analysis.
- The SR did not include at least one RCT, quasi-RCT, and/or controlled clinical trial.
- The SR did not report on at least one non-pharmacological support that targeted the acquisition of developmental or educational skills.
- The SR did not provide the names of all included practices and categories of support.
- The SR focussed solely on biological-based therapies such as dietary, sleep, exercise, chiropractic, massage, acupuncture, reflexology, kinesiology, shock therapy, neurofeedback, transcranial magnetic stimulation, hyperbaric oxygen therapy supports; or supports targeting access to or participation in healthcare. While non-pharmacological, these supports were beyond the scope of the umbrella review.



- The SR focused solely on techniques (defined as one specific strategy) and did not include at least one relevant support (i.e., a collection of techniques).
- The SR did not focus on delivery characteristics (i.e., setting, format, agent, or mode) and summarised outcomes across a range of practices across several different categories of support outlined in Sandbank (2020).
- The review summarised outcomes across a range of included and excluded practices.
- The SR did not report summarised outcomes of interest relevant to the current umbrella review- that is a statement of effect size(s) and confidence intervals and/or p-values for meta-analyses, or an in-text statement specifying the number of studies (k >1) evaluating an outcome of interest and the number or percentage of studies that reported positive, negative, and/or null effects for that outcome.
- The SR incorporated theoretical studies, text, and opinion as their primary source of evidence.
- The SR was limited by geographical region, that is, the search and/or inclusion/exclusion criteria were limited to specific countries, continents, or other geographical areas.
- The SR was a thesis, conference paper, newsletter, or protocol.
- The full-text was not available, or not available in English.
- The SR had been superseded by an updated version of the same review (completed after full-text review of all SRs for all other eligibility criteria)
- The review was a scholarly article corresponding to an existing report (completed after full-text review of all SRs for all other eligibility criteria)
- The final literature search was not conducted the last 10 years (i.e., it was conducted before 2012 in the case of the first update)

#### Literature search strategy

An updated literature search was conducted on November 19<sup>th</sup>, 2021 using the following databases: PsycINFO, Education Resources Information Centre (ERIC), Medline, PubMed, EMBASE, CINAHL, Cochrane Database of Systematic Reviews, Scopus, EBSCO Education Source, and Epistemonikos. The search terms were: (Autis\* OR ASD\* OR Asperger\* OR pervasive developmental disorder\* OR PDD\* OR pervasive child development disorder\* OR pervasive childhood developmental disorder\* OR PCDD\* OR disintegrative disorder\*) AND (intervention\* OR therap\* OR treat\* OR teach\* OR program\* OR package\*) AND (systematic review\* OR systematic literature review\* OR evidence synthes\* OR meta-analy\* OR meta-regression\*). The full search strategy for each database is provided in Appendix 5.2. The updated search was limited to SRs published from July 2020, as this was the search end date in the initial umbrella review. Articles from the initial umbrella review that were published in 2010 or 2011 were also excluded because they no longer met the 10-year cut-off. Ancestral searches were conducted using the reference lists of all included SRs and



relevant umbrella reviews or 'reviews of reviews' identified by the updated database search.

#### **Study selection**

All studies retrieved from the updated database searches were imported into the Covidence software platform. Duplicates identified by the software were removed prior to screening. Two reviewers (HW, KV) independently screened the titles and abstracts of the studies against the inclusion/exclusion criteria. Articles were excluded if they met one or more exclusion criteria.

To determine whether supports fell within the scope outlined by Sandbank et al. (2020), the two reviewers referred to a guiding document from the original synthesis of research evidence, which was created based on consensus across four reviewers (Whitehouse et al., 2020; see Appendix 5.3). When a SR identified in the title and abstract screening included a support not covered by this document, the two reviewers (HW + KV) independently determined whether it should be included based on the eligibility criteria. The two reviewers then met to discuss each question of eligibility regarding these new supports and resolved these via consensus.

Next, the two reviewers (HW, KV) independently screened the full-text reports of all potentially relevant articles according to the eligibility criteria. Where the design/s of included studies were not clearly specified, reviewers examined the SR reference list to determine if at least one study with an RCT, quasi-RCT, or controlled cohort design was included. Once the authors had finished individually screening all full-text reports they also excluded any SRs which had (a) been superseded by an updated version of the same review or (b) were scholarly articles corresponding to an existing report.

Following both independent title/abstract screening and independent full-text screening, the two reviewers (HW, KV) discussed and resolved any discrepancies. If an agreement could not be reached, another team member (AW and/or DT) was consulted. The percentage of agreement [agreements/(disagreements + agreements) × 100] was 96.7% for updated title/abstract screening and 81.5% for the updated full-text screening.

One reviewer (HW or KV) also independently determined whether each of the 58 studies included in the original umbrella review met all updated criteria and a second reviewer checked these determinations. Disagreements were resolved via consensus and, where necessary, a third reviewer was consulted (AW and/or DT). Agreement was not calculated on this step.

#### **Data extraction**

#### Data extraction for all included SRs

One reviewer (HW) extracted data for each of the included SRs using a standardised data extraction form (Appendix 5.4). This process had already been completed for those SRs included in the original research synthesis. The reviewers practiced extraction for one SR together and then were randomly assigned to extract data from the remaining SRs using a random list generator. First, data were extracted from the overall SR (SR-level extraction).



For those SRs identified in the updated search, data extraction included: (a) the type of SR, (b) the objectives of the SR, (c) the number of studies included, (d) the design of included studies, (e) the quality of included studies including the assessment tool used, (f) sources of funding and conflicts of interest, (g) location of the included studies, and (h) the characteristics of included participants, interventions/supports, comparison groups, and outcomes (PICO characteristics).

The second stage, outcome level extraction, involved extraction of data related to the effects of supports for each individual practice or category of support included in the SRs and primarily involved two reviewers (KV, HW). Again, this process had been completed for those SRs included in the original research synthesis. The authors practiced extraction for one narrative synthesis and one meta-analysis and were then randomly assigned the remaining articles. The data extracted at this stage included: (a) the name of the practice or category of support (b) the delivery setting (e.g., clinic, home, school), format (individual, group), agent (e.g., clinicians/researchers, parents/caregivers, peers/siblings), and mode (e.g. face-to-face, telepractice), (d) the effect of supports including effect sizes, confidence intervals, and heterogeneity statistics from meta-analyses, and verbatim summaries of effects from narrative syntheses (e) the direction of the effects of supports, and (f) any examination of the influence of amount of support, child characteristics and outcomes of interest. Information from each SR that was included in summary tables was indicated in bold (see section below titled *Selection of effects for the summary tables*).

A second reviewer (KV or KV) independently extracted information for a randomly selected 18% of SRs. For the remaining 82% of SRs, a second reviewer cross-checked the first reviewer's extraction against the original article. Disagreements were identified and resolved via consensus and, where necessary, a third reviewer (AW/DT) was consulted. For SR level extraction, the percentage of agreement was 89.8% for data independently extracted by two reviewers and 92.8% for the cross-checks. For the outcome level extraction, the percentage of agreement was 78.5% for data independently extracted by two reviewers and 95.3% for the cross-checks.

#### Focus of SRs

SRs were divided the into three groupings. First, practice/category-focused reviews examined the effect of support within a defined practice/category on child and family outcomes. These SRs enabled determination of the effect of support within a given practice and/or category on child and family outcomes (Questions 2 and 3) to be readily synthesised. These SRs also provided insights into the potential influence of child and delivery characteristics on the effect of supports for a given practice/category (Questions 4 and 5).

Second, outcome-focused reviews examined the effect of supports, combined across practices/categories, on an outcome of interest (e.g., social-communication). For SRs with this focus, it was not possible to delineate the effect of one practice/category of support from another on any given outcome. However, these SRs provided insights into the potential influence of delivery characteristics (Question 4) and child characteristics (Question 5) on the effect of supports relating to a given outcome.



Third, delivery-focused reviews examined the effect of supports with specific delivery characteristics (e.g., setting, format, agent, mode), combined across practices/categories, on child and family outcomes. These SRs also prevented the delineation of the effect of different practices/categories on outcomes. However, these SRs provided insights into how differences in delivery (Question 4) and child characteristics (Question 5) may influence the effects of supports.

#### Coding of the effects of supports

A positive effect of support represented an increase in child skills/participation and family wellbeing and a reduction in certain autism characteristics. Data extraction for the effect of supports focused on recording one pooled (meta-analysis) or summary (for narrative synthesis) effect for each relevant outcome reported in each SR. Effects derived from between-group and within-group analyses were eligible for extraction, with between-group analyses (i.e., between at least one group receiving support and another group) prioritised where available. On occasions where meta-analyses reported more than one pooled effect for a specific outcome (e.g., main analyses and sensitivity analyses), we extracted the effect that was presented by the SR authors as the primary analysis.

For meta-analyses, findings were recorded as either a positive pooled effect (90/95% confidence intervals of the pooled effect did not overlap with the null), a negative pooled effect (90/95% confidence intervals of the pooled effect did not overlap with the null), or a null effect (90/95% confidence intervals of the pooled effect overlapped with the null). Where a SR did not include a meta-analysis, the recording of an effect of support focused on the summary provided by the SR authors in the Results section. Findings could be recorded as either a summarised positive effect (60% or more of studies reported a positive effect of support), a summarised negative effect (60% or more of studies reported a null effect of support), a summarised null effect (60% or more of studies reported a null effect of support) or a summarised null effect (no direction of effect of support meeting a 60% threshold).

The influence of child and delivery characteristics on the effect of supports was summarised by coding the specific independent variable (child or delivery characteristic), the dependent variable(s) (child and family outcomes), and the nature of the influence on the effect of support (as reported by the SR authors, extracted verbatim).

#### Study quality assessment

Risk of Bias was assessed using the Critical Appraisal Checklist for Systematic Reviews and Research Syntheses (CACSRRS; Appendix 5.5) created by the Joanna Briggs Institute (2020). The form comprised 11 items related to the quality of: (a) the review question, (b) the inclusion criteria, (c) the sources and resources, (d) the criteria for appraising the studies, (e) agreement between raters on extraction and quality appraisal, (f) the methods used to combine studies, (g) the likelihood of publication bias, (h) recommendations for policy and/or practice, and (i) directives for new research. Each item was rated dichotomously, with "yes" indicating a low risk of bias for that item, and "no" indicating a high risk of bias for that item. The item regarding the likelihood of publication bias was rated for meta-analyses only



and was rated 'not applicable' for all other SRs. SRs were not excluded based on methodological quality. A summary rating of 'high' was awarded for systematic reviews that met  $\geq$ 80% of items using the CACSRRS. Systematic reviews that met fewer than 80% of items using the CACSRRS were rated as low. Risk of bias had already been rated for those SRs included in the original umbrella review. The quality of SRs identified in the updated search was independently rated by two reviewers (HW + KV). The percentage of agreement was 90.4%. Disagreements were resolved via consensus.

#### Selection of effects for the summary tables

The five summary tables provided synthesised information regarding:

- adverse effects
- the effects of specific practices/categories of support on child and family outcomes
- the influence of amount of support on child and family outcomes
- the influence of delivery characteristics (i.e., setting, format, agent, and mode) on child and family outcomes, and
- the influence of child characteristics (i.e., child age, core autism characteristics, cognition, and communication skills) on child and family outcomes.

Table 5.1 outlines the process for selecting information to be included in the summary tables. Information about adverse effects from all relevant SRs was included in the summary table. For each specific category/practice and child/family outcome, we included the relevant effect of support from the meta-analysis with the most recent search end date (referred to herein as the most recent meta-analysis). If there was no meta-analysis pertaining to this category/practice/delivery characteristic and outcome, we used the most recent relevant narrative synthesis. We presented data about influences on the effect of supports from the most recent meta-analysis for each influence type (amount, child characteristic or delivery characteristic), practice/category, and child outcome of interest. Narrative syntheses examining influences on the effects of supports were not included because they did not pool effects across studies.

Summary table	Information included in table
Adverse effects	Adverse effects from all SRs which have examined this outcome.
The effects of each practice/category of support	The effect of specific practices/categories of support on each child and family outcome based on the most recent meta-analysis (or narrative synthesis if no relevant meta- analysis).
The influence of amount of support	The influence of amount of support on each child and family outcomes based on the most recent meta- analysis.

Table 5.1. Information included in summary tables.



The influence of delivery characteristics (i.e., setting, format, agent, mode)	The influence of delivery characteristics on the effects of supports from the most recent meta-analysis for each delivery type, practice/category and child outcome of interest.
The influence of child characteristics (i.e., child age, core autism characteristics, cognition, and communication skills)	The influence of child characteristics on the effects of supports from the most recent meta-analysis for each characteristic type, practice/category and child outcome of interest.

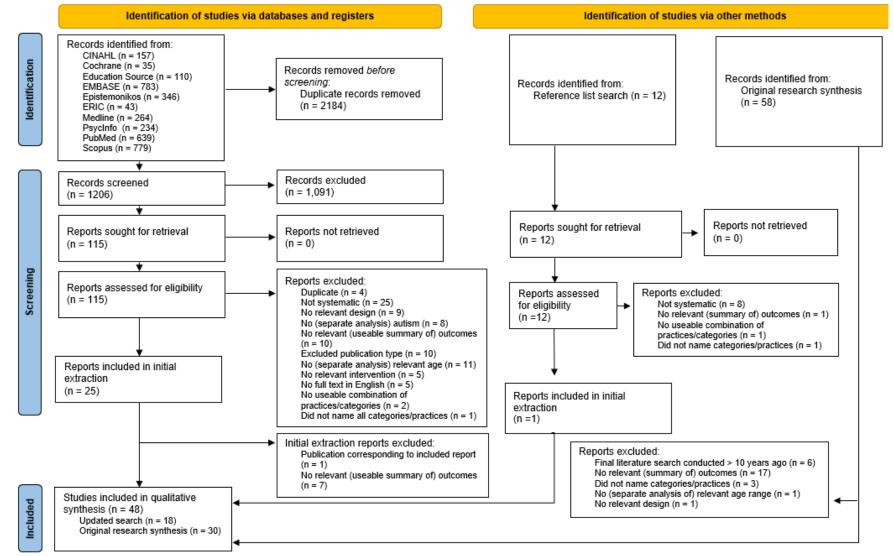
## 5.6 Results

#### **Study selection**

The PRIMSA flow diagram in Figure 5.1 represents the study selection process (Page et al., 2021). The database search yielded 3,390 records across databases and 1,206 records once duplicates were automatically removed. One-hundred-and-fifteen articles proceeded to full-text review and 90 articles were excluded at this stage (see Appendix 5.6). The most common reasons for exclusion were (a) the review did not meet criteria to be considered systematic; (b) there was no separate summary for individuals  $\leq$  18 years and/or there were no individuals  $\leq$  12 years, (c) there was no relevant outcome or no useable summary of relevant outcomes, or (d) the publication was a thesis, conference paper, doctoral dissertation, or umbrella review. Ancestral searches yielded an additional 12 articles, of which 11 were excluded. During extraction, 8 additional articles were excluded, these were predominantly narrative syntheses that did not provide a summary that could be used to determine the effects of supports. That is, it was not possible to determine the overall number of studies evaluating an outcome and/or the number of studies that reported positive, negative, and/or null effects for this outcome. This resulted in the inclusion of 18 new SRs. Twenty-eight of the 58 SRs from the original research synthesis were excluded according to the updated exclusion criteria. The most common reasons for exclusion were (a) the absence of a relevant summary and (b) the SR was published > 10 years ago. The original SRs that were excluded are also listed in Appendix 5.6. Thus, a total of 48 SRs (18 from the updated search and 30 from the original umbrella review) were included in the qualitative synthesis. These are listed in Appendix 5.7.







AutismCRC

National Guideline for supporting autistic children and their families Draft Administration and Technical Report

#### **Study characteristics**

Of the 48 SRs included in the umbrella review, 32 (67%) were meta-analyses, and 16 (33%) were narrative syntheses. The majority of SRs (n=35; 73%) were published between 2019 and 2022, with the remainder (n = 13, 27%) published between 2013 and 2018. The number of studies included in SRs ranged from 5 (Reichow et al., 2018) to 130 (Sandbank et al., 2020), with a median of 17. All but 1 SR (Sandbank et al., 2020) specified the final year of the search, and 37 (77%) of SRs mentioned the presence or absence (i.e., since database inception) of a starting year limit. Of these, 17 (46%) placed a limit on date, whereas 20 (54%) included all prior published research. The authors of 33 SRs (69%) provided information regarding sources of funding to conduct the SR and declarations of interest were reported in 41 SRs (85%). There were five (10%) instances in which authors identified a potential conflict of interest. A detailed outline of study characteristics is provided in Appendix 5.8.

#### **Focus of reviews**

There were 29 practice/category-focused SRs (60%; summarised in Appendix 5.9), 5 outcome-focused SRs (10%; summarised in Appendix 5.10), 13 delivery-focused SRs (27%; summarised in Appendix 5.11), and one SR that was both practice/category focused and delivery focused (Deb et al., 2020; summarised in Appendices 5.9 and 5.11).

#### **Study designs**

Eligibility criteria for the umbrella review stated that each SR must include at least one study with a controlled-group design (either an RCT, quasi-RCT, or controlled clinical trial). At least 43 SRs (90%) included at least one RCT, and 14 (29%) of these only included RCTs. At least 21 SRs (44%) included at least one non-randomised group design study with a control, 11 (23%) at least one non-randomised group design study without a control, 8 (17%) at least one single case experimental design, and 14 (29%) included other designs such as case studies, retrospective cohort studies, and qualitative studies.

#### **Comparison groups**

Only 29 SRs (60%) described the comparison group for each included study, while a further 10 SRs (21%) described the comparison group for a least one study. Of these, 26 SRs (67%) included one or more studies with a wait list control, 30 (78%) included at least one study with a treatment as usual control, and 35 (92%) included at least one study in which the comparison was another type of support.

#### **Participants**

Thirty-nine (81%) SRs provided details about the total number of participating individuals. Across these SRs, a total of 38,245 individuals were identified as participants, with SRs ranging from 66 participants (Hardy & Weston, 2020) to 6,240 participants (Sandbank et al., 2020). It was not possible to calculate the number of unique participants due to overlap between included SRs and non-specific reporting. Thirty-two SRs (71%) provided information



about the age range of included children. Within these SRs, the youngest child was 11 months old and the oldest individual was 44 years old. Twenty-one SRs reported the mean age across studies or the range of mean ages, the youngest mean age was 2.5 years and the oldest was 18.8 years. Twenty-one SRs (44%) provided the mean percentage of participating males and females, or the range of percentages of males and females across studies. Within these SRs, the percentage of males was most commonly reported and ranged from 21 to 100%, while two studies reported on the percentage of females, which ranged from 15.4% to 19.5%,

There was inconsistent reporting of diagnostic information, although there was evidence of broad representation of autistic children. Authors used terms such as autistic disorder, autism, autism spectrum disorder, Asperger's disorder, high functioning autism, child disintegrative disorder, and pervasive developmental disorders not otherwise specified (PDD-NOS). Children with increased likelihood of being autistic, but no formal diagnosis, were identified as being included in only three (6% of) SRs. Only 26 SRs (54%) identified co-occurring diagnoses for one or more included individuals. In the majority of these SRs, it was not clear if all co-occurring conditions were identified or only particular cooccurring conditions of interest. The most common cooccurring condition, where identified, was cognitive impairment (17 SRs, 35%) followed by anxiety and attention deficit hyperactivity disorder (6 SRs each, 13%).

#### **Study location**

Twenty-six SRs (54%) provided information about the geographical locations at which the original studies had been conducted. Of these, all included studies conducted in North America (100%), with Europe (19 SRs, 73%), Australia (21 SRs, 81%), Asia (14 SRs, 54%), South America/Caribbean (3 SRs, 12%). No studies were reported to have been conducted in Africa or the Pacific.

#### **Delivery characteristics**

As outlined in Appendices 5.9-5.11 there was substantial variability in setting, agent, format, mode, and amount of support across SRs. Information about the support setting for at least one included study was specified in 32 SRs (67%). Homes were the most common support setting (26 SRs, 81%), followed by clinics (21 SRs, 66%) and educational settings (19 SRs, 59%). 'Other' settings were reported in 15 SRs (47%). These included non-specific 'natural contexts', community centres hospitals, and a theatre. The use of equine-assisted therapy implied delivery in a community setting although this was not specifically stated.

Thirty-five SRs specified the delivery agent for at least one included study. Of these, 31 SRs (89%) included parents and/or caregivers, 23 SRs (74%) included clinicians and/or researchers, 22 SRs (71%) included early childhood staff such as teachers or teaching assistants, and 6 SRs (19%) included peers and/or siblings. Riding instructors were involved in the delivery of equine-assisted supports and several SRs referred to non-specific personnel (e.g., support staff, assistants).



Forty-one SRs specified the delivery format of at least one included study. Of these, all but one (98%) included delivery of supports to individuals, with group-based supports reported in 23 SRs (56%). Further, 38 studies specified the delivery mode of at least one included study. Of these, 24 SRs (63%) included face-to-face delivery, while 7 SRs (28%) included telehealth delivery. Other deliver modes included technology such as video games, apps, online platforms/website, and DVDs, as well as written instructions and materials.

Only 5 SRs (10%) specified the range of amount of support reported in the included SRs. The lowest amount reported was 4 hours and the highest amount was 3276 hours. Two SRs specified the mean amount of support which was 10.8 and 566 hours respectively.

#### **Risk of bias**

The quality of SRs, assessed using a modified version of the Critical Appraisal Checklist for Systematic Reviews and Research Syntheses (Joanna Briggs Institute, 2020), yielded scores of 7 to 11 out of 11 (mode = 8) for meta-analyses, and 6 to 9 out of 10 (mode = 9) for narrative syntheses. Twenty-eight SRs were considered "high quality" because they met  $\geq$  80% of the items, and the remaining 20 were considered "low quality". Only 5 SRs (10%; all meta-analyses) scored maximum points (Geretsegger et al., 2014; Oono et al., 2013; Reichow et al., 2018; Shi et al., 2021; Tachibana et al., 2018). A full summary of item scores and totals for each SR is provided in Appendix 5.12.

Common areas of strength (criterion met for  $\geq$ 80% of SRs) were in the inclusion of a clear statement of the review question (Item 1), appropriate inclusion criteria (Item 2), clear search strategy (Item 3), the use of an appropriate critical appraisal tool (Item 5), recommendations for policy/practice (Item 10), and suggestions for future research (Item 11). Common areas of weakness (criterion met for < 80% of SRs) related to accessing appropriate sources including grey literature (Item 4), the use of independent reviewers to assess critical appraisal (Item 6), adoption of methods to minimise extraction errors (Item 7), and a lack of appropriate methods for combining study findings (Item 8). Of the 32 SRs (65%) that included a meta-analysis, 23 (72%) included an assessment of potential publication bias (Item 9).

The quality of studies included within SRs was assessed by the original review authors using a variety of tools (see Appendix 5.8). The most common of these were the original and revised Cochrane Collaboration tools for assessing risk of bias (Higgins et al., 2011; Sterne et al., 2019) followed by the Evaluative Method for Determining Evidence-Based Practice in Autism (Reichow et al., 2008). Twenty-four SRs (50%) were identified as including at least one study at high risk of bias, 5 (10%) as including at least one study with moderate risk of bias, and 2 (4%) as only including studies at low risk of bias. A determination regarding overall risk of bias for included original studies could not be made for 17 SRs (29%) due to insufficient data or the reporting of bias on an item-by-item level, rather than for each study overall.



# Question 1: What non-pharmacological supports have been examined in SRs?

The range of non-pharmacological supports examined in the SRs is covered in Appendix 5.8.

## Question 2: What effects do non-pharmacological supports have on child outcomes?

The effect of non-pharmacological supports on child outcomes is presented in Appendix 5.13. The effect sizes (for meta-analyses) and author statements (qualitative summaries) are provided in Appendix 5.14. Adverse child effects are presented in Appendix 5.15.

# **Question 3: What effects do non-pharmacological supports have on family wellbeing?**

The effect of non-pharmacological supports on family outcomes is presented in Appendix 5.13. The effect sizes (for meta-analyses) and author statements (qualitative summaries) are provided in Appendix 5.14.

# Question 4: What delivery characteristics influence the effects of supports, with a focus on the amount of support, setting, format, agent, and mode?

The influence of delivery characteristics on child outcomes is reported in Appendix 5.16, while the influence of amount of support on child outcomes is reported in Appendix 5.17.

### Question 5: What child characteristics influence the effects of supports, with a focus on child age, core autism characteristics, cognition, and communication skills?

The relationship between child characteristics and child outcomes is reported in Appendix 5.18.



## 6. Systematic Review of Individual and Family Experiences of Accessing Services

## 6.1 Background

Understanding the experiences of autistic children and their families is a critical element of evidence-based practice. Accordingly, research that has examined these experiences may contribute evidence to inform the formulation of Guideline Recommendations. In this study, the GDG examined evidence from studies that explored the experiences of autistic children and their families who accessed supports in Australia, as part of community-based service provision. Prior to this systematic review, no similar review in the Australian context appears to have been conducted.

## 6.2 Aim

The aim of this systematic review was to identify and explore original research relating to the experiences of autistic individuals and their family members accessing supports and therapies during childhood.

## 6.3 Research question

What are the experiences of autistic individuals and their families in accessing therapies and supports during childhood?

## 6.4 Design

A systematic review was selected as the most appropriate method for addressing the research aim and questions. The review was conducted in accordance with the procedures outlined in the PRISMA statement (Page et al., 2021).

## 6.5 Method

#### **Eligibility Criteria**

Development of the eligibility criteria was an iterative process, with these stages described in detail below.

#### Stage 1

Both primary studies (peer-reviewed articles utilising either qualitative or quantitative methodologies) and published commentaries or viewpoints of the experiences of autistic individuals accessing or receiving therapies and supports were considered eligible for inclusion if:



- The article specified one or more aims (may be presented as a purpose, objective, aim, or research question) relating to examining the views, experiences, preferences, and/or perceptions of at least one child, and/or family member of at least one child, who accessed therapies and supports during childhood (0-12 years).
- The publication had an aim, objective, or research question which specifically examined the experiences of accessing therapies and supports, or an aspect of service delivery relating to accessing therapy and supports (e.g., planning, delivery) for:
  - Autistic children, or;
  - Parents/caregivers or family members (e.g., siblings, grandparents) of autistic children.
- The publication reports on experiences relevant to one of the guideline question areas (e.g., principles, goal setting).
- For qualitative or quantitative primary studies:
  - These must be published in a peer-reviewed journal.
- For viewpoint/commentary article:
  - These must be published in a peer-reviewed journal, and
  - Author/s must indicate within the article text that their experiences accessing therapies and supports, as an individual and/or parent/caregiver, informed the article.
- Publications reported on experiences accessing a non-pharmacological therapy or support. This could have been explicitly stated or inferred by consensus agreement between two members of the research team responsible for selecting the articles following the search. Evidence on which to make the inference may include reference to the goals, agents, settings, and/or outcomes of the therapies and supports described.
  - The publication reports on experiences during childhood. This can be retrospectively.
- The publication had a full-text copy available in the English language.

Studies were excluded if they met any of the following criteria:

- Publications which describe the experiences of children and families accessing complementary and alternative medicines and/or biologically-based.
- Articles for which the primary aim (may be presented as a purpose, objective, aim, or research question) is to evaluate the therapeutic effects of the therapy or support within a clinical trial.
- Experiences were examined in a thesis, conference abstracts, newsletter, or grey literature (e.g., blog posts, newsletters, websites).



#### Stage 2

Following initial searches, and in discussion with the Co-chairs of the GDG, a decision was made to further limit articles to those examining the experiences of autistic Australians and their families.

In line with above, the following inclusion criteria was added, with searches re-run to limit to Australian publications:

• The publication reports on experiences of Australian children and/or families. Where not explicitly stated, study authors will be contacted for confirmation, and where no response is received study location will be inferred by consensus agreement between two members of the research team. Evidence on which to make the inference will include the first authors research institute and/or the HREC which approved the study.

#### Stage 3

Following title and abstract screening by one author (RS), and in discussion with the working group, a decision was made to further refine the eligibility criteria to ensure that included studies were explicitly describing the experiences of autistic children, and their families, in accessing community-based therapies and supports.

Independent screening of the full text articles was then conducted (by RS) applying the following additional criteria.

- Publications must report experiences of autistic children, and their families, in accessing community-based (i.e., fee for service) therapies and supports. This could have been explicitly stated or inferred by consensus agreement between two members of the research team responsible for selecting the articles following the search.
- Publications will be excluded if therapies and supports were provided as part of a research study only (e.g., within a clinical trial or pilot study) rather than as part of community service provision.
- The final criteria applied to full-text evaluations is provided below.

Both primary studies (peer-reviewed articles utilising either qualitative or quantitative methodologies) and published commentaries or viewpoints of the experiences of autistic individuals accessing or receiving therapies and supports were considered eligible for inclusion if:

- The article specified one or more aims (may be presented as a purpose, objective, aim, or research question) relating to examining the views, experiences, preferences, and/or perceptions of at least one child, and/or family member of at least one child, who accessed therapies and supports during childhood (0-12 years).
- The publication had an aim, objective, or research question which specifically examined the experiences of accessing therapies and supports, or an aspect of



service delivery relating to accessing therapy and supports (e.g., planning, delivery) for:

- Autistic children, or;
- Parents/caregivers or family members (e.g., siblings, grandparents) of autistic children.
- The publication reports on experiences relevant to one of the guideline question areas (e.g., principles, goal setting).
- For qualitative or quantitative primary studies:
  - published in a peer-reviewed journal.
- For viewpoint/commentary article:
  - These must be published in a peer-reviewed journal, and
  - Author/s must indicate within the article text that their experiences accessing therapies and supports, as an individual and/or parent/caregiver, informed the article.
- Publications reported on experiences accessing a non-pharmacological therapy or support. This could have been explicitly stated or inferred by consensus agreement between two members of the research team responsible for selecting the articles following the search. Evidence on which to make the inference may include reference to the goals, agents, settings, and/or outcomes of the therapies and supports described.
- The publication reports on experiences during childhood. This can be retrospectively.
- The publication reports on experiences of Australian children or families.
  - Where not explicitly stated, study authors will be contacted for confirmation, and where no response is received study location will be inferred by consensus agreement between two members of the research team. Evidence on which to make the inference will include the first authors research institute and/or the HREC which approved the study.
- Publications must report experiences of autistic children, and their families, in accessing community-based (i.e., fee for service) therapies and supports. This could have been explicitly stated or inferred by consensus agreement between two members of the research team responsible for selecting the articles following the search.
- The publication had a full-text copy available in the English language

Studies were excluded if they met any of the following criteria:

• Publications which describe the experiences of children and families accessing complementary and alternative medicines and/or biologically-based.



- Articles for which the primary aim (may be presented as a purpose, objective, aim, or research question) is to evaluate the therapeutic effects of the therapy or support within a clinical trial.
- Publications will be excluded if therapies and supports were provided as part of a research study only (e.g., within a clinical trial or pilot study) rather than as part of community service provision.
- Experiences were examined in a thesis, conference abstracts, newsletter, or grey literature (e.g., blog posts, newsletters, websites).

#### Literature search strategy

A literature search was conducted on December 14<sup>th</sup> 2021 using the following databases: PsycINFO, Education Resources Information Centre (ERIC), Medline, PubMed, EMBASE, CINAHL, Scopus, EBSCO Education Source, and Epistemonikos. The search terms were: (Autism OR ASD OR Asperger OR Aspergers OR "pervasive developmental disorder" OR PDD OR "pervasive child development disorder" OR "pervasive childhood developmental disorder" OR PCDD OR "disintegrative disorder") AND (intervention OR interventions OR therapy OR therapies OR treatment OR treatments OR teach OR program OR programs OR package OR packages) AND (experience OR feedback OR "social validity" OR view OR opinion OR acceptance OR satisfaction OR perception OR criticism) AND Australia<sup>\*</sup>. The search was not limited by publication date. Ancestral searches were conducted using the reference lists of all included publications. The complete search string for each database is provided in Appendix 6.1.

#### **Study selection**

All studies retrieved from database searches were imported into the EndNote software platform. Duplicates identified by the software were removed prior to screening. Initial title and abstract screening (see Stage 2 above) of all identified studies was conducted by one reviewer (RS). Articles were excluded if they met one or more exclusion criteria. A second reviewer (DT) conducted consensus checks on all decisions made at this stage.

Full text screening was then conducted (by RS), against updated eligibility criteria (see Stage 3 above). Articles were excluded if they met one or more exclusion criteria. Consensus checks were then conducted by a second reviewer (DT). Following consensus checks, both reviewers met to resolve disagreements. The percentage of agreement [agreements/(disagreements + agreements) × 100] was 91.4% for the updated full-text consensus checks.

#### Data extraction and coding of included study data

One reviewer (RS) extracted key study details (including author, date, study aim, design, participants, type of therapy and supports included, settings) for each of the included studies into a standardised data extraction form (Appendix 6.2). Following this, included studies were imported into the NVivo Software Platform for coding of study results. The



same coding framework used for the systematic review of previous guidelines (Gale et al., 2013; see Chapter 4) was used to code the articles, according 17 underlying principles, with an option to code for 'other' when results did not fit an existing principle. To ensure participants quotes published in included qualitative studies were not taken out of context, only the study authors' interpretations of data collected were coded for the purpose of this review.

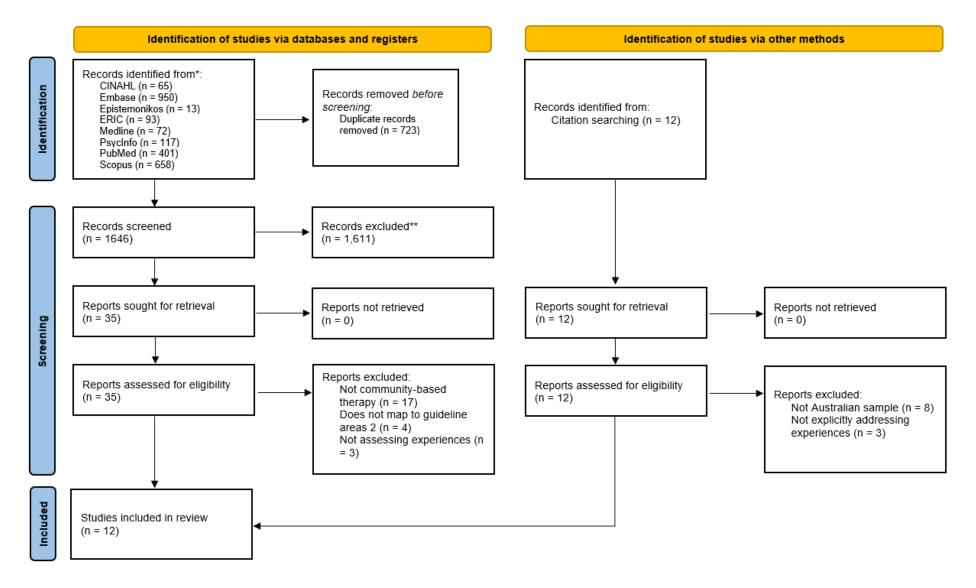
## 6.6 Results

#### **Study selection**

The PRISMA diagram in Figure 6.1 outlines the study selection process (Page et al., 2021). The database search yielded 2,369 records across databases and 1,646 records once duplicates were removed. Thirty-five articles proceeded to full-text review and 24 articles were excluded at this stage. The most common reasons for exclusion were (a) therapies and supports were not accessed as part of community-based services (e.g., provided as part of RCT or pilot); (b) study aims did not map onto guideline question areas, (c) studies were concerned with child outcomes accessing therapies and supports, not overall experiences of engaging with these. Ancestral searches yielded an additional 12 articles, of which 11 were excluded.



#### Figure 6.1 PRISMA Flow Diagram





#### **Study Characteristics**

A total of 12 studies were eligible for inclusion. Appendix 6.3 presents a summary of study characteristics, including illustrative quotes related to codes within the coding framework.

#### **Qualitative data**

A total of 110 references were coded across the 12 studies. Table 6.1 presents the codes, the number of studies for which the code was relevant, and then number of references (i.e., quotes) that were extracted. These quotes, where relevant to the formulation of Recommendations and Good Practice Points, feature in the corresponding evidence summaries.

Codes	Number of Studies	References
Accessible	0	0
Affirming	3	5
Assent (children)	0	0
Child and family-centred	4	18
Coordinated	2	5
Culturally aware and responsive	0	0
Developmental Perspective	1	1
Empirically Supported	5	11
Equity	10	20
Ethical	0	0
Evidence-based approach	1	1
Holistic	6	9
Informed consent (parents)	1	2
Lifespan perspective	2	3
Other	4	8
Personalised	5	11
Qualified practitioners	4	11
Strengths-focused	0	0
Supported	3	5

#### Table 6.1. Coding summary.



## 7. Community Consultation: Online Survey

## 7.1 Background

Integral to the development of the Guideline was consultation with the autistic and autism communities. Consistent with the recommendations in the Guidelines for Guidelines handbook (NHMRC, 2016), community consultation was conducted to ensure that all relevant stakeholders within Australia were provided with the opportunity to inform the development of the Guideline. This was key to enhancing the relevance and acceptability of the Guideline to the autistic and autism communities. The consultation process was also conducted to (a) complement the current research evidence, and/or (b) gather information and insight from relevant stakeholders where research evidence is currently lacking.

This consultation activity adopted an online survey methodology. This approach was used to enable broad participation and input from all relevant stakeholders, aged 12 years or older, who identified as members of the autistic and/or autism communities.

## 7.2 Aim

The aim of the online survey was to understand the experiences, views and preferences of the autistic and autism communities regarding the provision of supports for autistic children and their families.

## 7.3 Research questions

- What are the experiences, views and preferences of the autistic and autism communities regarding the provision of supports for autistic children and their families?
- What are the autistic and autism communities' views on best practice for supporting autistic children and their families?

## 7.4 Design

An online survey methodology was adopted. This was a one-off survey, accessed via a link on the Autism CRC website. Participants had complete flexibility and autonomy in choosing what questions they would like to answer.

The survey was open to individuals aged 18 years and older for 10.5 weeks, from 16<sup>th</sup> February to 30<sup>th</sup> April 2022. After launching the online survey, we sought a variation to our study protocol to include individuals aged 12-17 years. As such, the online survey was open to young people aged 12-17 years for 3.5 weeks, from 6<sup>th</sup> April to 30<sup>th</sup> April 2022.



## 7.5 Method

Ethical approval for this community consultation activity was provided by Griffith University Human Research Ethics Committee (2021/843).

### Eligibility

All relevant stakeholders aged 12 years and older, across the autistic and autism communities were eligible to participate in the online survey, including

- Autistic young people and adults
- Parents of autistic children
- Family members of autistic children
- Practitioners who provide services to autistic children and their families
- Members of organisations or services that provide support to autistic children and their families
- Any other relevant stakeholders (e.g., researchers, educators)

#### Recruitment

Participant recruitment for community consultation activities was predominantly facilitated by Autism CRC. Prior to the release of the consultation activities (including the online survey), Autism CRC invited members of their mailing list (*n*=8,432 representing autistic individuals, parents and family members, and practitioners/service providers working with autistic children and young people) to register their interest in receiving updates regarding development of the Guideline. All individuals who registered their interest in the Guideline received an initial invitation to participate, and subsequent reminders of the survey closing date over the >10-week consultation period. In addition, links to access the online survey were made available via the Autism CRC Supporting Children Guideline website page, and social media (Facebook and Twitter) accounts. Members of the GDG also promoted the online survey throughout their professional networks and social media pages.

After accessing the online survey link, prospective participants were presented with a short video outlining what participation in the survey would entail and highlighting accessibility features of the survey platform. Following this, participants were presented with a Participant Information Statement and Consent Form. All participants were required to provide informed consent before accessing the survey questions.

#### Tools

An iterative approach was taken to designing the online survey. The structure and items in the survey were predominantly informed by the set of questions developed by the GDG, underpinning all aspects of the Guideline's development related to supporting autistic children and their families. These questions cover five key areas of service provision: (1) overarching principles, (2) goal-setting, (3) selection and planning of supports, (4) delivery of



supports, and (5) monitoring and safeguarding of supports. The items in the online survey were developed in conjunction with the Delphi survey (see Chapter 9) to ensure that all stakeholders had an opportunity to provide feedback on all areas intended to be covered in the Guideline.

A draft version of the online survey was circulated to the GDG for feedback. A revised version of the survey (incorporating GDG feedback) was coded in REDCap (a secure webbased application for survey development and distribution) and piloted by five individuals, independent and external to the GDG, who represented a variety of perspectives. These five individuals included two autistic adults, two parents of autistic children, and one practitioner. Feedback provided through the piloting process led to further modifications, including reducing the length of the survey and addressing perceived repetitiveness of some items.

Additional consultation was sought by the Working Group from a member of the GDG regarding the appropriateness and accessibility of the online survey for Aboriginal and/or Torres Strait Islander Peoples. Based on this consultation, additional changes were made to the survey, to allow more flexibility and a streamlined approach to completing the online survey.

The final survey (see Appendix 7.1 and Appendix 7.2) distributed to the community, consisted of both closed questions (that included quantitative and qualitative items) and open ended questions organised across several sections: (a) participant demographics, (b) the opportunity for autistic people and parents of autistic children to share their story of accessing supports, (c) general thoughts about the development of a guideline, (d) a survey of language preferences in relation to autism, and (e) questions gathering information on the five key Guideline areas, as outlined above.

Questions regarding language preferences were included in the survey to ensure an evidence-based approach to selecting terminology for use in the Guideline, supporting documents, and other resources and activities associated with the Guideline (e.g., community webinars). The GDG developed the questions and an *a priori* decision-making framework (Appendix 7.3) that would be used to make the determination. The decision-making framework was designed to ensure terminology selected was both desirable and acceptable to autistic people and parents of autistic children, while taking into consideration of all members of the broader autistic and autism communities.

Participants were provided with multiple pathways to navigate through the survey, including the capacity to skip sections and/or exit the survey at multiple points. The final survey was estimated to take between 15 to 60 minutes to complete depending on which questions participants chose to answer.



#### Analysis

#### **Quantitative data**

The online survey included 17 items that asked participants to rate their agreement with statements on a 5-point Likert-type scale: (1) strongly disagree, (2) disagree, (3) neutral, (4) agree, (5) strongly agree. These statements related to guiding principles should be followed when providing supports to autistic children and their families. For these items, data were exported from REDCap into SPSS (v26) for quantitative analysis. For each item, the median rating and interquartile range was calculated separately for each stakeholder group. In addition, the percentage agreement with each item (i.e., the number of participants rating the item as '4' or '5'), the percentage disagreement with each item (i.e., the number of participants rating the item as '1' or '2'), and the percentage of neutral responses (i.e., the number of participants rating the item as '3') was calculated separately for each stakeholder group.

#### **Qualitative data**

Qualitative data gathered via the online survey, as well as all three other community consultation activities (focus groups, brief survey, parent reflections) were analysed using the Framework method (Gale et al., 2013). The framework method was also used to code the systematic review of existing guidelines (Chapter 4) and the systematic review of individual and family experiences of accessing services (Chapter 6). The process, as it pertained to coding of community consultation activities is presented here and involved the following steps:

#### **Coding framework**

A coding framework was developed to reflect, and allow coding of, participant responses to each of the Guideline questions. The codes within the framework reflected the statements presented in the Delphi survey to practitioners, which had in turn been developed through an iterative process that drew on various forms of input, including: (a) systematic review of existing guidelines from other jurisdictions around the world (see Chapter 4), (b) umbrella review of existing research evidence (see Chapter 5), (c) recent, relevant research articles (e.g., Lord et al., 2022, Trembath et al., 2021), (d) frameworks of evidence-based practice (e.g., Sackett et al., 2000), and (e) review and feedback from the GDG. Adopting this approach meant that the GDG could code responses in a consistent manner across the community-consultation activity (e.g., online survey, focus groups, Delphi study, brief survey, parent reflections), thereby ensuring that views and experiences could be compared and contrasted during the process of formulating Recommendations and making judgements within the evidence-to-decision framework. The code book, that contains the complete framework, along with instructions to coders (addressed below) is provided in Appendix 7.3). In applying the coding framework, research assistants had the option of applying an 'other' code to any comment that they felt did not fit with an existing code. This approach



was adopted to ensure that novel, including contrasting, views could be accounted for in the coding process.

#### **Coding Process**

A team of five research assistants was appointed to assist with the coding of all feedback gathered during the community consultation process. The team comprised people with a combination of relevant professional experience and, for two members, lived experience of autism.

The following processes were used to train and then support the research assistants to complete the coding:

- David Trembath (Co-chair) and Emma Hinze (research assistant) worked together, supported by the GDG, to establish the processes that would be used to code the data and support the research assistants in their work. The code book was created along with all administrative processes required to securely and reliably manage the data and coding processes.
- Each of the remaining four research assistants (Briohny Dempsey, Georgia Earl, Libby Groves, Rachelle Wicks) were invited to participate in the project, via an email that briefly outlined the Guideline project and their proposed role (i.e., supporting qualitative analysis). There was an opportunity to discuss the appointment, prior to agreeing. A variation to Griffith University Human Research Ethics Committee to support each person's involved was granted.
- David Trembath and Emma Hinze met with each of the research assistants to:
  - Provide an overview of the project.
  - Review the processes that would be used in data management and coding.
  - Review the codes relevant to each person's role in the coding.
  - Answer any questions arising.
- Each research assistant was then given access to the code book and relevant data, as well as training in NVivo which was used to support the coding process. Emma Hinze was responsible for coordinating data management and fielding queries on a daily basis, with David Trembath available to support Emma at all times.
- All coding occurred in NVivo. Research assistants were allocated different Guideline questions, and then coded the relevant responses from each community consultation activity. For example, the person who coded 'principles' did so for each of the community consultation activities to help ensure a consistent approach. The instructions that were to be followed are presented in Appendix 7.3, but in brief included:
  - Reviewing the code book
  - Within NVivo, reviewing each participant's response and coding according to the framework



- Completing memos in which the research assistant was asked to reflect on any patterns they were seeing in the data (e.g., prominent themes); differences, contrasts, and/or contradictions in the responses; any challenges they were experiencing in assigning codes; suggestions for possible new or revised codes; reasons for why they may have coded a specific way or anything else that they, at that time, felt was important. These memos (reflections) were used to help create an audit trail, to inform the coding process and interpretation of the data, and to support the research assistants in their work.
- During coding, the team met on a weekly basis to discuss the coding process, as well as to discuss their experience of completing the coding. This meeting was open to all members of the GDG involved in data gathering and coding. The rationale for this meeting was two-fold. First, the meetings provided an additional opportunity to ensure fidelity within the coding process (i.e., in addition to standardised training, standardised coding, and on-call support at all times). Second, the meetings provided an opportunity for team members to share and debrief about their experiences. It became apparent, from the first day of data gathering and coding, that the personal insights and experiences shared by members of the autistic and autism communities were often very confronting in terms of the challenging circumstances people had found themselves in, were experiencing currently, or foresaw themselves and their loved ones experiencing in the future. The focus of the debrief was to share individual feelings, support each other, and identify if any further support was required. Doing so ensured each team member was supported, and in doing so ensured the process was carried out with fidelity.

As indicated above, multiple approaches were used to help ensure the credibility of the coding process (i.e., akin to *reliability* in quantitative research) including employing people with relevant expertise, using a standardised code book and training procedures, ensuring on-call support on a daily basis and weekly team meetings for fidelity and support purposes, and ultimately presenting evidence using people's own words when presenting the evidence summaries. In addition, a credibility check was completed for every quote identified during the coding process was reviewed.

The credibility check was intended to (a) ensure that quotes were attributed to codes accurately and (b) ultimately provide readers of the Guideline with information to inform their interpretation of the data. The instructions were to:

- Review the contents (quote/s) one cell (participant) at a time.
- Ask yourself "Is this quote relevant to the code that has been applied?"
  - If the answer is yes, proceed to next step. In some cases, you may find that the quote is ambiguous because you are only reviewing part of a participant's more expansive response or due to the participant's expression. It is not intended that each quote will be a complete and cohesive statement in



relation to the code, and so provided that in your judgement the quote appears to be relevant, it can be marked yes

- If the answer is no, ask yourself "Is this quote potentially relevant to addressing one or more other guideline questions?
- If yes, highlight the quote in yellow.
- If no, highlight the quote in red, indicating that the quote does not appear to fit the current code, and does not appear relevant to addressing one or more guideline questions.

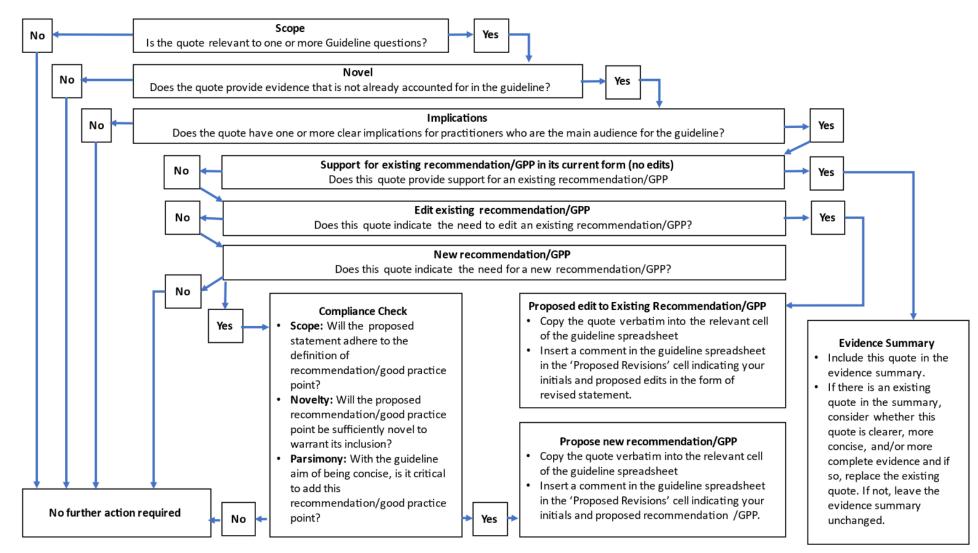
This approach resulted in the classification of each quote in each code as either 'relevant to the Guideline and code,' 'relevant to the Guideline, but cannot establish relevance to code,' or 'does not appear to be relevant to the Guideline.' The proportion of responses related to each classification is provided in the Results section for each community consultation study. It is important to note that the person completing the credibility check was reviewing the coded data, not the original transcripts. Accordingly, they did not necessarily have knowledge of the context (e.g., broader statement) from which the quotes had been extracted, which may account for some of the disagreements.

## Applying codes in the development of evidence summaries for Recommendations and Good Practice Points.

The following process was developed, and implemented by members of the GDG (Sarah Pillar, David Trembath, Kandice Varcin, Hannah Waddington, Andrew Whitehouse) to ensure that qualitative data gathered during the community consultation activities could (a) be considered in a systematic manner when formulating Recommendations and Good Practice Points and (b) used to populate the evidence summaries for each Recommendation and Good Practice Point in a consistent manner. Implementation of the process with fidelity was supported by (a) documenting the process, (b) producing a video to explain the process that was used to support implementation (including worked examples), and (c) daily interaction with Microsoft Teams to support implementation. Figure 7.1 presents the decisions each panel member made when reviewing each participant's quote, in relation to each code, and determining if/how it would inform the formulation of Recommendations and Good Practice Points and corresponding evidence summaries.



#### Figure 7.1 Applying codes in the development of evidence summaries for Recommendations and Good Practice Points.





Following application of this process, and at the point where the GDG had reviewed all Draft Recommendations and Good Practice Points, members of the GDG (Sarah Pillar, David Trembath, Kandice Varcin, Hannah Waddington, Andrew Whitehouse) then reviewed the original qualitative data for community consultation activities to identify further participant comments that were relevant to the evidence summaries. This included a quote-by-quote review for every response coded as 'other' during the coding process, to ensure that information that did not fit within the coding framework was considered on multiple occasions, in raw form (i.e., quote by quote) and collectively (when viewed alongside the complete set of data) to ensure that novel Recommendations and Good Practice Points could emerge.

## 7.6 Results

#### **Participant characteristics**

In total, 667 participants provided informed consent to participate in the online survey. This included 88 autistic adults, 229 parents of an autistic child, 21 family members of an autistic person, 107 individuals who provide services to autistic children and their families, 145 members of organisations or services that provide services to autistic children and their families, 38 participants belonging to 'Other' groups, and 39 participants that did not specify any group. Of note, no young people (aged 12-17 years) chose to provide feedback via the online survey.

Demographic information for each group (as self-identified by the person completing the survey) is presented in Tables 7.1 - 7.6.

#### **Autistic adults**

**Table 7.1** Demographic information of autistic people who provided informedconsent for the online survey (n=88).

Autistic Adults		
Other perspectives	Autistic adults brought the following additional perspectives:	
	• Parent/primary caregiver of an autistic person: n=38	
	• Family member of an autistic person: n=28	
	• An individual who provides services to autistic children: n=17	
	• Member of an organisation or service that provides services to autistic children and their families: n=12	
	• Other: n=15	
	11 participants did not provide a response.	
Age	Autistic adults were in the following age brackets:	



	· · · · · · · · · · · · · · · · · · ·	
	• 18-20 years: n=3 (3%)	
	• 21-30 years: n=14 (16%)	
	• 31-40 years: n=22 (25%)	
	• 41-50 years: n=23 (26%)	
	• 51-60 years: n=13 (15%)	
	• 61-70 years: n=9 (10%)	
	• 71-80 years: n=0 (0%)	
	• 81-90 years: n=1 (1%)	
	3 participants (3%) did not provide a response.	
Gender identity	66 autistic adults identified as female (75%), 11 identified as male (12.5%), 6 as non- binary (7%), 2 as other (2%) and 3 preferred not to say (3%).	
Aboriginal and/or Torres Strait Islander Peoples	1 autistic adult (1%) identified as Aboriginal. 84 autistic people did not identify as Aboriginal or Torres Strait Islander (95%). 3 participants (3%) did not provide a response.	
State/Territory	Autistic adults resided in the following States/Territories within Australia:	
	Australian Capital Territory: n=5 (6%)	
	• New South Wales: n=22 (25%)	
	Northern Territory: n=0 (0%)	
	• Queensland: n=16 (18%)	
	• South Australia: n=8 (9%)	
	• Tasmania: n=4 (4.5%)	
	• Victoria: n=20 (23%)	
	• Western Australia: n=11 (12.5%)	
	2 participants (2%) were not currently residing in Australia (and as such, were unable to progress any further through the survey).	
Location	58 autistic adults lived in a major city (66%) and 28 lived in regional/remote areas (32%). 2 participants (2%) did not provide a response.	
Place of birth	74 autistic adults (84%) were born in Australia. 11 were not born in Australia (12.5%). 3 participants (3%) did not provide a response.	
Languages other than English	81 (92%) autistic adults were living in homes where only English was spoken. 4 (4.5%) were living in homes where languages other than English was spoken. 3 participants (3%) did not provide a response.	
Formal diagnosis of autism	72 autistic adults (82%) had received a formal diagnosis of autism. 4 autistic adults (4.5%) were currently being assessed for a possible diagnosis of autism. 3 autistic adults (3%) self-identified as autistic but had not received a formal diagnosis of	



	autism. 3 participants (3%) chose not to share additional information about their diagnosis. 6 participants (7%) did not provide a response.	
Age of autism diagnosis	Of the 72 adults that had received a formal diagnosis, the average age of diagnosis was 36.25 years (SD = 15.93), with ages ranging from 3 years to 81 years. 3 participants (4.2%) did not provide a response.	
DSM-5 diagnosis level of support	<ul> <li>Of autistic adults diagnosed under the DSM-5, the following support levels were associated with the diagnosis:</li> <li>8 (27%) were diagnosed at Level 1.</li> <li>4 (14%) were diagnosed at Level 2.</li> <li>2 (7%) were diagnosed at Level 3.</li> <li>13 (45%) were unsure.</li> <li>2 (7%) preferred not to say.</li> </ul>	
Representative DSM-5 level of support	<ul> <li>Of autistic adults not diagnosed under the DSM-5, participants reported the following would have been most representative of their supports needs as a child:</li> <li>30 (45%) selected Level 1 as most representative.</li> <li>20 (30%) selected Level 2 as most representative.</li> <li>3 (5%) selected Level 3 as most representative.</li> <li>11 (17%) were unsure.</li> <li>2 (3%) preferred not to say.</li> </ul>	
Access to supports between 0-6 years	4 autistic adults (4.5%) reported receiving or accessing supports (for themselves) between the ages of 0-6 years. 74 autistic adults (84%) did not receive or access supports (for themselves) between the ages of 0-6 years. 3 participants (3%) chose not to share this information. 7 participants (8%) did not provide a response.	
Access to supports between 7-12 years	3 autistic adults (3%) reported receiving or accessing supports (for themselves) between the ages of 7-12 years. 75 autistic adults (85%) did not receive or access supports (for themselves) between the ages of 7-12 years. 3 participants (3%) chose not to share this information. 7 participants (8%) did not provide a response.	

#### Parents of autistic children

**Table 7.2.** Demographic information of parents of autistic children who provided informed consent for the online survey (n=229).

Parents of autistic children	
Other perspectives	<ul> <li>Parents of autistic children brought the following additional perspectives:</li> <li>Autistic person: n=38</li> <li>Family member of an autistic person: n=31</li> </ul>



	• An individual who provides services to autistic children: n=22	
	<ul> <li>Member of an organisation or service that provides services to autistic children and their families: n=44</li> </ul>	
	• Other: n=17	
	69 participants did not provide a response.	
Age	Parents of autistic children were in the following age brackets:	
	• 21-30 years: n=1 (0.4%)	
	• 31-40 years: n=59 (26%)	
	• 41-50 years: n=116 (51%)	
	• 51-60 years: n=32 (14%)	
	• 61-70 years: n=12 (5%)	
	• 71-80 years: n=3 (1%)	
	6 participants (3%) did not provide a response.	
Gender identity	211 parents identified as female (92.5%), 14 identified as male (6%), 1 as non-binary (0.4%), and 2 preferred not to say (2%). 1 participant (0.4%) did not provide a response.	
Aboriginal and/or Torres Strait Islander Peoples	3 parents (1%) identified as Aboriginal. 220 parents (96%) did not identify as Aboriginal or Torres Strait Islander. 6 participants (3%) did not provide a response.	
State/Territory	Parents of autistic children resided in the following States/Territories within Australia:	
	Australian Capital Territory: n=10 (4%)	
	• New South Wales: n=55 (24%)	
	Northern Territory: n=3 (1%)	
	• Queensland: n=56 (25%)	
	• South Australia: n=8 (3.5%)	
	• Tasmania: n=4 (2%)	
	• Victoria: n=52 (23%)	
	• Western Australia: n=34 (15%)	
	6 participants (3%) were not currently residing in Australia (and as such, were unable to progress any further through the survey).	
	1 participant (0.4%) did not provide a response.	
Location	171 parents lived in a major city (77%) and 52 lived in regional/remote areas (23%). 6 participants (3%) did not provide a response.	



Place of birth	185 parents (81%) were born in Australia. 37 were not born in Australia (16%). 7 participants (3%) did not provide a response.
Languages other than English	210 (92%) parents were living in homes where only English was spoken. 12 (5%) were living in homes where languages other than English was spoken. 7 participants (3%) did not provide a response.
Child's formal diagnosis of autism	244 children had received a formal diagnosis of autism. 19 children had not yet received a formal diagnosis of autism.
	1 parent chose not to share additional information about their child's diagnosis. 15 participants did not provide a response to these items.
Child's age of autism diagnosis	Of the 244 children that had received a formal diagnosis, the average age of diagnosis was 11.68 years (SD = 6.37), with ages ranging from 1 year to 41.5 years. 43 participants did not provide their child(ren)'s age.
Child's DSM-5 diagnosis level of	Of children diagnosed under the DSM-5, the following support levels were associated with the diagnosis:
support	• 39 (16%) were diagnosed at Level 1.
	• 146 (60%) were diagnosed at Level 2.
	• 42 (17%) were diagnosed at Level 3.
	• 13 (5%) were unsure.
	• 4 parents (2%) preferred not to say.
Child's Representative DSM-5 level of support	Of children not diagnosed under the DSM-5, parents reported the following would have been most representative of their child's supports needs when they were a child:
	• 18 (3%) selected Level 1 as most representative.
	• 36 (52%) selected Level 2 as most representative.
	• 13 (19%) selected Level 3 as most representative.
	• 2 (3%) were unsure.
Child's access to supports between 0-6 years	Of the 263 children that details were provided for, 195 children (74%) received or accessed supports between the ages of 0-6 years. 68 (26%) children did not receive or access supports between the ages of 0-6 years.
Child's access to supports between 7- 12 years	Of the 263 children that details were provided for, 199 children (76%) received or accessed supports between the ages of 7-12 years. 45 (17%) children did not receive or access supports between the ages of 7-12 years. Responses were not provided to this item for 19 children (7%).



#### Family members of an autistic person

**Table 7.3.** Demographic information of family members of an autistic person who provided informed consent for the online survey (n=21).

Family members of an autistic person	
Relationship	Family members of autistic people included:
	• Parent: n=7
	• Grandparent: n=6
	• Sibling: n=3
	• Cousin: n=1
	• Aunt: n=1
	3 participants did not specify their relationship.
Other perspectives	Family members of autistic people brought the following additional perspectives:
	Autistic person: n=2
	Parent of an autistic person: n=2
	• An individual who provides services to autistic children: n=3
	• Member of an organisation or service that provides services to autistic children and their families: n=6
	• Other: n=3
	4 participants did not provide a response.
Age	Family members of autistic children were in the following age brackets:
	• 21-30 years: n=3 (14%)
	• 31-40 years: n=1 (5%)
	• 41-50 years: n=3 (14%)
	• 51-60 years: n=6 (29%)
	• 61-70 years: n=3 (14%)
	• 71-80 years: n=4 (19%)
	1 participant (5%) did not provide a response.
Gender identity	18 family members identified as female (86%), 2 identified as male (9.5%), and 1 preferred not to say (5%).



Aboriginal and/or Torres Strait Islander Peoples	No family members identified as Aboriginal. 20 family members (95%) did not identify as Aboriginal or Torres Strait Islander. 1 participant (5%) did not provide a response.
State/Territory	<ul> <li>Family members of autistic people resided in the following States/Territories within Australia:</li> <li>Australian Capital Territory: n=0 (0%)</li> </ul>
	<ul> <li>New South Wales: n=6 (29%)</li> </ul>
	<ul> <li>Northern Territory: n=0 (0%)</li> </ul>
	• Queensland: n=4 (19%)
	• South Australia: n=2 (9.5%)
	• Tasmania: n=1 (5%)
	• Victoria: n=3 (14%)
	• Western Australia: n=5 (24%)
Location	15 family members lived in a major city (71%) and 5 lived in regional/remote areas (24%). 1 participant (5%) did not provide a response.
Place of birth	15 family members (71%) were born in Australia. 5 were not born in Australia (24%). 1 participant (5%) did not provide a response.
Languages other than English	19 (90%) family members were living in homes where only English was spoken. 1 (5%) was living in a home where languages other than English was spoken. 1 participant (5%) did not provide a response.

#### Individuals who provide services

**Table 7.4.** Demographic information of individuals who provide services to autistic children who provided informed consent for the online survey (n=107).

Individuals who provide services	
Profession	Individuals who provide services to autistic children and their families included:
	Art therapist: n=2
	Behaviour therapist (not board certified): n=8
	Board certified behaviour analyst: n=4
	Developmental educator: n=1
	• Educator (early childhood): n=3
	Educator (primary school): n=3
	• Educator (high school): n=2



	Exercise scientist: n=1
	Music therapist: n=2
	Occupational therapist: n=16
	Paediatrician: n=3
	Physiotherapist: n=5
	Play therapist: n=2
	Psychologist: n=31
	• Researcher: n=5
	• Social worker: n=1
	• Speech pathologist: n=19
	Support worker: n=1
	• Other: n=6
	8 participants did not specify their profession.
Other perspectives	Individuals who provide services to autistic children and their families brought the following additional perspectives:
	Autistic person: n=8
	Parent of an autistic person: n=9
	Family member of an autistic person: n=20
	<ul> <li>Member of an organisation or service that provides services to autistic children and their families: n=31</li> </ul>
	• Other: n=4
	29 participants did not provide a response.
Service role	Individuals were involved in the delivery of services to autistic children and their families in the following ways:
	Providing supports: n=84
	Providing advocacy: n=41
	Supervising others who provide supports: n=45
	Conducting research on supports: n=8
	<ul> <li>Responsible for staff and/or business processes that result in the delivery of supports: n=25</li> </ul>
	• Other: n=11
	9 participants did not provide a response.



Organisation type	87 individuals currently worked in private organisations (including non-government organisations) and 20 worked in government organisations. 8 participants did not provide a response.
Service setting	<ul> <li>Individuals who provide supports to autistic children did so across the following settings:</li> <li>Child's home: n=50</li> <li>Hospital (inpatient/outpatient): n=7</li> <li>Community clinic (including private practice): n=62</li> <li>University clinic: n=3</li> <li>Early childhood education centre: n=36</li> <li>Early childhood education centre in a specialised setting (catering only to children with additional earning needs): n=22</li> <li>Mainstream school: n=48</li> <li>Support class/unit within a mainstream school: n=22</li> <li>School specifically for autistic children: n=7</li> <li>School specifically for children with additional learning needs: n=22</li> <li>Other: n=4</li> </ul>
Service delivery	Individuals who provide supports to autistic children did so across the following modes: • Face-to-face: n=96 • Tele practice/videoconference: n=69 8 participants did not provide a response.
State/Territory	Individuals providing services (currently) practiced in/across the following States/Territories within Australia: • Australian Capital Territory: n=3 • New South Wales: n=27 • Northern Territory: n=1 • Queensland: n=26 • South Australia: n=6 • Tasmania: n=2 • Victoria: n=24 • Western Australia: n=13 11 participants did not provide a response.



Location	75 individuals provided services in a major city and 42 provided services in regional/remote areas. 8 participants did not provide a response.
Years of experience	Individuals who provide supports had on average 11.79 years ( <i>SD</i> = 8.78) experience working in clinical practice with autistic children. Years of experience ranged from 1 year to 35 years. 11 participants (10%) did not provide a response.
Caseload	Of individuals who provide supports, the proportion of their caseload that was autistic children in 2021 (i.e., the year prior to completing the online survey) included:
	• 0-25%: n=13 (12%)
	• 26-50%: n=19 (18%)
	• 51-75%: n=25 (23%)
	• 76-100%: n=42 (39%)
	8 participants (7.5%) did not provide a response.
Age groups	In 2021 (i.e., the year prior to completing the online survey) individuals provided supports to autistic children across the following age brackets:
	• 0-3 years: n=58
	• 4-6 years: n=87
	• 7-9 years: n=89
	10-12 years: n=80
	• 13-15 years: n=67
	• 16-18 years: n=50
	• 19 years and older: n=32
	8 participants did not provide a response.
Co-occurring conditions	As part of their practice, individuals provided supports to autistic children with the following co-occurring conditions:
	Physical disability (e.g., cerebral palsy): n=47
	Cognitive impairment (e.g., intellectual disability): n=88
	Health conditions (e.g., asthma, metabolic conditions): n=70
	Mental health conditions (e.g., anxiety, depression): n=85
	• Genetic conditions (e.g., Fragile X, Down syndrome): n=43
	• Sensory impairment (e.g., vision, hearing): n=41
	• Other: n=10
	9 participants did not provide a response.
Aboriginal and/or Torres Strait	In 2021 (i.e., the year prior to completing the online survey), 47 individuals (44%) provided supports to autistic children and their families who identify as Aboriginal



Islander families Peoples	and/or Torres Strait Islander. 51 individuals (48%) did not provide supports to children and families who identify as Aboriginal and/or Torres Strait Islander. 9 participants (8%) did not provide a response.
Languages other	In 2021 (i.e., the year prior to completing the online survey) 64 individuals (60%) provided supports to autistic children and their families who were from non-English speaking countries and spoke languages other than English in the home. 34 individuals (32%) provided supports only to autistic children who were from English-speaking countries and only spoke English in the home.
than English	9 participants (8%) did not provide a response.

#### **Members of organisations**

**Table 7.5**. Demographic information of members of organisations that provide services to autistic children and their families who provided informed consent for the online survey (n=145).

Members of organisati	ons
Organisational level response	<ul> <li>Members of organisations responded to the online survey as:</li> <li>Individual members: n=118 (83%)</li> <li>The nominated representative of the organisation (i.e., submitting on behalf of the organisation as a whole): n=24 (17%)</li> <li>3 participants did not provide a response.</li> </ul>
Other perspectives	<ul> <li>Members of organisations that services to autistic children and their families brought the following additional perspectives:</li> <li>Autistic person: n=1</li> <li>Parent of an autistic person: n=9</li> <li>Family member of an autistic person: n=21</li> <li>An individual who provides services to autistic children: n=48</li> <li>Member of an organisation or service that provides services to autistic children and their families: n=65</li> <li>Other: n=7</li> <li>34 participants did not provide a response.</li> </ul>
Professions	<ul> <li>Individuals involved with the organisations represented included:</li> <li>Aboriginal and Torres Strait Islander health workers or health practitioners: n=15</li> <li>Aboriginal and Torres Strait Islander health advocates: n=9</li> <li>Art therapists: n=6</li> <li>Behaviour therapists (not board certified): n=29</li> <li>Board certified behaviour analysts: n=24</li> <li>Developmental educators: n=19</li> </ul>



	Educators (early childhood): n=34
	Educators (primary school): n=23
	Educators (high school): n=12
	Exercise scientists: n=5
	General practitioners: n=3
	Music therapists: n=9
	• Nurses: n=9
	Occupational therapists: n=55
	Paediatricians: n=9
	Physiotherapists: n=27
	• Play therapists: n=3
	Psychiatrists: n=5
	Psychologists: n=49
	Researchers: n=18
	Social workers: n=23
	• Speech pathologists: n=57
	Support workers: n=29
	• Others: n=31
	52 participants did not provide a response.
Service setting	Organisations represented provided supports to autistic children across the following settings:
	• Child's home: n=69
	Hospital (inpatient/outpatient): n=4
	Community clinic (including private practice): n=65
	University clinic: n=4
	Early childhood education centre: n=52
	• Early childhood education centre in a specialised setting (catering only to children with additional earning needs): n=35
	Mainstream school: n=56
	Support class/unit within a mainstream school: n=44
	School specifically for autistic children: n=33
	School specifically for children with additional learning needs: n=38
	• Other: n=19
	52 participants did not provide a response.
State/Territory	Organisations represented provided services in/across the following States/Territories within Australia:
State/Territory	



	New South Wales: n=37
	Northern Territory: n=7
	• Queensland: n=43
	South Australia: n=17
	• Tasmania: n=8
	• Victoria: n=32
	Western Australia: n=22
	52 participants did not provide a response.
Location	80 organisations provided services in a major city and 67 provided services in regional/remote areas. 52 participants did not provide a response.

#### 'Other' Participants

**Table 7.6.** Additional information for individuals who provided informed consent and selected the 'Other' category in the online survey (n=38).

Other	
Other	Individuals who selected 'Other' described themselves as:
description	Members or representatives of a peak body: n=9
	• Researchers: n=8
	<ul> <li>Members of organisations that have an interest or involvement with autistic people: n=4</li> </ul>
	Autistic/neurodiverse people: n=4
	• Teacher: n=2
	Practitioner: n=2
	Consultant: n=1
	University employee: n=1
	7 participants did not provide a response
Other	Individuals who selected 'Other' brought the following additional perspectives:
perspectives	Autistic person: n=3
	Parent of an autistic person: n=6
	Family member of an autistic person: n=6
	An individual who provides services to autistic children: n=5
	• Member of an organisation or service that provides services to autistic children and their families: n=9
	• Other: n=10
	15 participants did not provide a response.



## **Quantitative data**

#### Language/Terminology preferences

The data for the language survey are presented in Table 7.7. Identity first-language (e.g., autistic, autistic children) was the most supported approach among the autistic community, parents of autistic children, service providers, and 'others,' while 'person on the autism spectrum' was more highly rated among family members and people working in organisations, based on totals produced by summing the proportion of people in each group who rated the terms as either 'like', 'somewhat like', or 'strongly like'. These terms were also highly acceptable across all groups, with a minimum 75% in each group rating identify first language acceptable. Consistent with the decision-making framework determined apriori, identity first language was adopted for use in the Guideline and related documents and community activities.

Terminolog					Which	of the	following	best	describe	es you	?		
preference	preferences		Autistic Person Caregiver		imary		amily ember	Service Provider		Organisation		Other	
		n	%	n	%	n	%	n	%	n	%	n	%
Autistic	Strongly dislike	2	3.3%	8	6.6%	0	0.0%	6	12.8%	7	13.7%	2	13.3%
	Dislike	2	3.3%	13	10.7%	1	12.5%	5	10.6%	9	17.6%	1	6.7%
	Somewhat dislike	4	6.7%	9	7.4%	2	25.0%	4	8.5%	6	11.8%	1	6.7%
	Neutral	4	6.7%	16	13.2%	1	12.5%	10	21.3%	12	23.5%	2	13.3%
	Somewhat like	3	5.0%	8	6.6%	0	0.0%	0	0.0%	5	9.8%	2	13.3%
	Like	8	13.3%	30	24.8%	2	25.0%	8	17.0%	8	15.7%	3	20.0%
	Strongly like	37	61.7%	37	30.6%	2	25.0%	14	29.8%	4	7.8%	4	26.7%

#### Table 7.7. Results of the language survey.



Autistic person	Strongly dislike	3	5.2%	8	6.8%	0	0.0%	3	6.4%	6	11.8%	2	13.3%
(e.g., autistic	Dislike	2	3.4%	15	12.7%	1	12.5%	5	10.6%	7	13.7%	2	13.3%
children)	Somewhat dislike	4	6.9%	9	7.6%	1	12.5%	4	8.5%	9	17.6%	0	0.0%
	Neutral	5	8.6%	17	14.4%	1	12.5%	8	17.0%	13	25.5%	2	13.3%
	Somewhat like	4	6.9%	10	8.5%	1	12.5%	2	4.3%	6	11.8%	2	13.3%
	Like	6	10.3%	34	28.8%	2	25.0%	13	27.7%	7	13.7%	3	20.0%
	Strongly like	34	58.6%	25	21.2%	2	25.0%	12	25.5%	3	5.9%	4	26.7%
Person with	Strongly dislike	30	50.8%	19	16.1%	0	0.0%	5	10.6%	2	3.8%	4	26.7%
autism (e.g.,	Dislike	6	10.2%	15	12.7%	0	0.0%	5	10.6%	3	5.8%	0	0.0%
children with autism)	Somewhat dislike	6	10.2%	7	5.9%	1	11.1%	5	10.6%	3	5.8%	1	6.7%
	Neutral	3	5.1%	25	21.2%	3	33.3%	7	14.9%	10	19.2%	5	33.3%
	Somewhat like	5	8.5%	18	15.3%	2	22.2%	7	14.9%	9	17.3%	1	6.7%
	Like	5	8.5%	17	14.4%	3	33.3%	13	27.7%	14	26.9%	3	20.0%
	Strongly like	4	6.8%	17	14.4%	0	0.0%	5	10.6%	11	21.2%	1	6.7%
Person on the	Strongly dislike	17	28.8%	9	7.6%	1	10.0%	5	10.6%	2	3.8%	4	25.0%
autism spectrum	Dislike	6	10.2%	8	6.8%	0	0.0%	7	14.9%	1	1.9%	0	0.0%
(e.g., children on the	Somewhat dislike	5	8.5%	10	8.5%	0	0.0%	5	10.6%	6	11.5%	1	6.3%
autism spectrum)	Neutral	11	18.6%	26	22.0%	1	10.0%	9	19.1%	4	7.7%	6	37.5%
	Somewhat like	6	10.2%	15	12.7%	2	20.0%	5	10.6%	7	13.5%	3	18.8%
	Like	10	16.9%	33	28.0%	5	50.0%	12	25.5%	16	30.8%	2	12.5%
	Strongly like	4	6.8%	17	14.4%	1	10.0%	4	8.5%	16	30.8%	0	0.0%



Person with	Strongly dislike	33	55.9%	41	35.0%	2	22.2%	15	31.9%	8	15.7%	9	56.3%
autism spectrum	Dislike	9	15.3%	15	12.8%	2	22.2%	8	17.0%	7	13.7%	1	6.3%
disorder (e.g., children	Somewhat dislike	8	13.6%	13	11.1%	0	0.0%	6	12.8%	5	9.8%	2	12.5%
with ASD)	Neutral	2	3.4%	14	12.0%	1	11.1%	5	10.6%	11	21.6%	4	25.0%
	Somewhat like	5	8.5%	12	10.3%	2	22.2%	4	8.5%	7	13.7%	0	0.0%
	Like	1	1.7%	10	8.5%	2	22.2%	6	12.8%	7	13.7%	0	0.0%
	Strongly like	1	1.7%	12	10.3%	0	0.0%	3	6.4%	6	11.8%	0	0.0%
Person with	Strongly dislike	23	39.0%	31	26.5%	0	0.0%	15	31.9%	15	30.0%	4	26.7%
autism spectrum	Dislike	11	18.6%	17	14.5%	3	33.3%	11	23.4%	16	32.0%	2	13.3%
condition (e.g., children	Somewhat dislike	8	13.6%	14	12.0%	0	0.0%	4	8.5%	3	6.0%	5	33.3%
with ASC)	Neutral	11	18.6%	24	20.5%	5	55.6%	9	19.1%	5	10.0%	4	26.7%
	Somewhat like	5	8.5%	9	7.7%	0	0.0%	3	6.4%	8	16.0%	0	0.0%
	Like	1	1.7%	11	9.4%	0	0.0%	3	6.4%	2	4.0%	0	0.0%
	Strongly like	0	0.0%	11	9.4%	1	11.1%	2	4.3%	1	2.0%	0	0.0%
Autistic	Unacceptable	7	11.7%	19	16.2%	2	20.0%	10	21.7%	10	20.0%	1	6.7%
	Acceptable	53	88.3%	98	83.8%	8	80.0%	36	78.3%	40	80.0%	14	93.3%
Autistic	Unacceptable	7	11.7%	26	22.4%	2	22.2%	7	15.2%	12	25.0%	2	13.3%
child	Acceptable	53	88.3%	90	77.6%	7	77.8%	39	84.8%	36	75.0%	13	86.7%
Child with	Unacceptable	32	54.2%	26	22.4%	0	0.0%	10	21.3%	3	5.9%	3	18.8%
autism	Acceptable	27	45.8%	90	77.6%	9	100.0%	37	78.7%	48	94.1%	13	81.3%
Child on	Unacceptable	21	35.6%	13	11.3%	1	10.0%	7	15.2%	4	7.7%	2	12.5%
the autism spectrum	Acceptable	38	64.4%	102	88.7%	9	90.0%	39	84.8%	48	92.3%	14	87.5%



Child with autism spectrum	Unacceptable	40	69.0%	56	48.3%	2	22.2%	2 2	48.9%	13	27.1%	7	43.8%
disorder (child with ASD)	Acceptable	18	31.0%	60	51.7%	7	77.8%	23	51.1%	35	72.9%	9	56.3%
Child with autism spectrum	Unacceptable	41	69.5%	46	40.0%	2	20.0%	2 2	47.8%	26	53.1%	6	40.0%
condition (child with ASC)	Acceptable	18	30.5%	69	60.0%	8	80.0%	24	52.2%	23	46.9%	9	60.0%

#### **Guiding Principles**

The percentage agreement, median, and interquartile range for each of the 17 items related to the Guiding Principles, for each stakeholder group, was included in the Evidence Summaries for the relevant Recommendations as an additional source of supporting evidence.

### **Qualitative data**

A total of 7,708 references (i.e., participant quotes) were coded using the framework, with the distribution of references (i.e., quotes) for each participant group presented in Table 7.8. These quotes, where relevant to the formulation of Recommendations and Good Practice Points, feature in the corresponding evidence summaries.

Table 7.8. Summary	of codes and	d references for	each participant group.
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Codes	Numb	Number of Coding References for Each Participant Grou						
	Parents	Family	Autistic Person	Service Provider	Organisati on	Other		
Principles								
Accessible	50	0	13	2	10	1		
Assent (children)	4	0	4	0	2	0		
Child and family-centred	45	1	15	22	14	4		
Coordinated	25	0	4	7	5	1		
Culturally aware and responsive	2	0	0	2	0	2		
Developmental perspective	9	1	2	2	2	1		



Empirically-supported	7	0	4	2	2	0
Equity	17	1	13	1	3	0
Ethical practice	66	1	17	19	21	8
Evidence-based practice approach	18	2	8	11	10	1
Holistic	34	3	7	26	19	8
Informed consent (parents)	0	0	0	0	0	1
Lifespan perspective	10	0	4	2	2	2
Other - Principle	135	1	52	16	18	8
Personalised	47	0	15	24	12	5
Qualified practitioners	58	0	12	12	16	5
Strengths focused	24	1	10	8	4	0
Supported	20	0	4	3	3	1
Understanding the child, family, and con	text	_			_	
Child Understanding	93	10	37	60	74	16
Context understanding	54	4	23	32	34	12
Family understanding	142	8	45	82	87	22
Other Understanding	37	2	18	12	16	3
Goal Setting						
Activities and participation	76	9	28	48	45	16
Environment	12	3	6	7	6	1
Mental and physical functions	22	3	4	14	15	2
Other	27	1	23	13	17	8
Selection - therapies and supports						
Non-Specific - Non-Supported	0	0	0	0	0	0
Non-Specific - Supported	20	1	12	9	19	9



Selection - other	13	1	8	6	7	2
Specific - Non-Supported	1	0	0	1	1	0
Specific - Supported	69	6	25	32	30	10
Delivery	-				-	
Amount	93	6	30	47	52	12
Individualised - Amount not specified	48	2	21	28	21	9
Individualised - Indicative amount	11	3	2	7	11	0
Not Applicable	7	0	0	2	3	1
Specified Amount	28	1	7	10	17	2
Clinic	36	6	11	30	23	4
Cultural setting	0	0	1	0	0	0
Education setting	45	3	16	30	30	9
Home	50	6	15	33	27	7
Other	41	3	15	27	31	11
Recreational setting	7	1	0	2	3	2
Social setting	25	1	5	26	20	7
Monitoring of Therapies and Supports						
Costs and benefits	29	2	6	12	21	6
Fidelity	5	0	1	4	4	1
Generalisation	2	0	0	4	2	1
Impact	38	3	13	28	29	6
Maintenance	0	0	0	1	0	1
Other	44	1	18	23	27	4
Progress	50	7	16	28	36	9
Unplanned outcomes	6	1	1	5	4	1



Safety and Wellbeing						
Assessment	6	0	6	7	9	0
Communication	26	3	6	7	14	6
Concerns	5	2	1	1	3	1
Empirical evidence	2	1	3	6	4	2
Experience	8	1	2	9	11	3
Monitoring	14	2	6	7	6	2
Other	47	6	24	26	18	12
Practice standards	9	2	6	13	12	4
Research	3	0	0	2	1	0
Rights	5	0	7	5	5	5
Supervision	0	1	0	3	5	1
Suggestion						
About child, family, and context	163	16	50	90	95	32
Alternatives	12	4	4	5	4	2
Autistic perspectives	9	0	11	6	4	0
Benefits	8	1	6	2	11	0
Clinical evidence	139	11	38	108	118	36
Enhance progress	0	0	0	1	1	0
Impede progress	3	0	1	0	0	0
Other	0	2	1	0	0	0
Relevance (current)	8	1	6	10	9	3
Relevance (future)	6	1	1	3	7	4
Research evidence	29	1	8	31	37	7
Risks	5	0	3	3	3	1



Theoretical Rationale	0	0	0	1	4	0
Who						
Who~ agencies	5	2	2	4	3	0
Who~ family	162	11	61	99	97	21
Who~ other	6	0	6	4	7	0
Who~ participation	3	1	1	2	3	2
Who~ support providers	132	13	46	81	78	16

As indicated above, credibility checks were completed for all quotes that featured in the analysis of qualitative data from the community survey. 99% were classified as 'relevant to the guideline and code,' <1% were classified as 'relevant to the guideline, but cannot establish relevance to code,' and 0% were classified as 'does not appear to be relevant to the Guideline. Readers are reminded that the person completing the credibility check was reviewing the coded data, not the original transcripts. Accordingly, they did not necessarily have knowledge of the context (e.g., broader statement) from which the quotes had been extracted.



# 8. Community Consultation: Focus Groups

## 8.1 Background

Integral to the development of the Guideline was consultation with the autistic and autism communities. Consistent with the recommendations in the Guidelines for Guidelines handbook (NHMRC, 2016) community consultation was conducted to ensure that all relevant stakeholders within Australia were provided with the opportunity to inform the development of the Guideline. This was key to enhancing the relevance and acceptability of the Guideline to the autistic and autism communities. The consultation process was also conducted to (a) complement the current research evidence, and/or (b) gather information and insight from relevant stakeholders where research evidence is currently lacking.

This consultation activity was conducted to ensure that the experiences, views and preferences of autistic individuals and parents of autistic children were captured in the development of the Guideline.

## 8.2 Aim

The aim of the focus groups were to understand the experiences, views and preferences of (a) autistic people and (b) parents of autistic children regarding accessing supports for autistic children and their families.

## 8.3 Research question

What are the experiences, views and preferences of autistic individuals and parents of autistic children regarding the provision of supports for children and their families?

# 8.4 Design

A qualitative methodology approach was adopted, through a series of focus groups. Eight, online focus groups were run over a 2-week period (7th – 18th March, 2022). Four of the focus groups were open to autistic adults and four were open to parents of autistic children.

# 8.5 Method

Ethical approval for this community consultation activity was provided by Griffith University Human Research Ethics Committee (2021/843).

## Eligibility

Autistic adults and parents of autistic children and young people were eligible to participate in the focus groups.



## Recruitment

Participant recruitment for the focus groups was predominantly facilitated by Autism CRC. An invitation to register interest in attending a focus group was distributed to members of Autism CRC mailing lists who identified as either an autistic individual, or the parent of an autistic child(ren). In addition, links to access the focus group registration survey were made available via the Autism CRC Supporting Children Guideline website, and social media (Facebook and Twitter) accounts. Members of the GDG also promoted the focus groups throughout their professional networks and social media pages. Recruitment occurred over a two-week period.

After following the registration link, prospective participants were presented with a Participant Information Statement and Consent Form and required to indicate consent before providing their details and preferences to attend the online focus group. Of the 49 registrations received from autistic individuals, all were allocated to a focus group based on their preferences. Parent registrations exceeded available focus group timeslots (n=115 registrations for 48 positions). Forty-eight parents were assigned to focus groups based on their preferences and in consecutive order of receiving their registration.

## Tools

Prior to attending their allocated focus groups, all participants received a link to a short demographic survey coded in REDCap (a secure web-based application for survey development and distribution). This demographic survey was completed online either prior to, or after, their participation in the focus group (see Appendix 8.1).

#### **Focus Group Question Guide**

A semi-structured question guide was developed and used across all eight focus groups. The question guide was predominantly informed by the set of questions developed by the GDG, underpinning all aspects of the Guideline's development related to supporting autistic children and their families. The questions developed for the focus groups covered the same six overarching questions posed to participants who completed the online survey:

- What are the most important considerations for practitioners trying to understand the child, family, and their context?
- From your perspective, what are the most important considerations for practitioners when planning, selecting, and prioritising goals for children?
- From your perspective, what are the most important considerations for practitioners when planning and selecting therapies and supports for children?
- From your perspective, what are the most important considerations for practitioners when delivering therapies and supports for children?
- From your perspective, what are the most important considerations for practitioners when monitoring progress and outcomes of therapies and supports for children?
- From your perspective, what are the most important considerations for practitioners to ensure the safety and wellbeing of autistic children and their families?



#### Focus group facilitation

Each focus group was facilitated, via Microsoft Teams, by two members of the GDG across a two-week period (7th – 18th March, 2022). One facilitator (David Trembath) was consistent across all eight groups, while the second facilitator alternated between different GDG members (Sarah Pillar, Felicity Rose, Kandice Varcin, Hannah Waddington, Andrew Whitehouse). The first facilitator was responsible for (a) coordinating the meeting, (b) introducing the Guideline development process and providing an orientation to the Focus Group, (c) facilitating the discussion, and (d) summarising and concluding the meeting. The second facilitator was responsible for (a) facilitating the discussion via the 'chat' comments (an option available to all participants throughout the entirety of the focus group, as an additional or alternate method of contributing) and (b) providing a summary of insights being shared via the chat comments at the conclusion of the discussion for each of the focus group questions.

Participants were invited to have their video function turned on for the focus group, but this was not a requirement. Participants were also invited to share information in the way they preferred (i.e., through verbal discussion or writing responses using the 'Chat' function).

Each focus group followed the same schedule:

- Fifteen minutes prior to the meeting, the two facilitators joined Microsoft Teams to review planning for the focus group. The 'waiting room' function was activated.
- At the scheduled start time, participants were admitted to the meeting.
- Facilitator 1 presented the introduction to the Guideline development process and focus group orientation (15 minutes).
- Facilitator 1 presented the six focus group questions, one at a time (allowing 15 minutes per question, including time for 2-minute summary of the chat comments by Facilitator 2).
- Facilitator 1 invited the participants to briefly introduce themselves the first time they shared responses to posed questions.
- Facilitator 1 presented a summary of the focus group outcomes, an overview of the next steps, and thanked the participants for their contribution (10 minutes).

A copy of the PowerPoint presentation that was used for all eight focus groups is provided in Appendix 8.2.

#### Analysis

Focus group transcriptions were auto generated by the Microsoft Teams platform. In two instances, where there was a technical or administrator error with the Microsoft Teams transcription, transcription was completed by Griffith University Transcription service. Transcriptions were checked for accuracy against the recording by a research assistant and de-identified prior to analysis. De-identified transcriptions files were uploaded to NVivo software for analysis. 'Chat' comments were copied from Microsoft Teams into a Word document.



Information collected during the focus groups were coded according to 'principles' using the process outlined in detail in relation to the online survey (Chapter 7). This approach – rather than coding according to each section of the code book (e.g., selection of supports, delivery of supports) was adopted *apriori* in the first instance, given that focus groups – by their nature of encouraging discussion – may see participants talk in relation to more than one aspect of the Guideline at once (e.g., a person simultaneously talking about goal setting, selecting an appropriate support, and safeguarding at the same time). However, to ensure that no specific insights, experiences, or suggestions that may be relevant to formulating Recommendations and Good Practice Points were missed, the GDG also reviewed every transcript (discussion and chat) generated from the groups in full to ensure that all information was considered in relation to all Guideline questions, Recommendations and Good Practice Points.

# 8.6 Results

## **Participant characteristics**

A total of 164 registrations for 96 focus group positions (i.e., 12 slots across 8 focus groups) were received. Of these, a total of 48 participants attended their allocated focus group, of which 20 (42%) were autistic adults, and 28 (58%) were parents of autistic children.

Of the 20 autistic adults that attended the focus groups, 15 (75%) provided some details about themselves through the online demographic survey (see Table 8.1). Of the 28 parents who attended the focus groups, 21 (75%) provided some details about themselves and their child(ren) through the online demographic survey (see Table 8.1).

**Table 8.1.** Demographic information for autistic adults and parents of autistic childrenwho attended the focus groups.

	Autistic Adults	Parents of Autistic Children
Other perspectives	Autistic adults attending the focus groups brought the following additional perspectives:	Parents of autistic children attending the focus groups brought the following additional perspectives:
	Parent/primary caregiver of an autistic child: n=12 Family member of an autistic person: n=4	Autistic person: n=4 Family member of an autistic person: n=1 Practitioner: n=4
	Practitioner: n=5 Member of an organisation or service that provides services to autistic children and their families: n=8 5 participants did not provide this information.	Member of an organisation or service that provides services to autistic children and their families: n=5 7 participants did not provide this information.



Age	Autistic adults were in the following age brackets:	Parents were in the following age brackets:
	31-40 years: n=5 (25%)	31-40 years: n=4 (14%)
	41-50 years: n=6 (30%)	41-50 years: n=8 (28.5%)
	51-60 years: n=4 (20%)	51-60 years: n=8 (28.5%)
	5 participants (25%) did not provide this	61-70 years: n=1 (4%)
	information.	7 participants (25%) did not provide this information.
Gender identity	12 autistic adults identified as female (60%), 2 identified as male (10%), and 1 as	20 parents identified as female (71.5%) and 1 as male (3.5%).
	non-binary (5%). 5 participants (25%) did not provide this information.	7 participants (25%) did not provide this information.
Aboriginal and/or Torres	No autistic adults identified as Aboriginal or Torres Strait Islander.	No parents identified as Aboriginal or Torres Strait Islander.
Strait Islander Peoples	5 participants (25%) did not provide this information.	7 participants (25%) did not provide this information.
State/Territory	Autistic adults resided in the following States/Territories within Australia:	Parents resided in the following States/Territories within Australia:
	Australian Capital Territory: n=1 (5%)	Australian Capital Territory: n=0 (0%)
	New South Wales: n=0 (0%)	New South Wales: n=11 (39%)
	Northern Territory: n=1 (5%)	Northern Territory: n=0 (0%)
	Queensland: n=8 (40%)	Queensland: n=2 (7%)
	South Australia: n=0 (0%)	South Australia: n=2 (7%)
	Tasmania: n=1 (5%)	Tasmania: n=0 (0%)
	Victoria: n=3 (15%)	Victoria: n=4 (14%)
	Western Australia: n=1 (5%)	Western Australia: n=2 (7%)
	5 participants (25%) did not provide this information.	7 participants (25%) did not provide this information.
Location	9 autistic adults lived in a major city (45%) and 6 lived in regional/remote areas (30%).	14 parents lived in a major city (50%) and 7 lived in regional/remote areas (25%).
	5 participants (25%) did not provide this information.	7 participants (25%) did not provide this information.
Place of birth	14 autistic adults (70%) were born in Australia. 1 (5%) was born outside of Australia.	16 parents (57%) were born in Australia. 4 parents (14%) were born outside of Australia.
	5 participants (25%) did not provide this information.	8 participants (29%) did not provide this information.



Languages other than English Formal diagnosis of autism	<ul> <li>15 autistic adults (75%) were living in homes where only English was spoken.</li> <li>5 participants (25%) did not provide this information.</li> <li>13 autistic adults (65%) had received a formal diagnosis of autism. 1 autistic adult (5%) self-identified as autistic but had not received a formal diagnosis of autism. 1 participant (5%) chose not to share additional information about their diagnosis.</li> <li>5 participants (25%) did not provide this information.</li> </ul>	<ul> <li>2 parents (7%) were living homes where a language other than English was spoken.</li> <li>19 (68%) were living in homes where only English was spoken.</li> <li>7 participants (25%) did not provide this information.</li> <li>1 parent (4%) had received a formal diagnosis of autism. 1 parent (4%) selfidentified as autistic but had not received a formal diagnosis of autism. 1 parent was currently being assessed for possible autism (4%). 1 participant (4%) chose not to share additional information about their diagnosis.</li> <li>7 participants (25%) did not provide this information.</li> </ul>
Age of autism diagnosis DSM-5	The average age of diagnosis was 38.46 years (SD = 10.28), with ages ranging from 12 years to 49 years. 7 participants (35%) did not provide a response. Of autistic adults diagnosed under the	information. 1 parent reported having a formal diagnosis of autism, diagnosed at age 48. 1 parent reported having a formal
diagnosis level of support	<ul> <li>DSM-5, the following support levels were associated with the diagnosis:</li> <li>1 was diagnosed at Level 2.</li> <li>1 was unsure.</li> <li>1 preferred not to say.</li> <li>12 participants did not provide a response.</li> </ul>	diagnosis of autism: they were unsure of their associated support level.
Representative DSM-5 level of support	Of autistic adults not diagnosed under the DSM-5, participants reported the following would have been most representative of their supports needs as a child: 3 selected Level 1 as most representative 8 selected Level 2 as most representative 0 selected Level 3 as most representative 1 preferred not to say. 3 participants did not provide a response.	Of parents who also identified as autistic, but not diagnosed under the DSM-5, the following was reported to be the most representative of their supports needs as a child: 1 selected Level 1 as most representative No other responses were provided to this item.
Access to supports between 0-6 years	No autistic adults reported receiving or accessing supports (for themselves) between the ages of 0-6 years.	No parents that also identified as autistic reported receiving or accessing supports (for themselves) between the ages of 0-6 years.



Access to supports between 7-12 years	No autistic adults reported receiving or accessing supports (for themselves) between the ages of 7-12 years.	No parents that also identified as autistic, reported receiving or accessing supports (for themselves) between the ages of 7-12 years.
Autistic children	Of the 12 autistic adults who were also parents of autistic children, 11 chose to share additional information about their child(ren). There were 22 autistic children amongst the participants in the autistic adults focus groups.	Of the 21 parents of autistic children, 20 chose to share additional information about their child(ren). There were 26 autistic children amongst the participants in the parents of autistic children focus groups.
Child age	The average (current) age of autistic children in the autistic adults focus groups was 14.19 years (SD = 5.54), with ages ranging from 4 years to 25 years.	The average (current) age of autistic children in the parent focus groups was 14.03 years (SD = 7.23), with ages ranging from 3 years to 28 years.
Child age of autism diagnosis	The average age of diagnosis amongst children was 6.95 years (SD = 4.06), with ages ranging from 2 years to 19 years.	The average age of diagnosis amongst children was 5.70 years (SD = 3.17), with ages ranging from 2 years to 13 years.
Child DSM-5 diagnosis level of support	Of children diagnosed under the DSM-5, the following support levels were associated with the children's diagnoses:	Of children diagnosed under the DSM-5, the following support levels were associated with the children's diagnoses:
	1 was diagnosed at Level 1.	4 were diagnosed at Level 1.
	15 were diagnosed at Level 2.	14 were diagnosed at Level 2.
	3 were diagnosed at Level 3.	3 were diagnosed at Level 3.
		1 participant was unsure of the support level associated with their child's diagnosis.
Child representative DSM-5 level of support	Of children not diagnosed under the DSM- 5, the following was reported to have been the most representative of their supports needs as a child:	Of children not diagnosed under the DSM- 5, the following was reported to have been the most representative of their supports needs as a child:
	1 selected Level 1 as most representative.	1 selected Level 1 as most representative.
	1 selected Level 2 as most representative.	1 selected Level 2 as most representative.
	1 selected Level 3 as most representative.	
Child access to supports between 0-6 years	14 children (64%) of participants in the autistic adults focus groups accessed supports at some stage between the ages of 0-6 years. 8 (36%) did not access supports between 0-6 years.	16 (61.5%) children of participants in the parent focus groups accessed supports at some stage between the ages of 0-6 years. 10 (38.5%) did not access supports between 0-6 years.



Child access to	18 (82%) children of participants in the	22 (85%) children of participants in the
supports	autistic adults focus groups accessed	parent focus groups accessed supports at
between 7-12	supports at some stage between the ages	some stage between the ages of 7-12
years	of 7-12 years. 2 families (9%) did not	years. 4 families (15%) did not access
	access supports between the ages of 7-12	supports between the ages of 7-12 years.
	years.	
	2 participants (9%) did not provide a response.	

### **Quantitative data**

No quantitative data were collected in this activity.

#### **Qualitative data**

A total of 826 references (i.e., quotes) were coded using the framework, with 407 from group focusing on autistic adults and 419 references from groups focusing on parents. The distribution of references for each code for each group are presented in Table 8.2. These quotes, where relevant to the formulation of Recommendations and Good Practice Points, feature in the corresponding evidence summaries.

Codes	Autistic Adults	Parents	
Principles			
Accessible	6	17	
Assent (children)	7	6	
Child and family-centred	81	61	
Coordinated	17	37	
Culturally aware and responsive	0	2	
Developmental perspective	1	5	
Empirically-supported	2	2	
Equity	1	11	
Ethical practice	8	12	
Evidence-based practice approach	12	12	

Table 8.2. Summary of codes and references for the two types of focus groups.



Holistic	56	66
Informed consent (parents)	2	0
Lifespan perspective	9	10
Other - Principle	110	87
Personalised	58	46
Qualified practitioners	13	17
Strengths focused	20	16
Supported	4	12

Credibility checks were completed for all quotes that featured in the analysis of qualitative data from the focus groups. 100% were classified as 'relevant to the guideline and code,' 0% were classified as 'relevant to the guideline, but cannot establish relevance to code,' and 0% were classified as 'does not appear to be relevant to the Guideline.' Readers are reminded that the person completing the credibility check was reviewing the coded data, not the original transcripts. Accordingly, they did not necessarily have knowledge of the context (e.g., broader statement) from which the quotes had been extracted.



# 9. Community Consultation: Delphi Study

# 9.1 Background

A separate community consultation process was undertaken, specifically with practitioners who provide supports to autistic children and their families. This consultation process adopted the Delphi technique. The Delphi technique refers to a method that is commonly used to collect expert-based opinions and identify consensus agreement on best practice (Jorm, 2015; Jünger et al., 2017; Niederberger & Spranger, 2020). Delphi studies are often used to inform clinical practice when there is insufficient evidence from meta-analyses, randomised controlled trials and/or correlational and observational studies (Jorm 2015; Jünger et al., 2017).

The Delphi study was conducted to directly inform Recommendations within the Guideline by: (a) identifying consensus amongst practitioners on what they consider to be best practice when providing supports to autistic children and their families, and (b) providing an opportunity for qualitative feedback from practitioners that participated in the Delphi surveys.

# 9.2 Aim

To identify consensus agreement amongst practitioners on what is considered best practice in the provision of supports for autistic children and their families.

# 9.3 Research question

What do practitioners consider to be best practice in the provision supports for autistic children and their families?

# 9.4 Design

The Delphi study involved two rounds of online surveys completed by practitioners. In both rounds, quantitative and qualitative data were collected. Quantitative data was used to determine consensus agreement/disagreement amongst practitioners. Qualitative data was collected to (a) inform the modification of items for the Round 2 survey (for those items where consensus was not achieved), and (b) directly inform Recommendations within the Guideline through qualitative evidence.

# 9.5 Method

Ethical approval for this community consultation activity was provided by Griffith University Human Research Ethics Committee (2021/843).



## Eligibility

Practitioners representing professional groups that (a) are directly involved in the provision of supports for autistic children and their families and (b) have expertise in children's physical health, mental health, social-communication development, physical development, cognitive development and/or sensory development were eligible to participate in the Delphi study.

## Recruitment

Practitioners were invited to participate in the Delphi study through their membership with one of five professional organisations (see Table 9.1 for a list of participating professional organisations). These professional organisations were each represented by a member on the Reference Group. The reference group members representing these professional organisations were asked to identify up to 20 practitioners from each of their professional organisations that may be willing to participate in the Delphi study. In total, 100 practitioners were invited to participate in the Round 1 survey (n=20 from each professional organisation).

Practitioners who completed the Round 1 survey (either fully or partially) were invited to participate in Round 2. As such, 72 practitioners were sent a personalised link to the Round 2 survey.

## Tools

### **Round 1 survey**

Survey items in Round 1 were developed through an iterative process that drew on various forms of input, including: (a) the review of existing guidelines from other jurisdictions around the world (see Chapter 4), (b) the umbrella review of existing research evidence (see Chapter 5), (c) recent, relevant research papers (i.e., Lord et al, 2022, Trembath et al., 2021), (d) frameworks of evidence-based practice (e.g., Sackett et al., 2000), and (e) review and feedback from the GDG.

The Round 1 survey was coded in REDCap (a secure web-based application for survey development and distribution) and piloted by five practitioners who were independent and external to the GDG. These five practitioners represented each professional group invited to participate in the Delphi study: a medical doctor, an occupational therapist, a physiotherapist, a psychologist, and a speech pathologist. Feedback provided through the piloting process led to minor modifications, including clarifying some terms and modifying the format of some items. The Round 1 survey took 40-60 minutes to complete by the pilot participants.

The final Round 1 survey (see Appendix 9.1) was distributed to practitioners via REDCap and included two parts. Part 1 was a demographic survey that asked practitioners about their professional affiliation, geographical location, experience and current practice in working with autistic children and their families. Part 2 asked practitioners to provide their views on what they considered to be best practice in supporting autistic children and their families.



Part 2 included 215 items that asked practitioners to rate their agreement with various statements on a 5-point scale: (1) strongly disagree, (2) disagree, (3) neutral, (4) agree, (5) strongly agree. There were also 26 additional items, distributed throughout each section of the survey, that gave practitioners an opportunity to provide optional qualitative feedback.

The Round 1 survey was open for a two-week period from March 7<sup>th</sup> to March 20<sup>th</sup>, 2022.

#### Round 2 survey

Survey questions in Round 2 were developed based on (a) quantitative ratings and qualitative feedback from practitioners in Round 1, and (b) qualitative feedback obtained through other community consultation activities that were being conducted in parallel to the Delphi study (i.e., online survey [Chapter 7], focus groups [Chapter 8]).

Quantitative items from Round 1 were reviewed against the predetermined consensus criteria (see below in the 'Quantitative analysis' section). Items with partial agreement (n=12), partial disagreement (n=3) or no agreement/disagreement (n=19) were considered for inclusion in the Round 2 survey. Each of these items was reviewed by two members of the GDG (AW, DT). Each member reviewed the distribution of quantitative ratings and the associated qualitative data (i.e., open-ended optional comments provided by practitioners for that item/section). They then met to determine which of the following options was most suitable for that item in Round 2:

- Include the item verbatim in Round 2 (n=19 items)
- Include a modified version of the items in Round 2, based on qualitative feedback from Round 1 associated with that item (n=10 items)
- Do not include the item in Round 2 in the verbatim or modified form, on the basis that the item contributes evidence towards a complementary pattern of responses that have one or more implications (potential Recommendations) in common (n=3 items). For example, there was no consensus agreement or disagreement that services should be predominately child, family, or community focused in Round 1, however, there was consensus agreement that the proportion of child/family/community focused services should be personalised to the child. As such, the items relating to services being predominately child, family, and/or community-focused were not included in the Round 2 survey.

Based on qualitative data obtained through the online survey (Chapter 7) and the focus groups (Chapter 8) that were being conducted in parallel to the Round 1 Delphi survey, we also included 18 new items for rating in Round 2. The new items related to how supports should be selected (n=2 items) and the knowledge, training and experience required by practitioners delivering supports to autistic children and their families (n=16 items).

The final Round 2 survey was distributed to practitioners via REDCap and included the outcomes for all items from Round 1, for practitioners to review (see Appendix 9.2). For those items with consensus agreement/disagreement, practitioners were provided with a summary of the percentage agreement/disagreement and the median and interquartile range for each item. For items with partial consensus agreement/disagreement and those without agreement/disagreement, practitioners were provided with a written summary of



results and a graphical (bar graph) distribution of ratings for those items. The survey was setup so that practitioners viewed the summary and the distribution of ratings before rating the item again in Round 2. For the new items, it was highlighted to practitioners that these were new additions to the Round 2 survey.

The Round 2 survey included 42 items for rating on the same 5-point scale as Round 1: (1) strongly disagree, (2) disagree, (3) neutral, (4) agree, (5) strongly agree. In Round 2, there were two items that gave practitioners the option to provide open-ended comments related to the new items.

The Round 2 survey was open from April 19<sup>th</sup> to May 5<sup>th</sup> (the survey was open for slightly more than 2 weeks to account for public holidays that occurred over this time).

## Analysis

#### **Quantitative analysis**

For both rounds, data were exported from REDCap into SPSS (v26) for analysis. Each quantitative survey item was reviewed against the predetermined consensus criteria by one member of the GDG (KV) and categorised (i.e., consensus agreement/disagreement, partial agreement/disagreement, no agreement/disagreement). We used the same predetermined consensus criteria adopted in the Delphi study for National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia (Whitehouse et al., 2018).

To determine if consensus had been achieved for quantitative items, two criteria were applied:

- For agreement with statements, we used a median rating of ≥4 (i.e., agree or strongly agree) and an interquartile range (IQR) of ≤1 for agreement with the item; for disagreement with statements, we used median ≤2 (i.e., disagree or strongly disagree) and an interquartile range (IQR) of ≤1 for disagreement with the item
- For agreement with statements, ≥70% of practitioners rated the item as ≥4 (i.e., agree or strongly agree) for agreement with the item; for disagreement with statements, ≥70% of practitioners rated the item as median ≤2 (i.e., disagree or strongly disagree) for disagreement with the item

Consensus agreement or consensus disagreement was achieved if both of the above criteria were met. If only one of the criteria was met, it was considered to be partial consensus agreement/disagreement. If neither criterion were met, the item was considered to not have consensus agreement or consensus disagreement.

In Round 1, items with consensus agreement or disagreement were converted into draft Recommendations and included in the first draft of the Guideline Recommendations (either as a Consensus-Based Recommendation or a Good Practice Point). Items with partial agreement/disagreement or no consensus agreement/disagreement were retained for review and consideration in the Round 2 survey (as outlined in the above section regarding the Round 2 survey development).

In Round 2, items with consensus agreement or disagreement were converted into draft Recommendations and incorporated into the second draft of the Guideline



Recommendations. Items with partial consensus agreement/disagreement or no consensus agreement/disagreement in Round 2 were not considered further and did not inform the Recommendations in the Guideline.

#### **Qualitative analysis**

Round 1 qualitative data was used to inform the modification of items in the Round 2 Delphi survey that did not have consensus agreement/disagreement in Round 1. In addition, all qualitative data from Round 1 and Round 2 were read and reviewed (quote by quote) during the Recommendation drafting process. During this process, the qualitative data were used to (a) cross-check and validate the drafted Recommendations against the qualitative data that had been collected, and, (b) where relevant, used as illustrative quotes in support, and/or contextualisation, of Recommendations.

# 9.6 Results

## **Participant characteristics**

Table 9.1 outlines the professional organisations and the number of practitioners represented in each round of the Delphi study.

#### Round 1

One hundred practitioners based in Australia were invited to participate in Round 1. Seventy-two practitioners representing six professions from five professional organisations participated in Round 1 (see Table 9.1). Of those, 68 completed the Round 1 survey in full, 4 partially completed the survey. The overall response rate in Round 1 was 72%. Practitioners had, on average, 15 years' experience in working in clinical practice with autistic children (M = 15 years, SD = 9.60; Range: 1.5-41 years).

The majority of practitioners (n=60, 83%) were currently providing supports to autistic children and their families. Other practitioners were involved in support provision through supervising others in their provision of supports (n=6, 8%), conducting research into clinical practice for autistic children and their families (n=2, 3%), or involved in professional organisations or departments (i.e., education) that support the provision of supports (n=3, 4%). Over half of the practitioners were currently involved in support provision through a combination of these practices (n=37, 51%).

In the previous year (i.e., in 2021), 93% (n=67) of practitioners had provided supports to autistic children aged 0-12 years. Two practitioners (3%) had only provided supports to individuals aged over 12 years in 2021, and three practitioners had not provided supports to autistic people in 2021 (4%).

Across their career, 60% (n=43) of practitioners had predominately provided supports to children aged 12 years or younger, 37.5% (n=27) had predominately provided supports to age groups younger and older than 12 years, and 3% (n=2) of practitioners had predominately provided supports to people over 12 years. The most frequently endorsed age groups that practitioners had provided supports across their career were: 4-6 years (n=63), 7-9 years (n=54), 10-12 years (n=41), and 0-3 years (n=35).



All states and territories were represented in the Round 1 survey. Practitioners were predominately currently practicing in New South Wales (n=22), Victoria (n=21), and Queensland (n=15) with smaller representation from Western Australia (n=5), South Australia (n=5), Australian Capital Territory (n=4), Tasmania (n=1), and Northern Territory (n=1). Seventy percent of practitioners worked with families in major cities, and 30% worked with families in regional/remote areas.

Of practitioners in Round 1, 69% (n=50) currently worked in private, non-government organisations, 15% (n=11) worked in government organisations, and 15% (n=11) worked in both private and government organisations. The most frequently endorsed settings in which practitioners provided supports to autistic children and their families were: community clinics (n=55), mainstream schools (n=33), the child's home (n=28), and early childhood education centres (n=22). Of the 72 practitioners in Round 1, 74% (n=53) delivered supports using both face-to-face and telehealth formats, 25% (n=18) delivered support in a face-to-face format only, and 1% (n=1) delivered supports to autistic children and their families via telehealth only.

#### Round 2

All seventy-two practitioners that participated in the Round 1 survey were invited to participate in Round 2. Fifty-nine practitioners representing six professions from five professional organisations participated in Round 1 (see Table 9.1). All practitioners completed the Round 2 survey in full. The overall response rate in Round 2 was 82%.

**Table 9.1.** Professional organisations, practitioner professions, and the number of participants in each Delphi survey round.

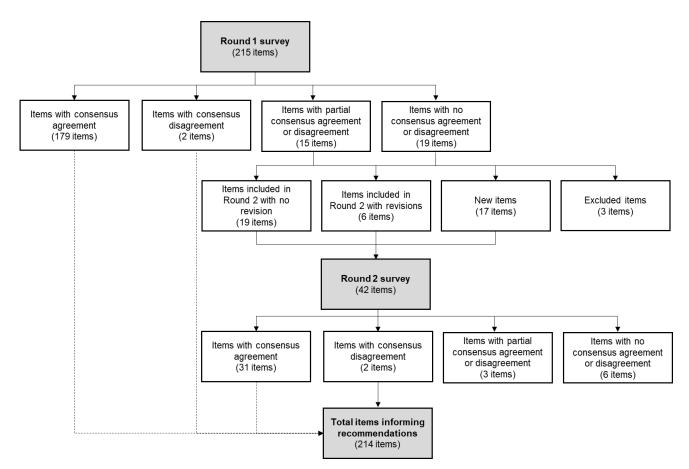
Professional organisation	Practitioners	Invited Round 1	Participated Round 1	Participated Round 2
Neurodevelopmental and Behavioural Paediatrics Society of Australia	Medical doctors	20	15 (14 paediatricians, 1 psychiatrist	12 (11 paediatricians, 1 psychiatrist)
Occupational Therapy Australia	Occupational therapists	20	18	15
Australian Physiotherapy Association	Physiotherapists	20	15	14
Australian Psychological Society	Psychologists	20	12	7
Speech Pathology Australia	Speech pathologists	20	12	11
Total		100	72	59



## **Quantitative data**

The summary of results for the items with quantitative ratings are presented in Figure 9.1. Across the two rounds, a total of 214 items with consensus agreement/disagreement informed Recommendations within the Guideline. Percentage agreement/disagreement, median, and interquartile ranges are provided in the Evidence Summaries within the Supporting Evidence document, for each Recommendation that was directly informed by evidence from the Delphi study.





## **Qualitative data**

As noted above, each round of the Delphi survey gave practitioners an opportunity to provide optional qualitative feedback. These responses were not coded using the coding framework (used for online survey, focus groups, brief survey, and parent reflection) because the coding framework reflected statements in the Delphi survey. Therefore, when making additional comments, they were indicating that the number and nature of statements in the Delphi survey, that were in turn reflected in the coding framework, were insufficient in accounting for their views and experiences (i.e., they had additional views and experiences to offer). Accordingly, every comment by every practitioner was considered on a case-by-case basis, when formulating Recommendations and Good Practice Points, and accompanying evidence summaries.



# 10. Community Consultation: Brief Online Survey

# 10.1 Background

Integral to the development of the Guideline was consultation with the autistic and autism communities. Consistent with the recommendations in the Guidelines for Guidelines handbook (NHMRC, 2016), community consultation was conducted to ensure that all relevant stakeholders within Australia were provided with the opportunity to inform the development of the Guideline. This was key to enhancing the relevance and acceptability of the Guideline to the autistic and autism communities. The consultation process was also conducted to (a) complement the current research evidence, and/or (b) gather information and insight from relevant stakeholders where research evidence is currently lacking.

This consultation activity was designed to capture the experiences, views and preferences of autistic children and young people in the Guideline development process. This activity was also open to autistic people who communicate in ways other than speech.

# 10.2 Aim

The aim of the brief online survey was to understand the experiences, views and preferences of autistic children and young people (and autistic people who communicate in ways other than speech) regarding the provision of supports for autistic children and their families.

# 10.3 Research question

What are the experiences, views and preferences of autistic children, young people and adults regarding accessing supports?

# 10.4 Design

An online survey methodology was adopted. This was a one-off survey, comprising three key questions, accessed via a link on the Autism CRC website. The survey was designed so that it could be completed by typing responses with or without the help of a parent/caregiver.

The survey was open from 6<sup>th</sup> April to 30<sup>th</sup> April, 2022.

# 10.5 Method

Ethical approval for this community consultation activity was provided by Griffith University Human Research Ethics Committee (2021/843). A variation was sought to our original, approved protocol, to include this activity to ensure that children and young people had the option to directly share their experiences, views and preferences in accessing supports.



## Eligibility

Autistic children and young people aged 0-17 years (and autistic people of all ages whose primary/preferred communication mode is not spoken language) were eligible to participate in the brief online survey.

## Recruitment

Participant recruitment for the brief online survey was predominantly facilitated by Autism CRC. Autism CRC sent an invitation and reminder emails to all individuals who registered their interest in the Guideline, informing them of the opportunity for autistic children and young people (including people who communicate in ways other than speech) to contribute to the Guideline's development via the brief online survey. The link to access the brief survey was also made available via the Autism CRC Supporting Children Guideline website, and social media (Facebook and Twitter) accounts. Members of the GDG also promoted the brief online survey throughout their professional networks and social media pages.

After accessing the brief online survey link, prospective participants and/or their parents were presented with a short video outlining what participation in the survey would entail and highlighting accessibility features of the survey platform. Following this, participants were presented with a Participant Information Statement and Consent Form. As part of the Informed Consent process, it was made clear that the parent is responsible for providing informed consent for their child's participation (when the child was under 18 years of age). All participants were required to provide informed consent before accessing the survey questions.

## Tools

The brief online survey was coded and distributed via REDCap (a secure web-based application for survey development and distribution). The survey comprised three sections: (1) a demographic survey, (2) the main set of survey questions for the child, young person, or adult, and (3) questions for the parent (see Appendix 10.1).

For the main set of survey questions, parents were asked to describe the activity to the child, young person or adult person in a way that best matches their understanding. Parents were encouraged to use the name of supports that would be most familiar to the child, young person or adult.

- The main part of the survey involved a set of three questions:
- What was/is your most favourite thing about [named support]?
- What was/is your least favourite thing about [named support]?
- What could make it better? (with reference to the [named support]?

For children aged 0-12 years, it was requested that parents ask the child to write or talk about supports they are currently accessing. For children >12 years, it was requested that parents write or talk about supports they accessed when they were under 12 years of age. Children, young people and adults could choose to type their responses independently into the survey, use a voice-to-text option, or have a parent type their responses. It was



requested that if the latter option is chosen, that the parent types exactly what the child, young person or adults says to ensure that their own words were captured. There was also the option to complete the set of three questions for more than type of support (i.e., by answering the set of three questions up to 5 times).

In order to help contextualise the responses of the children, young people, and adults, parents were asked to describe (a) what type of supports the child was talking about, (b) what their reflections were about (i.e., whether it was in relation to the entire time they accessed supports or just part of the time), (c) whether the survey was completed independently or with assistance from the parent, and (d) any other information they would like to provide.

All questions were optional. If parents had more than one child, they were able to repeat the survey for each child.

## Analysis

Information collected via the brief survey was coded according to 'principles' using the process outlined in detail in relation to the online survey (Chapter 7). This approach – rather than coding according to each section of the code book (e.g., selection of supports, delivery of supports) was adopted because the questions asked of participants in this study were deliberately of a general nature, to ensure participants were free to share whatever they felt was most relevant. However, to ensure that no specific insights, experiences, or suggestions that may be relevant to formulating Recommendations and Good Practice Points were missed, the GDG also reviewed the raw data (i.e., each participant's response to each question) to ensure that all information was considered in relation to all Guideline questions, Recommendations and Good Practice Points.

## 10.6 Results

## **Participant characteristics**

In total, 46 individuals provided informed consent for the brief online survey. Of these, 35 provided some information beyond informed consent (i.e., 11 individuals provided informed consent but no other information or responses to the survey items).



**Table 10.1.** Demographic information for participants who completed at least some items of the brief online survey.

Aspect	Summary	
Age	The average (current) age of autistic children, young people and adults completing the brief survey was 12.33 years (SD = 7.28), with ages ranging from 4 years to 37 years.	
	11 individuals did not provide a response.	
Gender identity	13 of the autistic children/young people/adults identified as female (28%), 17 identified as male (37%), 1 as non-binary (2%), and 1 preferred not to say (2%). 14 participants (30%) did not provide a response.	
Aboriginal and/or Torres Strait Islander Peoples	1 (2%) autistic person identified as Aboriginal. 32 (70%) did not identify as Aboriginal or Torres Strait Islander.	
	13 participants (28%) did not provide a response.	
Born in Australia	30 of the children/young people/adults (65%) were born in Australia. 2 (4%) were not born in Australia. 14 participants (30%) did not provide a response.	
Languages other than English	2 children/young people/adults (4%) were living homes where a language other than English was spoken. 31 (67%) were living in homes where only English was spoken.	
	13 participants (28%) did not provide a response.	
Formal diagnosis of autism	30 children/young people/adults (65%) had received a formal diagnosis of autism. 2 (4%) had not received a formal diagnosis of autism.	
	14 participants (30%) did not provide a response.	
Age of autism diagnosis       The average age of diagnosis was 6.29 years (SD = 4.29), with ages from 1 years to 18 years.		
	18 participants (39%) did not provide a response.	
DSM-5 diagnosis level of support	Of children/young people/adults diagnosed under the DSM-5, the following support levels were associated with the child/young person's diagnosis:	
	7 were diagnosed at Level 1.	
	11 were diagnosed at Level 2.	
	11 were diagnosed at Level 3.	
	1 participant preferred not to say the associated support level. 16 participants did not provide responses.	



Representative DSM-5 level of support	Of children/young people/adults not diagnosed under the DSM-5, participants reported the following would have been most representative of their support needs as a child: 2 selected Level 1 as most representative. 0 selected Level 2 as most representative. 5 selected Level 3 as most representative.
Access to supports between 0-6 years	<ul> <li>25 (54%) children/young people/adults accessed supports between the ages of 0-6 years. 6 families (13%) did not access supports between 0-6 years.</li> <li>15 participants (33%) did not provide responses.</li> </ul>
Access to supports between 7-12 yearszz	<ul> <li>26 (57%) children/young people/adults accessed supports between the ages of 7-12 years. 6 families (13%) did not access supports between the ages of 7-12 years.</li> <li>14 participants (30%) did not provide a response.</li> </ul>

## **Quantitative data**

No quantitative data were collected in this activity.

## **Qualitative data**

A total of 69 references (i.e., quotes) were coded using the framework, with the distribution of references for each code presented in Table 10.2. These quotes, where relevant to the formulation of Recommendations and Good Practice Points, feature in the corresponding evidence summaries.

Table 10.2. Summary of codes and references for the two types of focus groups.

Codes	Total Across All Participants
Principles	
Accessible	4
Assent (children)	2
Child and family-centred	16
Coordinated	1
Culturally aware and responsive	0
Developmental perspective	0
Empirically-supported	0



Equity	0
Ethical practice	8
Evidence-based practice approach	0
Holistic	6
Informed consent (parents)	0
Lifespan perspective	0
Other - Principle	4
Personalised	18
Qualified practitioners	0
Strengths focused	7
Supported	3

Credibility checks were completed for all quotes that featured in the analysis of qualitative data from the brief survey. 100% were classified as 'relevant to the guideline and code,' 0% were classified as 'relevant to the guideline, but cannot establish relevance to code,' and 0% were classified as 'does not appear to be relevant to the Guideline.' Readers are reminded that the person completing the credibility check was reviewing the coded data, not the original transcripts. Accordingly, they did not necessarily have knowledge of the context (e.g., broader statement) from which the quotes had been extracted.



# 11. Community Consultation: Parent Reflection

# 11.1 Background

Integral to the development of the Guideline was consultation with the autistic and autism communities. Consistent with the recommendations in the Guidelines for Guidelines handbook (NHMRC, 2016), community consultation was conducted to ensure that all relevant stakeholders within Australia were provided with the opportunity to inform the development of the Guideline. This was key to enhancing the relevance and acceptability of the Guideline to the autistic and autism communities. The consultation process was also conducted to (a) complement the current research evidence, and/or (b) gather information and insight from relevant stakeholders where research evidence is currently lacking.

This consultation activity was designed for parents of autistic people who communicate/d mostly in ways other than speech to share their reflections and observations of their child or young person accessing supports when they were between 0-12 years of age.

## 11.2 Aim

The aim of this consultation activity was to understand the experiences, views and preferences of autistic children and their families regarding the provision of supports, through parents' observations of their child accessing supports between 0-12 years of age.

# 11.3 Research question

What are the experiences, views and preferences of autistic children, young people and their families as shared through parent observation regarding accessing supports between 0-12 years of age?

# 11.4 Design

A qualitative, online survey methodology was adopted. This was a one-off survey designed for parents of autistic children or young people to complete, comprising a set of questions regarding their child or young person's experiences accessing supports. Access to the survey was via a link on the Autism CRC website.

The survey was open from 6<sup>th</sup> April to 30<sup>th</sup> April, 2022.

# 11.5 Method

Ethical approval for this community consultation activity was provided by Griffith University Human Research Ethics Committee (2021/843). A variation was sought to our original, approved protocol, to include this activity to ensure that children, young people and their family's experiences of accessing supports during childhood was included in the Guideline development process.



## Eligibility

Parents of children who accessed supports and communicate/d mostly in ways other than speech during the ages of 0-12 years.

## Recruitment

Participant recruitment for the parent reflection activity was predominantly facilitated by Autism CRC. Autism CRC sent an invitation and reminder emails to all individuals who registered their interest in the Guideline, informing them of the opportunity to contribute to the Guideline's development via the parent reflection activity. The link to access the parent reflection activity was also made available via the Autism CRC Supporting Children Guideline website, and social media (Facebook and Twitter) accounts. Members of the GDG also promoted the parent reflection activity throughout their professional networks and social media pages.

After accessing the parent reflection survey link, prospective participants were presented with a short video outlining what participation in the activity would entail and highlighting accessibility features of the survey platform. Following this, participants were presented with a Participant Information Statement and Consent Form. As part of the Informed Consent process, it was made clear that the parent was responsible for providing informed consent for their child. All participants were required to provide informed consent before accessing the survey questions.

## Tools

The parent reflection survey was coded and distributed via REDCap (a secure web-based application for survey development and distribution). The survey comprised three sections: (1) a demographic survey with questions for parents to complete about their child, young person or adult, (2) questions for the parent to complete about what types of supports, and over what timeframe, they are providing reflections, and (3) a set of questions for the parents to provide reflections on (see Appendix 11.1).

For the set of reflection questions, parents were asked to reflect on, and provide observations to, the following questions:

- What do you think they currently like (or did like if in the past) about accessing these supports? How do/did they show you through their emotions and actions?
- What do you think they do not like (or did not like if in the past) about accessing these supports? How do/did they show you through their emotions and actions?
- What do you think they would like to change about accessing these supports? How do/did they show you through their emotions and actions?
- Is there anything else you would like to share to help us understand their experiences of accessing supports?

For children aged 0-12 years, it was requested that parents reflect on the experiences of supports they are currently accessing. For children >12 years, it was requested that parents reflect on supports they accessed when their child was under 12 years of age.



All questions were optional.

## Analysis

Information collected via the parent reflect study was coded according to 'principles' using the process outlined in detail in relation to the online survey (Chapter 7). This approach – rather than coding according to each section of the code book (e.g., selection of supports, delivery of supports) was adopted because the questions asked of participants in this study were deliberately of a general nature, to ensure participants were free to share whatever they felt was most relevant. However, to ensure that no specific insights, experiences, or suggestions that may be relevant to formulating Recommendations and Good Practice Points were missed, the GDG also reviewed the raw data (i.e., each participant's response to each question) to ensure that all information was considered in relation to all Guideline questions, Recommendations and Good Practice Points.

## 11.6 Results

## **Participant characteristics**

In total, 25 parents/primary caregivers/legal guardians of autistic children, young people or adults provided informed consent to participate in this activity. Demographic information for the children, young people or adults that parents were providing reflections on, is presented in Table 11.1.

Aspect	Summary	
Age	The average (current) age of autistic children, young people and adults that parents provided reflections on was 11.68 years (SD = 6.61), with ages ranging from 2 years to 23 years.	
Gender identity	9 of the autistic children/young people/adults identified as female (36%), and 16 identified as male (64%).	
Aboriginal and/or Torres Strait Islander Peoples	3 (12%) autistic children/young people identified as Aboriginal. 21 (84%) did not identify as Aboriginal or Torres Strait Islander. 1 participant (4%) did not provide a response.	
Born in Australia	24 of the children/young people/adults (96%) were born in Australia. 1 child/young person/adult (4%) was not born in Australia.	
Languages other than English	3 children/young people/adults (12%) were living homes where a language other than English was spoken. 21 (84%) were living in homes where only English was spoken. 1 participant (4%) did not provide a response.	
Formal diagnosis of autism	All children/young people/adults (n=25, 100%) had received a formal diagnosis of autism.	

**Table 11.1.** Demographics of children, young people and adults from parent reflections and observation regarding accessing supports.



Age of autism diagnosis	The average age of diagnosis for children was 4.72 years (SD = 3.46), with ages ranging from 2 years to 14 years.	
DSM-5 diagnosis level of support	<b>f</b> Of the children/young people diagnosed under the DSM-5, parents reported the following support levels associated with their child/young person's diagnosis:	
	3 were diagnosed at Level 1.	
	11 were diagnosed at Level 2.	
	8 were diagnosed at Level 3.	
	1 participant was unsure of the associated support level.	
Representative DSM-5 level of support	Of children/young people not diagnosed under the DSM-5, parents reported the following would have been most representative of their supports needs as a child:	
	1 selected Level 1 as most representative.	
	2 selected Level 2 as most representative.	
	4 selected Level 3 as most representative.	
Access to supports between 0-6 years	21 (84%) out of the 25 children and families accessed supports at some stage between the ages of 0-6 years. 3 families (12%) did not access supports between 0-6 years. 1 participant (4%) did not provide a response.	
Access to supports between 7-12 years	16 (64%) out of the 25 children and families accessed supports at some stage between the ages of 7-12 years. 7 families (28%) did not access supports between the ages of 7-12 years. 2 participants (8%) did not provide a response.	

## **Quantitative data**

No quantitative data were collected in this activity.

## **Qualitative data**

A total of 70 references (i.e., quotes) were coded using the framework, with the distribution of references for each code presented in Table 11.2. These quotes, where relevant to the formulation of Recommendations and Good Practice Points, feature in the corresponding evidence summaries.



### Table 11.2. Summary of codes and references

Codes	Total Across All Participants
Principles	
Accessible	10
Assent (children)	0
Child and family-centred	11
Coordinated	4
Culturally aware and responsive	0
Developmental perspective	2
Empirically-supported	0
Equity	0
Ethical practice	3
Evidence-based practice approach	3
Holistic	3
Informed consent (parents)	0
Lifespan perspective	0
Other - Principle	4
Personalised	22
Qualified practitioners	0
Strengths focused	5
Supported	3

Credibility checks were completed for all quotes that featured in the analysis of qualitative data from the parent reflection activity. 100% were classified as 'relevant to the guideline and code,' 0% were classified as 'relevant to the guideline, but cannot establish relevance to code,' and 0% were classified as 'does not appear to be relevant to the Guideline.' Readers are reminded that the person completing the credibility check was reviewing the coded data, not the original transcripts. Accordingly, they did not necessarily have knowledge of the context (e.g., broader statement) from which the quotes had been extracted.



# 12. Community Consultation: Expression Through Artwork

# 12.1 Background

Integral to the development of the Guideline was consultation with the autistic and autism communities. Consistent with the recommendations in the Guidelines for Guidelines handbook (NHMRC, 2016), community consultation was conducted to ensure that all relevant stakeholders within Australia were provided with the opportunity to inform the development of the Guideline. This was key to enhancing the relevance and acceptability of the Guideline to the autistic and autism communities. The consultation process was also conducted to (a) complement the current research evidence, and/or (b) gather information and insight from relevant stakeholders where research evidence is currently lacking.

This consultation activity was designed for autistic people who may prefer to share their experiences, views and preferences regarding supports for autistic children and their families through artistic expression.

# 12.2 Aim

To capture the experiences, views and preferences of autistic people (of all ages) regarding the provision of supports for autistic children and their families, through artistic expression.

## 12.3 Research question

What are the experiences, views and preferences of autistic people (as expressed through artwork) regarding the provision and accessing of supports?

# 12.4 Design

A qualitative methodology approach was adopted, through artwork. Autistic people could submit a piece of art (e.g., a drawing, painting, or any other artwork) online (via a secure online portal) about their experiences and/or feelings of accessing supports.

This activity was open from 6<sup>th</sup> April to 30<sup>th</sup> April, 2022.

# 12.5 Method

Ethical approval for this community consultation activity was provided by Griffith University Human Research Ethics Committee (2021/843). A variation was sought to our original, approved protocol, to include this activity to ensure that autistic people had the option to share their experiences, views and preferences through artistic expression regarding the provision and accessing of supports during childhood.



## **Participant eligibility**

Autistic children, young people and adults who accessed supports between the ages of 0-12 years.

### Recruitment

Participant recruitment for the sharing of experiences through artwork was predominantly facilitated by Autism CRC. Autism CRC sent an invitation and reminder emails to all individuals who registered their interest in the Guideline, informing them of the opportunity for autistic people to contribute to the Guideline's development through artistic expression. A link to access information about this activity and how to upload artwork was also made available via the Autism CRC Supporting Children Guideline website, and social media (Facebook and Twitter) accounts. Members of the GDG also promoted this activity throughout their professional networks and social media pages.

After clicking on the link, prospective participants were presented with a short video outlining what participation in this activity would entail. Following this, participants were presented with a Participant Information Statement and Consent Form. For children aged under 18 years, informed consent was the responsibility of their parent.

### **Tools**

This activity was accessed via REDCap (a secure web-based application for survey development and distribution). The activity involved a brief (optional) demographic survey about the autistic person submitting the artwork.

Regarding the artwork, autistic people were invited to produce a piece of art (e.g., a drawing, painting, or any other artwork) about their experiences and/or feelings of accessing supports. Parents (where relevant) were asked to describe the activity to the child, young person or adult person in a way that best matches their understanding.

For children aged 0-12 years, it was requested that parents ask the child to create a piece of art about supports they are currently accessing. For children >12 years, it was requested that they create a piece of art about supports they accessed when they were under 12 years of age.

Participants could then take a photo or scan the artwork and upload it via a provided link in the online survey form.

To help us understand and interpret the artwork, participants were asked to answer some brief questions (to the extent that it was possible) including, 'what is the artwork about?' and any other information they would like to share to help us understand their artwork.

There were also some questions for the parent, where relevant, including what they think the artwork reflects about their child's experiences/feelings accessing supports and what types of supports are reflected. The demographic questions, activity instructions, and associated questions are outlined in Appendix 12.1 and Appendix 12.2.



## Analysis

There were no submissions through this mode.

## 12.6 Results

## **Participant characteristics**

No autistic people chose to share their experiences, views, or preferences regarding the provision and accessing of supports through this mode.

### **Quantitative data**

No quantitative data were collected in this activity.

### **Qualitative data**

There were no submissions through this mode.



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# 14. Appendices

The appendices have been prepared for the Draft Administration and Technical Report in draft form. These documents will be further updated and formatted prior to the release of the final Guideline.

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National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia

 Appendix 2.1
 Guideline Development Group – Terms of Reference

# Developing a national guideline for supporting the development and participation of children on the autism spectrum, and their families, in Australia

Terms of Reference for the Guideline Development Group

#### Background

The Autism Cooperative Research Centre (Autism CRC) has commissioned Professor Andrew Whitehouse and Associate Professor David Trembath to develop a national guideline that outlines clinical recommendations for supporting the development and participation of children on the autism spectrum, and their families, in Australia ('the project').

#### Purpose

The Autism CRC has asked Prof Whitehouse and A/Prof Trembath to form a team ('Guideline Development Group') that will conduct the background research for the project and prepare the draft and final documents. The Guideline Development Group will exist for the duration of the project.

#### Anticipated timeline for the project

The project is scheduled to commence on Oct 1<sup>st</sup> 2021, and be completed by Sept 30<sup>th</sup> 2022.

#### Membership of the Guideline Development Group

Membership of the Guideline Development Group is informed by the 'Guideline for Guidelines' recommendations provided by the National health and Medical Research Council. The Guideline Development Group comprises Prof Andrew Whitehouse (co-chair), A/Prof David Trembath (co-chair), clinical researchers (X 4), an individual with ethics expertise (X 1), an individual with expertise in the methodology for guideline development (X 1), and representatives from the following communities: autistic adults (X 2), parent/families members of individuals on the autism spectrum (X 2), clinician with a current caseload including children on the autism spectrum (X 2), First Nations peoples (X 1).

#### **Appointment of Chair**

The co-chairs of the Guideline Development Group are Professor Whitehouse and Associate Professor Trembath, who will each have clearly delegated duties.

#### **Responsibilities of Project Team Members**

Prof Whitehouse (co-Chair) will:

• Along with David Trembath, assumes overall responsibility for delivering the project.

- Coordinate and chair meetings with the Reference Group
- Coordinate all engagement with stakeholders external to the Guideline Development Group, including (but not limited to) the Reference Group, the Autism CRC and the National Disability Insurance Agency.
- Along with a A/Prof Trembath, line manage the clinical researchers.
- Participate in the day-to-day research activities of the project, as guided by A/Prof Trembath.

#### A/Prof Trembath (co-Chair) will:

- Along with Chair, assume overall responsibility for delivering the project.
- Coordinate and chair meetings with the Guideline Development Group.
- Coordinate all engagement with the Guideline Development Group.
- Along with Prof Whitehouse, line manage the activities of the clinical researchers
- Guide the day-to-day research activities of the project.

The clinical researchers will:

- Attend meetings as required throughout the duration of the project.
- Work under the supervision of Prof Whitehouse and A/Prof Whitehouse to undertake the day-to-day activities of the project.

Other members of the Guideline Development Group:

- Attend meetings as required throughout the duration of the project (all).
- Provide input in the areas of expertise and experience they bring to the Guideline
   Development Group, such as lived experience of autism, ethics, guideline methodology, and cultural knowledge.
- Respond to 'out of meeting' emails from Chair/Deputy Chair requesting guidance.
- Provide feedback on documents that are prepared for the Guideline, within an agreed timeframe (likely 14 days).

#### Meetings

The Guideline Development Group will meet as often as it agrees or as required, but likely no more than 10 times throughout the duration of the project. The Project Team could expect to meet bimonthly by videoconference. The Project Team will meet via videoconference at the request of either of the co-chairs or at the request of two or more members of the Project Team. A quorum will be a majority of the Members present in person or by teleconference, including one of the co-Chairs.

#### Code of conduct for the Project Team

The Guideline Development Group recognises that this is a sensitive project that requires completion within a relatively short timeframe. As such, the Guideline Development Group agrees to the following:

- Conflicts of interest will be declared at the outset of the project, and be updated as any new potential conflicts emerge.
- All communication between Guideline Development Group members will be conducted in a respectful, constructive and cooperative way, and avoiding self-interest.
- The guideline generated by the Guideline Development Group will be based on a balanced evaluation of the strength of the evidence.
- All discussions within the Project Team will remain confidential to that Project Team until the conclusion of the project.

#### Reporting

The Project Team reports to the Autism CRC Ltd Board.

#### By signing below, I indicate that I agree to these Terms of reference.

Name	
Signature	

National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia

 Appendix 2.2
 Guideline Development Group – Declaration of Interests

#### **Autism CRC National Practice Guideline**

#### **Disclosure of Interests**

Date:	5 May 2022
First Name:	Gary
Surname:	Allen

#### **Origin of Form**

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (<u>https://www.icmje.org/disclosure-of-interest/</u>)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form
   (<u>https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf</u>)

#### Instructions

The purpose of this form is to provide readers of your review with information about your other interests that could influence how they receive and understand your work. We ask you to disclose all relationships/activities/interests listed below that are related to your involvement in the development of the National Practice Guideline (herein referred to as the *guideline*). "Related" means any relation with for-profit or not-for-profit third parties whose interests may be affected by the content of the guideline. Disclosure represents a commitment to transparency and does not necessarily indicate a bias. Please think broadly when disclosing all relationships/activities/interests that may be relevant to your involvement in the guideline. If you are in doubt about whether to list a relationship/activity/interest, it is preferable that you do so.

Each person will be asked to complete their own form and you are responsible for the accuracy and completeness. In submitting this form, you certify that you have answered every question and have not altered the wording of any of the questions on this form.

If new interests arise during the project, you are required to submit an updated form.

#### 1. Support for your involvement in the development of the guideline.

This section asks for information about your role in the development of the guideline. The time frame for this reporting is that of the work itself, from the initial conception and planning to the present. The requested information is about resources that you received, either directly or indirectly (via your institution), to enable you to complete the work. Writing "None" means that you did the work without receiving any financial support from any third party -- that is, the work was supported by funds from the same institution that pays your salary and that institution did not receive third-party funds with which to pay you. If you or your institution received funds from a third party to support the work, such as a government granting agency, charitable foundation or commercial sponsor, then provide the details. For example, if you received an honorarium from Autism CRC in relation to your involvement, you would name Autism CRC and then indicate the amount of funds received.

Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	None	
Consulting fee or	I am a senior consultant with,	AHRECS ( <u>www.ahrecs.com</u> ) currently
honorarium	and Managing Director of	pays me around \$5000 per month.
	Australasian Human Research	
	Ethics Consultancy Services	Enabled.vip ( <u>www.enabled.vip</u> ) is
	(AHRECS). I am also the Co-	currently a voluntary role, though the
	Founder and CEO of	hope is that it will eventually be a paid
	Enabled.vip.	role
	I am a paid member of the National Mutual Acceptance Committee.	
	I am a full time staff member in	
	the Office for Research, Griffith	
	University	
Support for travel to	None	
meetings for the		
guideline or other		
purposes		
Other	None	

Please add more rows if necessary.

#### 2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the guideline, and up until the point it is submitted to Autism CRC (i.e., 2019-2022). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

Name all entities with whom	Specifications/comments
you have this relationship or	(e.g., description of support,
indicate none (add rows as	if payments were made to
needed)	you or your institution)

Crante or contracte from any	None	
Grants or contracts from any entity (if not indicated in item	None	
#1 above).		
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for	None	
lectures, presentations,	None	
speakers bureaus, manuscript		
writing or educational events		
	None	
Payment for expert testimony		
Support for attending meetings and/or travel	None	
	Nous	
Patents planned, issued or	None	
pending Destining on a Data Safatu	None	
Participation on a Data Safety	None	
Monitoring Board or Advisory		
Board	Nous	
Leadership or fiduciary role in	None	
other board, society, committee		
or advocacy group, paid or		
unpaid	N	
Grants or contracts from any	None	
entity (if not indicated in item		
#1 above).	N.	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for	None	
lectures, presentations,		
speakers bureaus, manuscript		
writing or educational events	N	
Payment for expert testimony	None	
Support for attending meetings	None	
and/or travel	N.	
Patents planned, issued or	None	
pending		
Participation on a Data Safety	None	
Monitoring Board or Advisory		
Board		
Leadership or fiduciary role in	None	
other board, society, committee		
or advocacy group, paid or		
unpaid	NT.	
Stock or stock options	None	
Receipt of equipment,	None	
materials, drugs, medical		
writing, gifts or other services		

# **3.** Relevant other activities or relationships, including non-financial relationships (no time limit)

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or	None
supports that may be covered	
within the scope of the	
guideline	
A personal relationship with	None
another person (e.g., spouse,	
family member) involved in	
the development, delivery,	
and/or evaluation of therapies	
and/or supports that may be	
covered within the scope of the	
guideline	
Development and/or delivery	None
of professional preparation	
programs that may be relevant to the guideline (e.g., allied	
health professional preparation	
programs)	
A personal relationship with	None
another person (e.g., spouse,	
family member) involved in	
the development and/or	
delivery of professional	
preparation programs that may	
be relevant to the guideline	
(e.g., allied health professional	
preparation programs)	
Personal and/or family member	None
experience of accessing	
therapies and/or support that	
may be covered in the guideline	
Other	None
Ould	TIONC

#### Declaration

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than 'none' to any of the questions above, these will be reviewed by Dr Gary Allen, Senior Policy Officer Human Research Ethics and Research Integrity at Griffith University. In each case, appropriate processes will be put in place to management any conflicts arising. Team members should not be concerned about answering 'yes' to any of the questions. 'Yes' answers do not indicate good or bad, but are simply something to declare on the form and consider for inclusion in the declarations section of the guideline.

#### **Autism CRC National Practice Guideline**

#### **Disclosure of Interests**

Date:	12/05/2022
First Name:	Katharine Elisabeth
Surname:	Annear

#### **Origin of Form**

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (<u>https://www.icmje.org/disclosure-of-interest/</u>)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form (<u>https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf</u>)

#### Instructions

The purpose of this form is to provide readers of your review with information about your other interests that could influence how they receive and understand your work. We ask you to disclose all relationships/activities/interests listed below that are related to your involvement in the development of the National Practice Guideline (herein referred to as the *guideline*). "Related" means any relation with for-profit or not-for-profit third parties whose interests may be affected by the content of the guideline. Disclosure represents a commitment to transparency and does not necessarily indicate a bias. Please think broadly when disclosing all relationships/activities/interests that may be relevant to your involvement in the guideline. If you are in doubt about whether to list a relationship/activity/interest, it is preferable that you do so.

Each person will be asked to complete their own form and you are responsible for the accuracy and completeness. In submitting this form, you certify that you have answered every question and have not altered the wording of any of the questions on this form.

If new interests arise during the project, you are required to submit an updated form.

#### 1. Support for your involvement in the development of the guideline.

This section asks for information about your role in the development of the guideline. The time frame for this reporting is that of the work itself, from the initial conception and planning to the present. The requested information is about resources that you received, either directly or indirectly (via your institution), to enable you to complete the work. Writing "None" means that you did the work without receiving any financial support from any third party -- that is, the work was supported by funds from the same institution that pays your salary and that institution did not receive third-party funds with which to pay you. If you or your institution received funds from a third party to support the work, such as a government granting agency, charitable foundation or commercial sponsor, then provide the details. For example, if you received an honorarium from Autism CRC in relation to your involvement, you would name Autism CRC and then indicate the amount of funds received.

Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant		
Consulting fee or honorarium	The Cooperative Research Centre for Living with Autism (Autism CRC)	Honorarium \$5000
Support for travel to meetings for the guideline or other purposes		
Other		

Please add more rows if necessary.

#### 2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the guideline, and up until the point it is submitted to Autism CRC (i.e., 2019-2022). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	Department of Social Services – Information Linkages and Capacity Building Grant	Grant made to The Autistic Self Advocacy Network of Australia and New Zealand – my role is subcontracted Operations Manager
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	

Support for attending meetings and/or travel	National Disability Insurance Agency	The NDIA Autism Advisory Group – travel and honorarium The Children, Families and Young People's Reference Group for the Independent Advisory Council to the NDIA– travel and honorarium
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	Non Executive Director Autism CRC Developmental Educators Australia Inc	Annual Directors Fees Chair - Voluntary position – self-regulating professional body
Stock or stock options	None	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	None	

# 3. Relevant other activities or relationships, including non-financial relationships (no time limit)

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	Lecturer B (Teaching Specialist) Dpt Disability and Community Inclusion, College of Nursing and Health Sciences, Flinders University, South Australia
A personal relationship with another person (e.g., spouse, family member) involved in	None

the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	
Personal and/or family member experience of accessing therapies and/or support that	None
may be covered in the guideline Other	None

#### Declaration

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than 'none' to any of the questions above, these will be reviewed by Dr Gary Allen, Senior Policy Officer Human Research Ethics and Research Integrity at Griffith University. In each case, appropriate processes will be put in place to management any conflicts arising. Team members should not be concerned about answering 'yes' to any of the questions. 'Yes' answers do not indicate good or bad, but are simply something to declare on the form and consider for inclusion in the declarations section of the guideline.

#### **Autism CRC National Practice Guideline**

#### **Disclosure of Interests**

Date:	4 <sup>th</sup> May 2022
First Name:	Valsamma
Surname:	Eapen

#### Origin of Form

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (<u>https://www.icmje.org/disclosure-of-interest/</u>)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form (<u>https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf</u>)

#### Instructions

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Each person will be asked to complete their own form and you are responsible for the accuracy and completeness. In submitting this form, you certify that you have answered every question and have not altered the wording of any of the questions on this form.

If new interests arise during the project, you are required to submit an updated form.

#### 1. Support for your involvement in the development of the guideline.

This section asks for information about your role in the development of the guideline. The time frame for this reporting is that of the work itself, from the initial conception and planning to the present. The requested information is about resources that you received, either directly or indirectly (via your institution), to enable you to complete the work. Writing "None" means that you did the work without receiving any financial support from any third party -- that is, the work was supported by funds from the same institution that pays your salary and that institution did not receive third-party funds with which to pay you. If you or your institution received funds from a third party to support the work, such as a government granting agency, charitable foundation or commercial sponsor, then provide the details. For example, if you received an honorarium from Autism CRC in relation to your involvement, you would name Autism CRC and then indicate the amount of funds received.

Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	None	
Consulting fee or	None	
honorarium		
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

Please add more rows if necessary.

#### 2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the guideline, and up until the point it is submitted to Autism CRC (i.e., 2019-2022). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	
Patents planned, issued or pending	None	

Participation on a Data Safety	None	
Monitoring Board or Advisory		
Board		
Leadership or fiduciary role in	None	
other board, society, committee		
or advocacy group, paid or		
unpaid		
Stock or stock options	None	
Receipt of equipment,	None	
materials, drugs, medical		
writing, gifts or other services		

# 3. Relevant other activities or relationships, including non-financial relationships (no time limit)

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
Personal and/or family member experience of accessing therapies and/or support that may be covered in the guideline	None

Other None
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#### Declaration

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than 'none' to any of the questions above, these will be reviewed by Dr Gary Allen, Senior Policy Officer Human Research Ethics and Research Integrity at Griffith University. In each case, appropriate processes will be put in place to management any conflicts arising. Team members should not be concerned about answering 'yes' to any of the questions. 'Yes' answers do not indicate good or bad, but are simply something to declare on the form and consider for inclusion in the declarations section of the guideline.

#### **Autism CRC National Practice Guideline**

#### **Disclosure of Interests**

Date:	12.5.2022
First Name:	Jess
Surname:	Feary

#### **Origin of Form**

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (<u>https://www.icmje.org/disclosure-of-interest/</u>)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form (<u>https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf</u>)

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#### 1. Support for your involvement in the development of the guideline.

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Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	None	
Consulting fee or honorarium	Autism CRC	\$4000 (not yet received)
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

Please add more rows if necessary.

#### 2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the guideline, and up until the point it is submitted to Autism CRC (i.e., 2019-2022). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any	Australian Government	Aspect awarded contract for
entity (if not indicated in item	Department of Education Skills	Positive Partnerships from
#1 above).	and Employment	2021-2024.
Royalties or licenses	None	
Consulting fees	La Trobe University	Personal payment for marking of Early Start Denver Model video submissions.
Payment or honoraria for		
lectures, presentations, speakers bureaus, manuscript	La Trobe University	Delivered lecture as part of autism subject at La Trobe
writing or educational events		University
Payment for expert testimony	None	

Support for attending meetings and/or travel	Every Child Conference (San Francisco)	Travel costs covered to present keynote at Every Child conference in San Francisco
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	
Stock or stock options	None	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	None	

# 3. Relevant other activities or relationships, including non-financial relationships (no time limit)

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	Co-authored research papers on the Early Start Denver model. Contributed to the book 'Implementing the Group-Based Early Start Denver Model for Toddlers with Autism' Certified trainer and Certified therapist for Early Start Denver Model Develop and delivery workshops for Positive Partnerships that includes information about supports for autistic students.
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or	None

delivery of professional preparation programs that may be relevant to the guideline	
(e.g., allied health professional preparation programs)	
Personal and/or family member experience of accessing therapies and/or support that may be covered in the guideline	None
Other	Worked for Victorian Department of Education and Training. Assisted with the development of the Victorian Autism Education Strategy.

#### **Disclosure of Interests**

Date:	9/05/2022
First Name:	Emma
Surname:	GOODALL

## Origin of Form

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If new interests arise during the project, you are required to submit an updated form.

#### 1. Support for your involvement in the development of the guideline.

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	None	
Consulting fee or honorarium	Autism CRC	Honorarium for attendance at online meetings, reviewing document and providing input. \$3,500
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

Please add more rows if necessary.

## 2. Relevant financial activities outside the guideline (2019-2022)

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	Jessica Kingsley Publishing Springer	Royalties for books paid 6 monthly various amounts Payments for books (2019- 2022 \$1,000)
Consulting fees	Educational Services Australia	Subject matter expert content and resources reviews (2019,
	PINN – project evaluation	\$10,000) Evaluation planning, delivery and report (2022, \$8,000)

National Autistic Society, Cork	Payments from \$100 up to
	\$2000 for presentations and
	keynotes. Flights and
Spectrum Space	accommodation for live
	conferences
None	
Positive Partnerships	Paid travel for work meetings
	and workshops
None	
None	
Australasian Society for	Executive Committee member
Autism Research	
Australian Autism Alliance	Co-chair
Australian Autism Research	Executive committee member
Council	
AutismCRC Biobank	Access Committee member
None	
None	
	Autism, Reframing Autism, Yellow Ladybugs, Aspect, Spectrum Space None Positive Partnerships None None Australasian Society for Autism Research Australian Autism Alliance Australian Autism Research Council AutismCRC Biobank None

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	I have led and contributed to research that has examined the outcomes relating to developing interoception and improving self-regulation and self-management. My research is published as an MScR thesis and a book a well as forming the basis of a federally funded website developed by Education Services Australia.
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied	I am the content writer for Positive Partnerships, a federally funded program that delivers workshops, webinars and online learning for educators and parents of school age students on the autism spectrum (2020-present).

health professional preparation programs)	Wrote and delivered autism information workshops for the South Australian Dept for Education (2015 up to Jan 2020)
A personal relationship with	None
another person (e.g., spouse,	
family member) involved in	
the development and/or	
delivery of professional	
preparation programs that may	
be relevant to the guideline	
(e.g., allied health professional	
preparation programs)	
Personal and/or family member	None
experience of accessing	
therapies and/or support that	
may be covered in the	
guideline	
Other	None

#### **Disclosure of Interests**

Date:	12 May 2022
First Name:	Teresa
Surname:	Pilbeam

#### **Origin of Form**

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (<u>https://www.icmje.org/disclosure-of-interest/</u>)
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If new interests arise during the project, you are required to submit an updated form.

#### 1. Support for your involvement in the development of the guideline.

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	None	
Consulting fee or honorarium	Yes - Autism CRC	\$4,000 honorarium yet to be claimed
Support for travel to meetings for the guideline or other purposes Other	Yes – Invitation from the GDG to attend the NACCHO conference in Darwin in June 2022 as a GDG representative. Yes – Autism Queensland	Flights and accommodation to be paid by GDG. I will be taking annual leave to attend this event and unpaid leave if I have no annual leave available. I work full-time for Autism Queensland who require that I take a half day of annual leave to attend each of the GDG meetings and additional leave if required to complete readings or meeting preparation. The leave requests are not guaranteed approval by my line manager and will only be approved if I am not required to complete duties allocated to me on those meeting days. Autism Queensland have requested that they be acknowledged on the final publication of the GDG findings and recommendations.

Please add more rows if necessary.

## 2. Relevant financial activities outside the guideline (2019-2022)

Name all entities with whom	Specifications/comments
you have this relationship or	(e.g., description of support,
indicate none (add rows as	if payments were made to
needed)	you or your institution)

Grants or contracts from any entity (if not indicated in item #1 above). Royalties or licenses Consulting fees	Yes – see Question 3 points 2 and 3 for additional detail, None Yes - RARE AWARENESS EDUCATION, SUPPORT AND TRAINING (RAREST) STAKEHOLDER REFERENCE GROUP – funded by the Department of Health Independent Consultant collaborating to progress the implementation of the National Strategic Action Plan for Rare Diseases. Member: 2022-current	Remuneration will be paid in alignment with the Health Consumers NSW Remuneration and Reimbursement of Health Consumers Position Statement.
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony Support for attending meetings and/or travel	None Yes – Autism Queensland - negative-financial with conservative and discretionary support for approving my annual leave applications to attend the GDG meetings	I work full-time for Autism Queensland who require that I take a half day of annual leave to attend each of the GDG meetings and additional leave if required to complete readings or meeting preparation. The leave requests are not guaranteed approval by my line manager and will only be approved if I am not required to complete duties allocated to me on those meeting days. In return for conservative and discretionary negative- financial leave approval, Autism Queensland have requested that they be acknowledged on the final publication of the GDG findings and recommendations. Autism Queensland have also requested, post-publication of my biography on the Autism CRC website, that I acknowledge them as a key contributor to my skill set utilised by the GDG. I have worked for Autism Queensland

		for almost six (6) years of my 32-year career as a teacher and I have been an informal family carer for over 24 years as a parent of an adult daughter on the autism spectrum. If I were to acknowledge Autism Queensland I would also like to acknowledge my daughter Clarisse for being on the spectrum and having a rare neurological condition, the Queensland Department of Education for employing me as a Special Needs Education Teacher, the network of Carer organisations for taking me into their fold as a person with lived experience, the Federal Department of Social Services for inviting me to be a member and co-chair on various councils and committees, and the Queensland Government Department of Communities,	
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		Disabilities, and Carers who	
		provided me the opportunity to	
		lead carer reform as a member	
		and co-chair for multiple	
		terms. Of course, special	
		acknowledgement must go to	
		my parents, husband and three	
		other children for supporting	
		me in my advocacy work for decades and providing me with	
		wise words and guidance.	
Patents planned, issued or	None	The words and Buildinee.	
pending			
Participation on a Data Safety	None		
Monitoring Board or Advisory			
Board			
Leadership or fiduciary role in	Yes -	Volunteer roles with travel and	
other board, society, committee	RARE VOICES AUSTRALIA – not- for-profit advocacy organisation	accommodation paid for attendance at Federal	
or advocacy group, paid or unpaid	Independent Board Director	Government Councils and	
unputu	providing oversight of the	Working Groups prior to 2020.	
	organisation's operations and		
	strategic direction.		
	Member: 2022-current		
	DISABILITY EMPLOYMENT		
	DISABILITY EMPLOYMENT ADVISORY COUNCIL – Federal		
	ADVISORY COUNCIL – Federal Department of Social Services		
	ADVISORY COUNCIL – Federal		

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on the Council to provide lived		
experience and professional		
perspectives associated with		
autism when navigating the		
disability employment space.		
Member: 2019-2021		
NATIONAL DISABILITY		
STRATEGY REFORM WORKING		
GROUP – Federal Department of		
Social Services		
Independent Carer		
Representative to support the		
review of the National Disability		
Strategy and provide insight on		
how the Strategy is interpreted		
across Australia's remote		
Aboriginal and Torres Strait		
Islander communities,		
particularly for those First		
Nation's peoples on the autism		
spectrum.		
Member: 2018-2022		
NATIONAL DISABILITY AND		
CARERS ADVISORY COUNCIL –		
Federal Department of Social		
Services		
Independent Carer		
Representative advising on key		
issues regarding the		
implementation of the National		
Disability Strategy (NDS) and the		
National Disability Insurance		
Scheme (NDIS).		
Member/Acting Chair Carer		
Reform: 11/2016-2019		
Member: National Disability		
Strategy Reform Working Group		
2018-2019		
QUEENSLAND CARERS ADVISORY		
COUNCIL – State Government		
Department of Communities,		
Disability and Carers		
Independent Carer		
Representative to guide and assist		
with prioritizing key issues		
relevant to reviewing Carer policy		
particularly legal implications of		
the Carer Recognition Act.		
Appointed as lead writer in the		
development of a discussion		
paper to reflect concepts and		
challenges for Carers in		

	Co-Chair: 2018-2019		
	MONTROSE RESPITE AND THERAPY SERVICES – State based not-for-profit disability service provider Independent Board Director providing expertise on the NDIS, consumer-directed program development and service delivery. Board Director: 11/2014-current Chair: Board Performance Planning Review Committee 2015-2018 Chair: Awareness and Fundraising Committee 2014- 2017 Chair: Services and Programs 2017-2019		
Grants or contracts from any entity (if not indicated in item	None		
#1 above). Royalties or licenses	None		
Consulting fees	None		
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None		
Payment for expert testimony	None		
Support for attending meetings and/or travel	Yes – Invitation from the GDG to attend the NACCHO conference in Darwin in June 2022 as a GDG representative.	Flights and accommodation to be paid by GDG. I will be taking annual leave to attend this event and unpaid leave if I have no annual leave available.	
Patents planned, issued or pending	None		
Participation on a Data Safety Monitoring Board or Advisory Board	None		
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	Yes – this question has been repeated and relevant declaration can be found where this question appears earlier in this table.		
Stock or stock options Receipt of equipment, materials, drugs, medical writing, gifts or other services	None None		

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	Specifications/comments (e.g., description of the relationship/activity/organisations involved)Yes – I am employed full-time as a Teacher with Autism Queensland. I currently work within the Specialist Disability School Service (SDSS) which is funded to Autism Queensland by the Queensland Department of Education. The support that is provided to schools is typically in one-off collaborative sessions where I draw upon current evidence-informed research and best practice to support access, participation, and achievement of students with disabilities in schools across Queensland.Yes - In my previous role as Manager of the National Indigenous Programs with Autism Queensland I delivered activities to raise awareness and provide education about autism and the pathways to support services available for Aboriginal and/or Torres Strait Islander peoples. The Early Intervention 
	implementation of the National Strategic Action Plan for Rare Diseases. Member: 2022-current

RARE VOICES AUSTRALIA – not-for-profit advocacy organisation Independent Board Director providing oversight of the organisation's operations and strategic direction. Member: 2022-current	
DISABILITY EMPLOYMENT ADVISORY COUNCIL – Federal Department of Social Services Independent Carer Representative advisory position on the Council to provide lived experience and professional perspectives associated with autism when navigating the disability employment space. Member: 2019-2021	
NATIONAL DISABILITY STRATEGY REFORM WORKING GROUP – Federal Department of Social Services Independent Carer Representative to support the review of the National Disability Strategy and provide insight on how the Strategy is interpreted across Australia's remote Aboriginal and Torres Strait Islander communities, particularly for those First Nation's peoples on the autism spectrum. Member: 2018-2022	
NATIONAL DISABILITY AND CARERS ADVISORY COUNCIL – Federal Department of Social Services Independent Carer Representative advising on key issues regarding the implementation of the National Disability Strategy (NDS) and the National Disability Insurance Scheme (NDIS). Member/Acting Chair Carer Reform: 11/2016-2019 Member: National Disability Strategy Reform Working Group 2018- 2019	
QUEENSLAND HEALTH – State Health Department Independent Carer Representative providing lived perspectives of a parent of a child with complex disabilities. Carer Representative: Queensland Children's Hospital Stakeholder Committee 04/2012-02/2013 Consumer Participant: Highly Specialised Complex Services Project Steering Group 06/2016-2018 Consumer Participant: eHealth Reform Initiatives Working Group 07/2016-2018	
QUEENSLAND CARERS ADVISORY COUNCIL – State Government Department of Communities, Disability and Carers Independent Carer Representative to guide and assist with prioritizing key issues relevant to reviewing Carer policy particularly legal implications of the Carer Recognition Act. Appointed as lead writer in the development of a discussion paper to reflect concepts and challenges for Carers in Education. Member: 11/2013-2018 Co-Chair: 2018-2019	
MONTROSE RESPITE AND THERAPY SERVICES – State based not-for- profit disability service provider Independent Board Director providing expertise on the NDIS, consumer-directed program development and service delivery. Board Director: 11/2014-current Chair: Board Performance Planning Review Committee 2015-2018 Chair: Awareness and Fundraising Committee 2014-2017	

	Chair: Services and Programs 2017-2019	
	CARERS AUSTRALIA – National not-for-profit peak body Queensland Carer Representative to support and advise upon the strategic direction of the organisation, promote the Carer role nationally through consultation forums and conferences, and wrote a submission to the 2014 Department of Defence White Paper. Member: Finance, Audit and Risk Group Board Director: 12/2013-11/2015 Vice President: 12/2015-08/2016	
	CARERS QUEENSLAND – State not-for-profit peak body Independent Carer Representative with lived experience to identify and guide opportunities for innovation to support sustainability of client services during transition to the NDIS and initiated state-wide Carer Conversations through consultative forums to guide consumer- informed program development. Chair: Board Performance Policy Board Director: 11/2011-08/2016	
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None	
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	Yes – I am employed full-time as a Teacher with Autism Queensland. I currently work within the Specialist Disability School Service (SDSS) which is funded to Autism Queensland by the Queensland Department of Education. The support that is provided to schools is typically in one-off collaborative sessions where I draw upon current evidence-informed research and best practice to support access, participation, and achievement of students with disabilities in schools across Queensland.	
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None	
Personal and/or family member experience of accessing therapies and/or support that may be covered in the guideline	Yes - My adult daughter is on the autism spectrum and my lived experience of supporting her navigate government and non- government systems for 24 years influences my perspectives I provide on the GDG. She has no direct influence on topics for discussion associated with the GDG as those agenda items are confidential.	
Other	None	

#### **Disclosure of Interests**

Date:	21/10/202, updated 12/07/2022
First Name:	Sarah
Surname:	Pillar

## Origin of Form

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If new interests arise during the project, you are required to submit an updated form.

## 1. Support for your involvement in the development of the guideline.

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	Autism CRC	0.4FTE, 12 month contract payment to institution (CliniKids, Telethon Kids Institute)
Consulting fee or honorarium	None	
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

Please add more rows if necessary.

## 2. Relevant financial activities outside the guideline (2019-2022)

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	CliniKids, Telethon Kids Institute	I am employed as the 'Integration Project Manager' at CliniKids Telethon Kids Institute. CliniKids provide support services to autistic children, as well as those with developmental delays. The majority of children receiving services through CliniKids receive funding for services through the NDIS. CliniKids also provides training to

		clinicians in autism supports and is integrated with a research team who are engaged in the evaluation of autism supports.
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	
Stock or stock options	None	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	None	

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	I am involved in the delivery or supervision of the delivery of a range of supports, including PACT, JASPER, and a range of speech pathology supports.
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied	None

health professional preparation programs)	
A personal relationship with	None
another person (e.g., spouse,	
family member) involved in	
the development and/or	
delivery of professional	
preparation programs that may	
be relevant to the guideline	
(e.g., allied health professional	
preparation programs)	
Personal and/or family member	None
experience of accessing	
therapies and/or support that	
may be covered in the	
guideline	
Other	None

#### **Disclosure of Interests**

Date:	9 May 2022
First Name:	Felicity
Surname:	Rose

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If new interests arise during the project, you are required to submit an updated form.

#### 1. Support for your involvement in the development of the guideline.

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	None	
Consulting fee or honorarium	Autism CRC	Honorarium (\$4,000)
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

Please add more rows if necessary.

## 2. Relevant financial activities outside the guideline (2019-2022)

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	Autism CRC Autism CRC	Project Manager on a Project Grant for Telethon Kids Institute to co-ordinate project "Implementation of the National Guideline for the Assessment and Diagnosis of ASD in Australia – Health Sector Capacity Building" (\$468,000, 2021-2022) Employed by Autism CRC
		from April 2016 to July 2021
Royalties or licenses	None	
Consulting fees	None	

Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	
Stock or stock options	None	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	None	

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	I am currently employed by Telethon Kids Institute and CliniKids as a project manager. CliniKids is a service provider of therapies and supports that may be covered within the scope of the Guideline.
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional	None

preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	
Personal and/or family member experience of accessing therapies and/or support that may be covered in the guideline	I have personal and / or family member experience of accessing therapies and / or supports covered in the guideline through various services providers and using private and public funding.
Other	None

#### **Disclosure of Interests**

Date:	09/05/2022
First Name:	Nancy
Surname:	Sadka

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If new interests arise during the project, you are required to submit an updated form.

#### 1. Support for your involvement in the development of the guideline.

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	None	
Consulting fee or honorarium	Autism CRC	Honorarium to participate in the development of the guideline (\$4,000)
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

Please add more rows if necessary.

## 2. Relevant financial activities outside the guideline (2019-2022)

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	
Patents planned, issued or pending	None	

Participation on a Data Safety	None	
Monitoring Board or Advisory		
Board		
Leadership or fiduciary role in	None	
other board, society, committee		
or advocacy group, paid or		
unpaid		
Stock or stock options	None	
Receipt of equipment,	None	
materials, drugs, medical		
writing, gifts or other services		

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
Personal and/or family member experience of accessing therapies and/or support that may be covered in the guideline	None

Other None
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Declarations of Interests A/Prof Natalie Silove

#### **Expertise:**

Natalie Silove is a Developmental Paediatrician, Senior Staff Specialist and Head of the Child Development Services at The Sydney Childrens Hospital Network Westmead. Natalie is an Associate Clinical Professor at Sydney University and a Co joint at UNSW. Natalie has acted as advisor to State and Commonwealth Governments with regards policies relating to children with disability and autism spectrum disorder. She acts as a medical specialist advisor to the NSW Education Standards Authority and generated the first FRACP consensus statement and guidelines for diagnosis and assessment in autism spectrum disorder.

#### **Clinical Research: NHMRC Grants**

*Current* :

- APP1125449 Prof Adam Guastella, Prof Geraldine Dawson, Prof Cheryl Dissanayake, Prof Valsamma Eapen, Dr Jun Ju Song, Prof Ruth Feldman, A/Prof Natalie Silove. Oxytocin enhancement of social learning in the treatment of toddlers with autism. NHMRC Project Grant 2017-2020 \$1,228,465
- APP1130251 A/Prof Parisa Aslani, A/Prof Michael Kohn, A/Prof Natalie Silove, A/Prof Patrick Kelly, A/Prof Simon Clarke. Asking the right question about attention-deficit hyperactivity disorder in children: a cluster randomised controlled trial. NHMRC Project Grant 2017-2019 \$484,930

#### Past: (AI)

- 2011-2013 Reddihough D, Marraffa C, Hazell P, Multi-site randomised controlled trial of Fluoxetine versus placebo for the treatment of restricted, repetitive and stereotyped behaviours in children and adolescents with autism. NHMRC Project Grant #607332 \$481,825
- 2012-2016 Einfeld, S., Sanders, M., Tonge, B. Mental health in children with developmental disabilities. NHMRC Program Grant APP1016919. \$5,242,755.
- 2012-2014 Eapen V, Williams K, Jalaludin B. Universal surveillance and Early Identification of Developmental Disorders. NHMRC Partnership Project APP1013690 \$680,59

#### **Other Grants :**

- 2019 :Australian Rotary Health/Mental Health of Young Australians Research Grant. A brief, integrated parent mediated intervention for children with Autism Spectrum Disorder; Dadds M, Guastella A, Hawes D, Tully L, Silove N, Eapen V; 2019
- **2019: Department and Education NSW grant :** Validation of telehealth assessments to evaluate response to reading intervention \$101 000.00, 2019
- 2007: ARC Linkage Grant Comparative Analysis of Early Intervention Programs for Young Children with Autism. Collaborative project with ASPECT, Sydney University, Macquarie University and The Children's Hospital Completed 2007

#### Sponsor funded Multi-centre international trials

- 2019 present: An Open-Label Extension Study to Assess the Long-Term Safety and Tolerability of ZYN002 Administered as a Transdermal Gel to Children and Adolescents with Fragile X Syndrome – CONNECT-FX Open Label Extension (OLE) Clinical study Of caNNabidiol in childrEn and adolesCenTs with Fragile X (CONNECT-FX OLE)
- 2. 2018 present: A Randomized, Double-Blind, Placebo-Controlled Multiple-Center, Efficacy and Safety Study of ZYN002 Administered as a Transdermal Gel to Children and Adolescents with Fragile X Syndrome CONNECT-FX. Covance Pty Ltd
- 2017 June 2018 : A Phase 1/2, Open Label Study to Assess the Safety and Efficacy of ZYN002 Administered as a Transdermal Gel to Children and Adolescents with Fragile X Syndrome. Covance Pty Ltd. 2012-2013:
- 4. An open label study to evaluate the long term safety and tolerability of AFQ056 in adolescent patients with Fragile X Syndrome. Novartis Pharmaceuticals Australia Pty Ltd.. 2011- 2012: Protocol CAFQ056A2212.
- 5. A randomized, double-blind, placebo-controlled, parallel group study to evaluate AFQ056 in adolescent patients with Fragile X Syndrome. Novartis Pharmaceuticals Australia Pty Ltd:

- A Multi Centre, Double Blind, Three Arm, Parallel group Study Comparing the Efficacy of Immediate Release Methylphenidate (Ritalin) and modified Release Methylphenidate with Placebo in Children with Attention – Deficit/Hyperactivity Disorder (Protocol number MD-11003-002)
- An Open Label Safety Study of Methylphenidate Modified Release (Metadate CD) in Children with Attention –deficit/Hyperactivity Disorder (ADHD)who participated in study MD 1003-002 (Protocol No. MD-1003-004) July 2003

#### **Disclosure of Interests**

Date:	19/10/21
First Name:	Rhylee
Surname:	Sulek

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   (<u>https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf</u>)

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## 1. Support for your involvement in the development of the guideline.

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	Position supported by funding	Autism CRC funding provided to
	from the Autism CRC	Griffith University
Consulting fee or	None	
honorarium		
Support for travel to	None	
meetings for the		
guideline or other		
purposes		
Other	None	

Please add more rows if necessary.

## 2. Relevant financial activities outside the guideline (2019-2022)

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	Previous funding to support work on EI Review? Named CI on successful Griffith University MHIQ Capacity Grant	Autism CRC funding provided to Griffith University Project funding.
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	

Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	
Stock or stock options	None	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	None	

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
Personal and/or family member experience of accessing therapies and/or support that	None

may be covered in the guideline	
Other	None

#### **Disclosure of Interests**

Date:	02/05/22
First Name:	David
Surname:	Trembath

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If new interests arise during the project, you are required to submit an updated form.

## 1. Support for your involvement in the development of the guideline.

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	Autism CRC	Project funding awarded to Griffith University (CIA, 2022-2022, \$250,800) to support the guideline development.
Consulting fee or honorarium	None	
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

Please add more rows if necessary.

## 2. Relevant financial activities outside the guideline (2019-2022)

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item	Queensland Government, Australia	Advance Queensland Industry Research Fellowship. \$150,000. Optimising telepractice service delivery for individuals on the autism spectrum and their families. (2021-2022)
#1 above).	Griffith University, Australia	Research grant, \$71,112.86, funding for research aimed at laying the foundations for the development of a clinical decision support system for children on the autism spectrum and their families. Trembath, D., Wee-Cheung Liew, A., Whitehouse, A., & Upson, G. (2021-2021)

Autism CRC	Research grant, \$121,000. Synthesis of evidence for autism early intervention approaches.
	Trembath, D. (2020-2020)
Commonwealth Department of Health	Consultancy/commercial research. Alcohol, Tobacco and Other Drugs – Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Services – 4-GO41V23. Dawe, S., Harnett, P., Trembath, D. (2021-2024)
Griffith University, Australia	Research grant. \$228,000. Funding to support the development of the Child Health, Learning, and Disability Network at Griffith University (CIA, 2019-2021)
Channel 7 Children's Foundation Grant	Project grant. \$100,000. Evaluation of Lego Robotics program for autistic students (AI, 2020- 2022)
Menzies Health Institute Queensland	Research grant, \$50,000. Promoting Knowledge Translation in Teachers of Students with Autism through Peer-to-Peer Professional Development: A Collaborative Interdisciplinary Project. Paynter, J., Adams, D., Simpson, K., Clark, M., Trembath, D., & Westerveld, M. (2018-2019)
Australian Government Department of Social Services, \$232,961.	Research grant, \$232,961. Supporting Best Practice in the Assessment and Treatment of Minimally Verbal Children with Autism. Trembath, D., Tucker, M., et al. (2017-2019)
Menzies Health Institute Queensland	Research grant. \$160,000. From Cell to Community: New Frontiers in Integrative Restorative Neurorehabilitation. Lloyd D, Coppieters M, St John J, McConnel H, Zeeman H, Grant G, Thiel D, Trembath D, Pizzolato C, Foster M, Buys N, Lakhani A, Potter L, Canning S. (2018-2019)
Department of Social Services	Research Grant, \$89,445.43. Debunking Autism Treatment Myths. Paynter, J., Keen, D., Trembath, D., Fordyce, K., Joosten, A., Hoppenbrouwers, G., DeBlassio, A., Ecker, U., & Imms, C. (2016-2019)
Autism CRC	Research grant, \$661,989 Longitudinal Study of Students with Autism (LASA), Roberts, J., Trembath, D., Westerveld, M., Keen, D., Simpson, K. Paynter, J., Adams, D. & Howlin, P. (2016-2021)
Autism CRC	Research grant, \$49,986. "How was your day?" Home conversations about their school day in children with Autism Spectrum Disorder. Stirling, L., Dissanayake, C., Sofronoff, K., Westerveld, M., Trembath, D., & Ashburner, J. (2015-2019)
Autism CRC	Research grant, \$25,000. Relate: Technology Supporting Communication in Children on the Autism Spectrum. Trembath, D., Iacono, T., Cox, J., Johnson, R., Rose, V. (2016-2019)
Education Queensland Horizon Grants Scheme	Research grant, \$96,645.61. Listening to the evidence: Using what works to improve educational outcomes for students with autism. Keen, D., Paynter, J., & Trembath, D. (2017-2019)

Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers	Speech Pathology Australia	Honorarium for role as Project Officer responsible for leading the revision of the Speech Pathology Australia Position Statement and Practice Guideline for working with individuals on the autism spectrum (2020-2021, \$7,500)
bureaus, manuscript writing or	Humanity Health Group	Griffith University consultancy and commercial research (CCR) to provide professional development to Humanity Health Group (2021, \$2500).
educational events	Speech Pathology Australia	Honorarium for preparation of self-guided learning package relating to Autism CRC synthesis of evidence report (2021, \$1,400)
	Speech Pathology Australia	Honorarium for presentation of professional development event (webinar) relating to Autism CRC synthesis of evidence report (2021, \$840)
	University of Sydney (2021) Deakin University (2021) Macquarie University (2021) Victoria University (2019) Curtin University (2019)	Thesis examination (<\$500 on each occasion)
Payment for	None	
expert testimony Support for attending meetings and/or travel	Australian Swim Schools Association Griffith University	Complementary associate membership to attend webinar titled 'Teaching children with Autism' for research purposes. Registration support to attend the Aspect Research
	Association for Applied Behaviour Analysis Australia	Centre for Autism Practice Conference 2021 Registration to enable access to online platform to deliver invited address (no exchange of funds)
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	National Health and Medical Research Council	Committee fees for work as member of the Grant Management Solution Working Group as per NHMRC schedule.
Leadership or fiduciary role in	Australasian Society for Autism Research	Executive Committee member (unpaid)
other board, society, committee or advocacy group, paid or unpaid	AEIOU Augmentative and Alternative Communication (journal)	Member of Research Advisory Committee (unpaid) Associate Editor (unpaid)
	Journal of Research in Autism Spectrum Disorders (journal)	Extended Editorial Board Member (unpaid)

	Department of Social Services	Member representing Speech Pathology Australia on the Expert Reference Group to implement the National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia (unpaid)
Stock or stock options	None	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	None	

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Relationship with Autism CRC	Griffith University is a member of Autism CRC Ltd. I am the 'Alternative Member Representative' for Griffith University, should the primary representative be unavailable and/or my involvement is otherwise required.
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	I have led and contributed to research that has examined the outcomes of peer- and parent-mediated augmentative and alternative communication (AAC), parent-mediated therapies and supports, community-based early intervention services. Therapies and supports included in this research include Speech Generating Devices, Key Word Sign, Music and Movement Therapy, the Early Start Denver Model, TOBY Playpad, the AEIOU program, Lego Robotics. I have co-led research that has examined the effects of a range of non- pharmacological therapies and supports via systematic reviews. My research has involved collaboration with a range of service providers including Autism Queensland, AEIOU Foundation, the Autism Specific Early Learning and Care Centres from around Australia, the Nerang Alliance of school and early childhood education centres, Autism Spectrum Australia, CliniKids, Autism SA, ASPECT, and Sanctuary Early Learning Adventure. A complete list of my research publications presenting this research is available at https://scholar.google.com.au/citations?user=q9a9_dUAAAAJ&hl=en
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None

delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	of Sydney, La Trobe University, and Griffith University. I have also acted as an external reviewer (accreditation) for the Massey University speech pathology program in New Zealand. From 2018- 2020, I was tasked with developing and acting as Program Director for two programs in Applied Behaviour Analysis (Graduate Certificate, Masters) at Griffith University.
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
Personal and/or family member experience of accessing therapies and/or support that may be covered in the guideline Other	I have family members who are accessing therapies and supports via the National Disability Insurance Scheme.

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than 'none' to any of the questions above, these will be reviewed by Dr Gary Allen, Senior Policy Officer Human Research Ethics and Research Integrity at Griffith University. In each case, appropriate processes will be put in place to management any conflicts arising. Team members should not be concerned about answering 'yes' to any of the questions. 'Yes' answers do not indicate good or bad, but are simply something to declare on the form and consider for inclusion in the declarations section of the guideline.

### **Autism CRC National Practice Guideline**

#### **Disclosure of Interests**

Date:	30/04/2022
First Name:	Kandice
Surname:	Varcin

## **Origin of Form**

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (<u>https://www.icmje.org/disclosure-of-interest/</u>)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form (<u>https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf</u>)

## Instructions

The purpose of this form is to provide readers of your review with information about your other interests that could influence how they receive and understand your work. We ask you to disclose all relationships/activities/interests listed below that are related to your involvement in the development of the National Practice Guideline (herein referred to as the *guideline*). "Related" means any relation with for-profit or not-for-profit third parties whose interests may be affected by the content of the guideline. Disclosure represents a commitment to transparency and does not necessarily indicate a bias. Please think broadly when disclosing all relationships/activities/interests that may be relevant to your involvement in the guideline. If you are in doubt about whether to list a relationship/activity/interest, it is preferable that you do so.

Each person will be asked to complete their own form and you are responsible for the accuracy and completeness. In submitting this form, you certify that you have answered every question and have not altered the wording of any of the questions on this form.

If new interests arise during the project, you are required to submit an updated form.

### 1. Support for your involvement in the development of the guideline.

This section asks for information about your role in the development of the guideline. The time frame for this reporting is that of the work itself, from the initial conception and planning to the present. The requested information is about resources that you received, either directly or indirectly (via your institution), to enable you to complete the work. Writing "None" means that you did the work without receiving any financial support from any third party -- that is, the work was supported by funds from the same institution that pays your salary and that institution did not receive third-party funds with which to pay you. If you or your institution received funds from a third party to support the work, such as a government granting agency, charitable foundation or commercial sponsor, then provide the details. For example, if you received an honorarium from Autism CRC in relation to your involvement, you would name Autism CRC and then indicate the amount of funds received.

Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	Autism CRC, Griffith University	Autism CRC research funding provided to Griffith University as salary support for Research Fellow position on the development of the National Practice Guideline. Amount: \$65,531
Consulting fee or honorarium	None	
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

Please add more rows if necessary.

## 2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the guideline, and up until the point it is submitted to Autism CRC (i.e., 2019-2022). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	Autism CRC, Griffith University	Autism CRC funding provided to Griffith University as salary support for Research Fellow position on evidence synthesis project commissioned by NDIS from June 2020-December 2020.
Royalties or licenses	None	
Consulting fees	None	

Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	La Trobe University	Payment made to a research account at CliniKids, Telethon Kids Institute for the provision of ADOS-2 training services.
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	
Stock or stock options	None	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	None	

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Relationship with Autism CRC	Griffith University is a member of Autism CRC Ltd. I have no other association with Autism CRC Ltd. to declare.
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the	I was previous employed by (2016-2019), and have ongoing research collaborations with, CliniKids, Telethon Kids Institute – a clinical and research centre that provides diagnostic and intervention services for children on the autism spectrum.
guideline	In my previous position at CliniKids, Telethon Kids Institute, I was the project coordinator for the Australian Infant Communication and Engagement Study (AICES), a randomized controlled trial evaluating pre-emptive support for infants with early behavioural signs of autism.
	I was a project team member and co-author of a report commissioned by the National Disability Insurance Agency in 2020: Whitehouse, A., <b>Varcin, K.</b> , Waddington, H., Sulek, R., Bent, C., Ashburner, J., Eapen, V., Goodall, E., Hudry, K., Roberts, J., Silove, N., Trembath, D. Interventions for children on the autism spectrum: A synthesis of research evidence. Autism CRC, Brisbane, 2020.
	<ul> <li>I am a co-author on the following publications, relating to early therapies and support for children on the autism spectrum:</li> <li>Whitehouse, A.J., Varcin, K.J., Alvares, G.A., Barbaro, J., Bent, C., Boutrus, M., Chetcuti, L., Cooper, M.N., Clark, A., Davidson, E. and Dimov, S., 2019. Preemptive intervention versus treatment as usual for infants showing early behavioural risk signs of autism spectrum</li> </ul>

	<ul> <li>disorder: a single-blind, randomised controlled trial. <i>The</i> <i>Lancet Child &amp; Adolescent Health</i>, 3(9), pp.605-615.</li> <li>Whitehouse, A.J., Varcin, K.J., Pillar, S., Billingham, W., Alvares, G.A., Barbaro, J., Bent, C.A., Blenkley, D., Boutrus, M., Chee, A. and Chetcuti, L., 2021. Effect of preemptive intervention on developmental outcomes among infants showing early signs of autism: A randomized clinical trial of outcomes to diagnosis. <i>JAMA</i> <i>pediatrics</i>, 175(11), pp.e213298-e213298.</li> <li>Trembath, D., Waddington, H., Sulek, R., Varcin, K., Bent, C., Ashburner, J., Eapen, V., Goodall, E., Hudry, K., Silove, N. and Whitehouse, A., 2021. An evidence- based framework for determining the optimal amount of intervention for autistic children. <i>The Lancet Child &amp;</i> <i>Adolescent Health</i>, 5(12), pp.896-904.</li> <li>I have published numerous other papers peer-reviewed journals, in the autism field. https://arpeats.orifith.edu.ou/26307.konding</li> </ul>
	autism field: <u>https://experts.griffith.edu.au/26397-kandice-</u> varcin/publications
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
Personal and/or family member experience of accessing therapies and/or support that may be covered in the guideline	None
Other	I am a qualified trainer on the Autism Diagnostic Observation Schedule-2, where I lead or co-lead training courses in Australia (approximately 2 per year). I receive payment for my time in delivering these courses.

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development

Group. If the co-Chairs have answered other than 'none' to any of the questions above, these will be reviewed by Dr Gary Allen, Senior Policy Officer Human Research Ethics and Research Integrity at Griffith University. In each case, appropriate processes will be put in place to management any conflicts arising. Team members should not be concerned about answering 'yes' to any of the questions. 'Yes' answers do not indicate good or bad, but are simply something to declare on the form and consider for inclusion in the declarations section of the guideline.

### **Autism CRC National Practice Guideline**

#### **Disclosure of Interests**

Date:	3/05/2022
First Name:	Hannah
Surname:	Waddington

## Origin of Form

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (<u>https://www.icmje.org/disclosure-of-interest/</u>)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form (<u>https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf</u>)

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Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

Please add more rows if necessary.

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	Autism CRC	Autism CRC research funding provided to Victoria University of Wellington via Griffith University as salary support for Research Fellow position on the development of the National Practice Guideline. Amount: AUD\$55,872
Consulting fee or honorarium	None	
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

### 2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the guideline, and up until the point it is submitted to Autism CRC (i.e., 2019-2022). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	Health Research Council of New Zealand	Randomised controlled trial examining low intensity therapy and parent coaching for young autistic children (PA, 2020-2023, NZD\$300k). <b>H. Waddington</b> , Whitehouse, A. J. O.

	Cure Kids, New Zealand	Randomised controlled trial
		comparing naturalistic
		developmental behavioural
		intervention, acceptance and
		commitment therapy, or a combination of these
		approaches on outcomes for
		young autistic children and
		their families (AI, 2022-2023,
		NZD\$500k). McLay, L.,
		Emerson, L., Waddington, H.,
		Macfarlane, S.
	Victoria University of	Funding to explore the effect
	Wellington	of teaching non-autistic older
		siblings to interact with their
		autistic younger sibling
		through play (PI, 2020-2022,
		NZD\$29k). <b>H. Waddington.</b>
	IHC Foundation, New Zealand	Funding to develop an autism
		diagnostic clinic together with Autism New Zealand (AI,
		2021-2022, NZD\$34k). L. van
		der Meer, D. Dougan, <b>H.</b>
		Waddington
	IHC Foundation, New Zealand	Funding for further training in
		the early start Denver model
		(AI, 2020-2021, NZD\$78k). L.
		van der Meer, D. Dougan, H.
		Waddington
	Auckland University of	Funding to train Auckland
	Technology, New Zealand	Well Child Tamariki Ora
		Nurses to identify early signs
		of autism (AI, 2019-2020,
		20k). D. Shepherd, L. van der
	HIC Foundation	Meer, H. Waddington.
	IHC Foundation	Funding for delivery of
		community therapy based on the early start Denver model
		(AI, 122k, 2019-2020). L. van
		der Meer, D. Dougan, <b>H</b> .
		Waddington
	Victoria University of	Research establishment grant-
	Wellington	training Wellington Well Child
		Tamariki Ora nurses to identify
		early signs of autism (PI, 10k,
		2018). H. Waddington.
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for	None	
lectures, presentations,		
speakers bureaus, manuscript		
writing or educational events	News	
Payment for expert testimony	None	

Support for attending meetings and/or travel	Autism CRC	Support to attend the Autism CRC participant day in Brisbane, 2022 (NZD\$1332)
	Victoria University of Wellington	Support to virtually attend the International Society for Autism Research Conference,
		2021 (USD\$375)
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee	Autism New Zealand	Member of research advisory group (unpaid)
or advocacy group, paid or unpaid	Autism Intervention Trust	Victoria University of Wellington Representative (unpaid)
	University of Canterbury	Member of New Zealand Research Priorities advisory group (unpaid)
	Victoria University of	Clinic Lead, Victoria
	Wellington	University of Wellington Autism Clinic (unpaid)
	Advances in Neurodevelopmental Disorders (journal)	Extended editorial board member (unpaid)
Stock or stock options	None	
Receipt of equipment,	None	
materials, drugs, medical		
writing, gifts or other services		

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Relationship with	Victoria University of Wellington is a member of Autism CRC ltd. I am
Autism CRC	the "Member Representative" for Victoria University of Wellington.
Development,	I lead an autism clinic that predominantly provides support to young
delivery, and/or	autistic children and their families based on the early start Denver model. I
evaluation of	have led and contributed to research that has examined the outcomes of
therapies and/or	parent, peer, sibling, and teacher mediated support for autistic children
supports that may be	based on the early start Denver model. I have assisted in research
covered within the	examining JASPER-based treatment for a Maori child and led a literature
scope of the	review examining this approach. My research has involved collaboration
guideline	with a range of service providers including Autism New Zealand,
	Wellington Kindergarten Associations, Wellington District Health Boards,
	Well Child/Tamariki Ora, IDEA Services, and CliniKids. A complete list
	of my research publications is available at:
	https://scholar.google.co.nz/citations?user=23bLgJoAAAAJ&hl=en&oi=ao

A personal	None
relationship with	
another person (e.g.,	
spouse, family	
member) involved in	
the development,	
delivery, and/or	
evaluation of	
therapies and/or	
supports that may be	
covered within the	
scope of the	
-	
guideline	I leader in a decadional march along at V <sup>7</sup> the site I Taking of CVV (11)
Development and/or	I lecture in educational psychology at Victoria University of Wellington
delivery of	and Have provided guest lectures on early support for the University of
professional	Canterbury.
preparation programs	
that may be relevant	
to the guideline (e.g.,	
allied health	
professional	
preparation	
programs)	
A personal	None
relationship with	
another person (e.g.,	
spouse, family	
member) involved in	
the development	
and/or delivery of	
professional	
preparation programs	
that may be relevant	
to the guideline (e.g.,	
allied health	
professional	
preparation	
programs)	
Personal and/or	None- I have autistic family members but am based in New Zealand, so
family member	they are not covered by the guideline.
experience of	
accessing therapies	
and/or support that	
may be covered in	
the guideline	
Other	None
	Trone

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than 'none' to any of the questions above, these will be reviewed by Dr Gary Allen, Senior Policy Officer Human Research Ethics and Research Integrity at

Griffith University. In each case, appropriate processes will be put in place to management any conflicts arising. Team members should not be concerned about answering 'yes' to any of the questions. 'Yes' answers do not indicate good or bad, but are simply something to declare on the form and consider for inclusion in the declarations section of the guideline.

### **Autism CRC National Practice Guideline**

#### **Disclosure of Interests**

Date:	29 <sup>th</sup> April 2022
First Name:	Andrew
Surname:	Whitehouse

## Origin of Form

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (<u>https://www.icmje.org/disclosure-of-interest/</u>)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form (<u>https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf</u>)

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Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

Please add more rows if necessary.

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	Yes	The Telethon Kids Institute received funding for a researcher (Sarah Pillar) to support the development of the Guideline. Andrew Whitehouse did not receive any salary or other financial support for working on the guideline.
Consulting fee or honorarium	None	
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

## 2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the guideline, and up until the point it is submitted to Autism CRC (i.e., 2019-2022). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	Since 2019, Andrew Whitehouse has received research funding from the	Research funding received that is specific to autism intervention:
	following organisations: National Health and Medical Research Council (NHMRC), Autism CRC, the Waterloo Foundation,	1. NHMRC Investigator Grant (CIA Whitehouse, APP1173896). Improving clinical outcomes for children with autism spectrum disorder: A research

	the National Disability Insurance Agency, Griffith University, the New Zealand Health Research Council, the Western Australian State Government (Telethon- Perth Children's Hospital Research Fund), and the Angela Wright Bennett Foundation.	<ul> <li>program spanning basic, clinical and implementation science. 2020-2024.</li> <li>2. Telethon-Perth Children's Hospital Research Fund (CIB Whitehouse). A randomised-controlled trial of groupbased very early intervention for infants with autism risk behaviours 2018-2020. or developmental delay 2016-2018.</li> <li>3. Angela Wright Bennett Foundation (CIA Whitehouse) Funding provided as part of Whitehouse's Chair position, which has been used to trial a new intervention for newborns with a family history of autism. 2019-2024.</li> <li>4. Commonwealth Department of Social Services, via Autism CRC (CIA Whitehouse). Implementation of the National guideline for the Assessment and Diagnosis of Autism in Australia. 2021-2022.</li> <li>5. Health Group Seed Grant Scheme, Griffith University (CIB Whitehouse) Laying the foundation for optimal clinical decision-making for children with autism spectrum. 2020-2021.</li> <li>6. New Zealand Health Research Council (CIB Whitehouse, 20/581) Low-intensity therapy and parent coaching for young children with ASD: An RCT. 2020-2023.</li> <li>7. National Disability Insurance Agency, via Autism CRC (CIA Whitehouse) Loying the foundation (CIB Whitehouse) Exercise intervention in developmental coordination disorder. 2020-2022.</li> </ul>
Royalties or licenses	Pearson Publishing, UWA Publishing	Andrew Whitehouse is the co-author of the Communication Checklist - Adult (2009) and Communication Checklist -

Consulting fees	None	Self Report (2009) and in receipt of small royalties based on sales (<\$5,000p.a). Andrew Whitehouse is the author of a book with UWA Publishing ( <i>Will</i> <i>Mozart make my Baby Smart</i> ) and in receipt of small royalties based on sales (<\$5,000p.a). Andrew Whitehouse is the Research
		Strategy Director for the Autism CRC. This is an honorary position and is not supported by any financial remuneration.
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	Autism CRC	Andrew Whitehouse received support for travel and accommodation to attend the Autism CRC Participant Day in April 2022.
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	Autism Awareness Australia, Kids are Kids, Ocean Heroes, Australasian Society for Autism Research, Furthering Autistic Children's Education And Schooling	<ol> <li>Director of Autism Awareness Australia (<u>https://www.autismawareness.com.au/</u>). Role is unpaid.</li> <li>Director of Ocean Heroes: https://oceanheroes.com.au/ . Role is unpaid.</li> </ol>
		3. President, Australasian Society for Autism Research (https://asfar.org.au/ ). Role is unpaid.
		4. Director of Furthering Autistic Children's Education and Schooling Inc. Role is unpaid.
		5. Patron of 'Kids are Kids' (www.kidsarekids.org.au/) which is a service provider for children with developmental difficulties, including autism. Role is unpaid.

		6. Invitee to the Expert Reference Group to implement the National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia. Role is unpaid.
Stock or stock options	None	
Receipt of equipment,	None	
materials, drugs, medical		
writing, gifts or other		
services		

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	<ul> <li>Andrew Whitehouse is the Director of a private allied health clinic, CliniKids: https://clinikids.telethonkids.org.au/.</li> <li>CliniKids is auspiced under the Telethon Kids Institute, and provides diagnostic and intervention services for children on the autism spectrum. The interventions offered within CliniKids are Early Start Denver Model (ESDM), Preschool Autism</li> <li>Communication Therapy (PACT), Joint Attention, Symbolic</li> <li>Play, Emotional Regulation (JASPER), iBASIS-VIPP, as well as general speech pathology, occupational therapy and clinical psychology services. Andrew Whitehouse does not receive any financial or non-financial remuneration for his role as Director of the clinic.</li> <li>Andrew Whitehouse contributed to the development of the iBASIS-VIPP intervention for infants showing early behavioural signs of autism.</li> <li>Andrew Whitehouse contributed to the development of connected Caregiving intervention for infants who have been taken into out of home foster care.</li> <li>Andrew Whitehouse Chaired the development of the National Guideline for the Assessment and Diagnosis of Autism in Australia.</li> </ul>
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None

Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
Personal and/or family member experience of accessing therapies and/or support that may be covered in the guideline	Andrew Whitehouse has first degree and second degree family member who are participants within the National Disability Insurance Scheme.
Other	None

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than 'none' to any of the questions above, these will be reviewed by Dr Gary Allen, Senior Policy Officer Human Research Ethics and Research Integrity at Griffith University. In each case, appropriate processes will be put in place to management any conflicts arising. Team members should not be concerned about answering 'yes' to any of the questions. 'Yes' answers do not indicate good or bad, but are simply something to declare on the form and consider for inclusion in the declarations section of the guideline.

National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia

 Appendix 2.3
 Reference Group – Terms of Reference

# Developing a national guideline for supporting the development and participation of children on the autism spectrum, and their families, in Australia

Terms of Reference for the Reference Group

7<sup>th</sup> February 2022

#### Background

Autism CRC has commissioned the development of a national guideline that outlines clinical recommendations for supporting the development and participation of children on the autism spectrum, and their families, in Australia ('the project'), to be led by Professor Andrew Whitehouse and Associate Professor David Trembath.

#### Purpose

Autism CRC has asked Prof Whitehouse and A/Prof Trembath to form a group of individuals representing key stakeholders ('Reference Group') that will provide input to the guideline development process throughout the duration the project.

#### Anticipated timeline for the project

The project is scheduled to commence on Oct 1<sup>st</sup> 2021, and be completed by Sept 30<sup>th</sup> 2022.

### Membership of the Reference Group

Stakeholder organisations represented in the Reference Group will be determined by the co-chairs of the project (Prof Andrew Whitehouse and A/Prof David Trembath), informed by the 'Guideline for Guidelines' recommendations provided by the National Health and Medical Research Council. Stakeholders will be asked to nominate one individual to represent their organisation on the Reference Group. A proxy may attend a meeting if the nominated individual is unable to attend. The Chair of the Reference Group must be informed of the substitution at least one working day prior to the scheduled nominated meeting.

#### **Appointment of Chair**

Professor Whitehouse will chair the Reference Group meetings.

### **Responsibilities of Reference Group Members**

The responsibilities of the Committee are as follows:

- Provide feedback on the proposed process for developing the Guideline;
- Provide input on documents and components to be included in the literature review;
- Nominate experts within their professional group to participate in the consultative phase of the project;
- Provide advice on the most essential key components to include in the Guideline;
- Provide feedback on draft versions of the Guideline.

## Meetings

The Reference Group will meet as often as it agrees or as required, but likely no more than four times throughout the duration of the project. The Reference Group could expect to meet quarterly via videoconference. The Reference Group will meet at the request of either of the Chair or at the request of a majority of Reference Group members. A quorum will be the Chair plus a majority of the total number of members of the Reference Group.

## Code of conduct for the Reference Group

The Reference Group recognises that this is a sensitive project that requires completion within a relatively short timeframe. As such, the Reference Group agrees to the following:

- Conflicts of interest will be declared at the outset of the project, and be updated as any new potential conflicts emerge.
- As individuals, and collectively, we will work at all times with the children and families in mind.
- All communication between Reference Group members will be conducted in a respectful, constructive and cooperative way, and avoiding self-interest.
- Discussions within the Reference Group meetings may be relayed to members within the organisation that the member represents, but should not be discussed beyond that.

## Reporting

The Reference Group will report to the Autism CRC Ltd Board or its delegated officers.

## By signing below, I indicate that I agree to these Terms of Reference.

Name	
Signature	

National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia

 Appendix 2.4
 Reference Group – Declaration of Interests

### **Autism CRC National Practice Guideline**

#### **Disclosure of Interests**

Date:	21 June 2022
First Name:	Sam
Surname:	Bennett

## Origin of Form

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (<u>https://www.icmje.org/disclosure-of-interest/</u>)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form (<u>https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf</u>)

## Instructions

The purpose of this form is to provide readers of your review with information about your other interests that could influence how they receive and understand your work. We ask you to disclose all relationships/activities/interests listed below that are related to your involvement in the development of the National Practice Guideline (herein referred to as the *guideline*). "Related" means any relation with for-profit or not-for-profit third parties whose interests may be affected by the content of the guideline. Disclosure represents a commitment to transparency and does not necessarily indicate a bias. Please think broadly when disclosing all relationships/activities/interests that may be relevant to your involvement in the guideline. If you are in doubt about whether to list a relationship/activity/interest, it is preferable that you do so.

Each person will be asked to complete their own form and you are responsible for the accuracy and completeness. In submitting this form, you certify that you have answered every question and have not altered the wording of any of the questions on this form.

If new interests arise during the project, you are required to submit an updated form.

### 1. Support for your involvement in the development of the guideline.

This section asks for information about your role in the development of the guideline. The time frame for this reporting is that of the work itself, from the initial conception and planning to the present. The requested information is about resources that you received, either directly or indirectly (via your institution), to enable you to complete the work. Writing "None" means that you did the work without receiving any financial support from any third party -- that is, the work was supported by funds from the same institution that pays your salary and that institution did not receive third-party funds with which to pay you. If you or your institution received funds from a third party to support the work, such as a government granting agency, charitable foundation or commercial sponsor, then provide the details. For example, if you received an honorarium from Autism CRC in relation to your involvement, you would name Autism CRC and then indicate the amount of funds received.

Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	None	
Consulting fee or honorarium	None	
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

Please add more rows if necessary.

## 2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the guideline, and up until the point it is submitted to Autism CRC (i.e., 2019-2022). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	
Patents planned, issued or pending	None	

Deutisingtion on Det Off	Neue
Participation on a Data Safety	None
Monitoring Board or Advisory	
Board	
Leadership or fiduciary role in	None
other board, society, committee	
or advocacy group, paid or	
unpaid	
Grants or contracts from any	None
entity (if not indicated in item	
#1 above).	
Royalties or licenses	None
Consulting fees	None
Payment or honoraria for	None
lectures, presentations,	
speakers bureaus, manuscript	
writing or educational events	
Payment for expert testimony	None
Support for attending meetings	None
and/or travel	
Patents planned, issued or	None
pending	
Participation on a Data Safety	None
Monitoring Board or Advisory	
Board	
Leadership or fiduciary role in	None
other board, society, committee	
or advocacy group, paid or	
unpaid	
Stock or stock options	None
Receipt of equipment,	None
materials, drugs, medical	
writing, gifts or other services	

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies and/or supports that may be	None

covered within the scope of the guideline	
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
Personal and/or family member experience of accessing therapies and/or support that may be covered in the guideline	None
Other	None

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than 'none' to any of the questions above, these will be reviewed by Dr Gary Allen, Senior Policy Officer Human Research Ethics and Research Integrity at Griffith University. In each case, appropriate processes will be put in place to management any conflicts arising. Team members should not be concerned about answering 'yes' to any of the questions. 'Yes' answers do not indicate good or bad, but are simply something to declare on the form and consider for inclusion in the declarations section of the guideline.

#### **Autism CRC National Practice Guideline**

#### **Disclosure of Interests**

Date:	21 June 2022
First Name:	Karen
Surname:	Brown

#### **Origin of Form**

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (<u>https://www.icmje.org/disclosure-of-interest/</u>)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form
   (<u>https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf</u>)

#### Instructions

The purpose of this form is to provide readers of your review with information about your other interests that could influence how they receive and understand your work. We ask you to disclose all relationships/activities/interests listed below that are related to your involvement in the development of the National Practice Guideline (herein referred to as the *guideline*). "Related" means any relation with for-profit or not-for-profit third parties whose interests may be affected by the content of the guideline. Disclosure represents a commitment to transparency and does not necessarily indicate a bias. Please think broadly when disclosing all relationships/activities/interests that may be relevant to your involvement in the guideline. If you are in doubt about whether to list a relationship/activity/interest, it is preferable that you do so.

Each person will be asked to complete their own form and you are responsible for the accuracy and completeness. In submitting this form, you certify that you have answered every question and have not altered the wording of any of the questions on this form.

If new interests arise during the project, you are required to submit an updated form.

#### 1. Support for your involvement in the development of the guideline.

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Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	None	
Consulting fee or honorarium	Yes	Occupational Therapy Australia received an honorarium payment of \$1,000 to support staff attendance and input to the National Autism Practice Guideline Reference Group. Karen Brown did not receive any direct financial support for working on the guideline.
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

Please add more rows if necessary.

#### 2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the guideline, and up until the point it is submitted to Autism CRC (i.e., 2019-2022). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations,	None	

1 1		
speakers bureaus, manuscript		
writing or educational events		
Payment for expert testimony	None	
Support for attending meetings	None	
and/or travel		
Patents planned, issued or	None	
pending		
Participation on a Data Safety	None	
Monitoring Board or Advisory		
Board		
Leadership or fiduciary role in	None	
other board, society, committee		
or advocacy group, paid or		
unpaid		
Grants or contracts from any	None	
entity (if not indicated in item		
#1 above).		
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for	None	
lectures, presentations,		
speakers bureaus, manuscript		
writing or educational events		
Payment for expert testimony	None	
Support for attending meetings	None	
and/or travel		
Patents planned, issued or	None	
pending		
Participation on a Data Safety	None	
Monitoring Board or Advisory	Trone	
Board		
Leadership or fiduciary role in	None	
other board, society, committee		
or advocacy group, paid or		
unpaid		
Stock or stock options	None	
Receipt of equipment,	None	
materials, drugs, medical		
writing, gifts or other services		

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or supports that may be covered	None

within the scope of the guideline	
A personal relationship with	None
another person (e.g., spouse,	
family member) involved in	
the development, delivery,	
and/or evaluation of therapies	
and/or supports that may be	
covered within the scope of the guideline	
Development and/or delivery	None
of professional preparation	None
programs that may be relevant	
to the guideline (e.g., allied	
health professional preparation	
programs)	
A personal relationship with	None
another person (e.g., spouse,	
family member) involved in	
the development and/or	
delivery of professional	
preparation programs that may	
be relevant to the guideline	
(e.g., allied health professional	
preparation programs)	NY
Personal and/or family member	None
experience of accessing	
therapies and/or support that	
may be covered in the	
guideline Other	Neue
Other	None

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than 'none' to any of the questions above, these will be reviewed by Dr Gary Allen, Senior Policy Officer Human Research Ethics and Research Integrity at Griffith University. In each case, appropriate processes will be put in place to management any conflicts arising. Team members should not be concerned about answering 'yes' to any of the questions. 'Yes' answers do not indicate good or bad, but are simply something to declare on the form and consider for inclusion in the declarations section of the guideline.

### **Autism CRC National Practice Guideline**

#### **Disclosure of Interests**

Date:	16/5/2022
First Name:	Tamara
Surname:	Cavenett

## Origin of Form

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (<u>https://www.icmje.org/disclosure-of-interest/</u>)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form (<u>https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf</u>)

## Instructions

The purpose of this form is to provide readers of your review with information about your other interests that could influence how they receive and understand your work. We ask you to disclose all relationships/activities/interests listed below that are related to your involvement in the development of the National Practice Guideline (herein referred to as the *guideline*). "Related" means any relation with for-profit or not-for-profit third parties whose interests may be affected by the content of the guideline. Disclosure represents a commitment to transparency and does not necessarily indicate a bias. Please think broadly when disclosing all relationships/activities/interests that may be relevant to your involvement in the guideline. If you are in doubt about whether to list a relationship/activity/interest, it is preferable that you do so.

Each person will be asked to complete their own form and you are responsible for the accuracy and completeness. In submitting this form, you certify that you have answered every question and have not altered the wording of any of the questions on this form.

If new interests arise during the project, you are required to submit an updated form.

### 1. Support for your involvement in the development of the guideline.

This section asks for information about your role in the development of the guideline. The time frame for this reporting is that of the work itself, from the initial conception and planning to the present. The requested information is about resources that you received, either directly or indirectly (via your institution), to enable you to complete the work. Writing "None" means that you did the work without receiving any financial support from any third party -- that is, the work was supported by funds from the same institution that pays your salary and that institution did not receive third-party funds with which to pay you. If you or your institution received funds from a third party to support the work, such as a government granting agency, charitable foundation or commercial sponsor, then provide the details. For example, if you received an honorarium from Autism CRC in relation to your involvement, you would name Autism CRC and then indicate the amount of funds received.

Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	None	
Consulting fee or	Yes	Autism CRC
honorarium		Received an honorarium of \$1000 for membership of the Reference Group
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

Please add more rows if necessary.

## 2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the guideline, and up until the point it is submitted to Autism CRC (i.e., 2019-2022). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	

Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	Yes	President of the Board, Australian Psychological Society, paid part-time.
Stock or stock options	None	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	None	

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies	None

and/or supports that may be covered within the scope of the guideline	
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	Australian Psychological Society (the society for which I'm president) provides courses and CPD in the area of Autism for psychologists. I have limited, if any, connection with this work and do not believe it presents a conflict of interest to my decision making.
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
Personal and/or family member experience of accessing therapies and/or support that may be covered in the guideline	None
Other	None

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than 'none' to any of the questions above, these will be reviewed by Dr Gary Allen, Senior Policy Officer Human Research Ethics and Research Integrity at Griffith University. In each case, appropriate processes will be put in place to management any conflicts arising. Team members should not be concerned about answering 'yes' to any of the questions. 'Yes' answers do not indicate good or bad, but are simply something to declare on the form and consider for inclusion in the declarations section of the guideline.

#### **Disclosure of Interests**

Date:	9 July 2022
First Name:	Daniel
Surname:	Coase

## Origin of Form

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (<u>https://www.icmje.org/disclosure-of-interest/</u>)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form (<u>https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf</u>)

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If new interests arise during the project, you are required to submit an updated form.

#### 1. Support for your involvement in the development of the guideline.

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	Autism CRC	Member of an organisation that received an honorarium of \$1000 for membership of the Reference Group
Consulting fee or honorarium	None	
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

Please add more rows if necessary.

## 2. Relevant financial activities outside the guideline (2019-2022)

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	

Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	
Stock or stock options	None	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	None	

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies	None

and/or supports that may be covered within the scope of the guideline	
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
Personal and/or family member experience of accessing therapies and/or support that may be covered in the guideline	None
Other	None

#### **Disclosure of Interests**

Date:	21/06/2022
First Name:	Amy
Surname:	Fitzpatrick

## Origin of Form

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#### 1. Support for your involvement in the development of the guideline.

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	None	
Consulting fee or	None	
honorarium		
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

Please add more rows if necessary.

## 2. Relevant financial activities outside the guideline (2019-2022)

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	
Patents planned, issued or pending	None	

Participation on a Data Safety	None
Monitoring Board or Advisory	
Board	
Leadership or fiduciary role in	None
other board, society, committee	
or advocacy group, paid or	
unpaid	
Grants or contracts from any	None
entity (if not indicated in item	
#1 above).	
Royalties or licenses	None
Consulting fees	None
Payment or honoraria for	None
lectures, presentations,	
speakers bureaus, manuscript	
writing or educational events	
Payment for expert testimony	None
Support for attending meetings	None
and/or travel	
Patents planned, issued or	None
pending	
Participation on a Data Safety	None
Monitoring Board or Advisory	
Board	
Leadership or fiduciary role in	None
other board, society, committee	
or advocacy group, paid or	
unpaid	
Stock or stock options	None
Receipt of equipment,	None
materials, drugs, medical	
writing, gifts or other services	

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies and/or supports that may be	None

covered within the scope of the guideline	
Development and/or delivery	None
of professional preparation programs that may be relevant	
to the guideline (e.g., allied	
health professional preparation	
programs)	
A personal relationship with	None
another person (e.g., spouse,	
family member) involved in	
the development and/or	
delivery of professional	
preparation programs that may	
be relevant to the guideline	
(e.g., allied health professional	
preparation programs)	
Personal and/or family member	Yes. Child and myself receiving therapies similar or the same
experience of accessing	as some interventions covered in the guideline.
therapies and/or support that	
may be covered in the	
guideline	
Other	None

## **Disclosure of Interests**

Date:

19th May, 2022 First Name: Trish Surname: Hanna

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## Support for your involvement in the development of the guideline.

This section asks for information about your role in the development of the guideline. The time frame for this reporting is that of the work itself, from the initial conception and planning to the present. The requested information is about resources that you received, either directly or indirectly (via your institution), to enable you to complete the work. Writing

"None" means that you did the work without receiving any financial support from any third party -- that is, the work was supported by funds from the same institution that pays your salary and that institution did not receive third-party funds with which to pay you. If you or your institution received funds from a third party to support the work, such as a government granting agency, charitable foundation or commercial sponsor, then provide the details. For example, if you received an honorarium from Autism CRC in relation to your involvement, you would name Autism CRC and then indicate the amount of funds received.

Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

Please add more rows if necessary.

## Name all entities that provided support (or indicate none)

#### Description of support (e.g., amount of funding, time in lieu)

Grant

Autism CRC : Autism practice guidelines

Consulting fee or honorarium

Received an honorarium of \$1000 for membership of the Reference Group

Support for travel to meetings for the guideline or other purposes

None

Other

None

## • Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be

considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the guideline, and up until the point it is submitted to Autism CRC (i.e., 2019-2022). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

## Name all entities with whom you have this relationship or indicate none (add rows as needed)

# Specifications/comments (e.g., description of support, if payments were made to you or your institution)

Grants or contracts from any entity (if not indicated in item #1 above).

None

Royalties or licenses

None

Consulting fees

None

Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events

None

Payment for expert testimony

None

Support for attending meetings and/or travel None

Patents planned, issued or pending

None

Participation on a Data Safety Monitoring Board or Advisory Board None

Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid None

Grants or contracts from any entity (if not indicated in item #1 above). None

Royalties or licenses

None

Consulting fees

None

Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events

None

Payment for expert testimony

None

Support for attending meetings and/or travel None

Patents planned, issued or pending

None

Participation on a Data Safety Monitoring Board or Advisory Board None Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid None

Stock or stock options

None

Receipt of equipment, materials, drugs, medical writing, gifts or other services

None

# • Relevant other activities or relationships, including non-financial relationships (no time limit)

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

## Specifications/comments (e.g., description of the relationship/activity/organisations involved)

Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline

None

A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline

None

Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)

None

A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)

None

Personal and/or family member experience of accessing therapies and/or support that may be covered in the guideline

None

Other

None

#### **Disclosure of Interests**

Date:	29/06/2022
First Name:	Nicole
Surname:	Haynes

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Grant	Autism CRC	Member of an organisation that received an honorarium of \$1000 for membership of the Reference Group
Consulting fee or honorarium		
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

Please add more rows if necessary.

## 2. Relevant financial activities outside the guideline (2019-2022)

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	

Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	Australian Physiotherapy Association	National Paediatric Chair and member of the National Advisory Council for the APA.
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	
Stock or stock options	None	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	None	

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	Business owner, share holder and clinician in a company that provided therapeutic supports to autistic children.
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies	None

and/or supports that may be covered within the scope of the guideline	
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
Personal and/or family member experience of accessing therapies and/or support that may be covered in the guideline	None
Other	None

## Page 1 of 4OFFICIAL

## **Autism CRC National Practice Guideline**

#### **Disclosure of Interests**

Date:	21/6/22
First Name:	Patrick
Surname:	Kelly

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## 1. Support for your involvement in the development of the guideline.

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	Patrick Kelly National president AASE	Member of an organisation that received an honorarium of \$1000 for membership of the Reference Group
Consulting fee or honorarium	None	
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

Please add more rows if necessary.

## 2. Relevant financial activities outside the guideline (2019-2022)

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	

Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
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Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	
Stock or stock options	None	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	None	

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	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies	None

and/or supports that may be covered within the scope of the	
guideline	
Development and/or delivery	None
of professional preparation	
programs that may be relevant	
to the guideline (e.g., allied	
health professional preparation	
programs)	
A personal relationship with	None
another person (e.g., spouse,	
family member) involved in	
the development and/or	
delivery of professional	
preparation programs that may	
be relevant to the guideline	
(e.g., allied health professional	
preparation programs)	
Personal and/or family member	None
experience of accessing	
therapies and/or support that	
may be covered in the	
guideline	
Other	None

#### **Disclosure of Interests**

Date:	11/07/2022
First Name:	Mullan
Surname:	James

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#### 1. Support for your involvement in the development of the guideline.

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	None	
Consulting fee or	None	
honorarium		
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

Please add more rows if necessary.

## 2. Relevant financial activities outside the guideline (2019-2022)

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	
Patents planned, issued or pending	None	

Participation on a Data Safety	None
Monitoring Board or Advisory	
Board	
Leadership or fiduciary role in	None
other board, society, committee	
or advocacy group, paid or	
unpaid	
Grants or contracts from any	None
entity (if not indicated in item	
#1 above).	
Royalties or licenses	None
Consulting fees	None
Payment or honoraria for	None
lectures, presentations,	
speakers bureaus, manuscript	
writing or educational events	
Payment for expert testimony	None
Support for attending meetings	None
and/or travel	
Patents planned, issued or	None
pending	
Participation on a Data Safety	None
Monitoring Board or Advisory	
Board	
Leadership or fiduciary role in	None
other board, society, committee	
or advocacy group, paid or	
unpaid	
Stock or stock options	None
Receipt of equipment,	None
materials, drugs, medical	
writing, gifts or other services	

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies and/or supports that may be	None

covered within the scope of the guideline	
Development and/or delivery	None
of professional preparation	
programs that may be relevant	
to the guideline (e.g., allied	
health professional preparation	
programs)	None
A personal relationship with another person (e.g., spouse,	None
family member) involved in	
the development and/or	
delivery of professional	
preparation programs that may	
be relevant to the guideline	
(e.g., allied health professional	
preparation programs)	
Personal and/or family member	None
experience of accessing	
therapies and/or support that	
may be covered in the	
guideline	
Other	None

#### **Disclosure of Interests**

Date:	11/05/2022
First Name:	Sujeeva Ashanthi
Surname:	Munasinghe

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If new interests arise during the project, you are required to submit an updated form.

#### 1. Support for your involvement in the development of the guideline.

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	None	
Consulting fee or	None	
honorarium		
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

Please add more rows if necessary.

## 2. Relevant financial activities outside the guideline (2019-2022)

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	Private Paediatric Practice	Dr Ashanthi Munasinghe works in Private Paediatric practice (Hollywood Medical Specialist Centre, Nedlands WA) for 1 day each week and in Public Paediatric practice 3 days per week working for the Child Development Service (Child & Adolescent Health Service WA). In both roles I

		am involved in the assessment and ongoing follow-up of children (aged 0-18y) with developmental issues including ASD. The role involves assessment, ongoing monitoring of developmental progress, support for pharmacological interventions and health reviews for the children seen.
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid		Ordinary member of the Neurodevelopmental & Behavioural Paediatric Society of Australasia- a not for profit organization of doctors with a specialist clinical or academic interest in neurodevelopmental paediatrics
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	
Stock or stock options	None	

Receipt of equipment,	None	
materials, drugs, medical		
writing, gifts or other services		

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or	None
supports that may be covered	
within the scope of the	
guideline	
A personal relationship with	None
another person (e.g., spouse,	
family member) involved in	
the development, delivery,	
and/or evaluation of therapies	
and/or supports that may be	
covered within the scope of the	
guideline	
Development and/or delivery	None
of professional preparation	
programs that may be relevant	
to the guideline (e.g., allied	
health professional preparation	
programs)	None
A personal relationship with	None
another person (e.g., spouse,	
family member) involved in	
the development and/or	
delivery of professional preparation programs that may	
be relevant to the guideline	
(e.g., allied health professional	
preparation programs)	
Personal and/or family member	None
experience of accessing	
therapies and/or support that	
may be covered in the	
guideline	
Other	None

## Declaration

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than 'none' to any of the questions above, these will be

reviewed by Dr Gary Allen, Senior Policy Officer Human Research Ethics and Research Integrity at Griffith University. In each case, appropriate processes will be put in place to management any conflicts arising. Team members should not be concerned about answering 'yes' to any of the questions. 'Yes' answers do not indicate good or bad, but are simply something to declare on the form and consider for inclusion in the declarations section of the guideline.

#### **Disclosure of Interests**

Date:	5 May 2022
First Name:	Gabrielle
Surname:	O'Kane

## **Origin of Form**

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (<u>https://www.icmje.org/disclosure-of-interest/</u>)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form
   (<u>https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf</u>)

## Instructions

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Each person will be asked to complete their own form and you are responsible for the accuracy and completeness. In submitting this form, you certify that you have answered every question and have not altered the wording of any of the questions on this form.

If new interests arise during the project, you are required to submit an updated form.

#### 1. Support for your involvement in the development of the guideline.

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	None	
Consulting fee or honorarium	Autism CRC	An honorarium of \$1,000 for my involvement in the Reference Group for Autism CRC Project
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

Please add more rows if necessary.

## 2. Relevant financial activities outside the guideline (2019-2022)

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	Therapeutic Good Administration	Gabrielle O'Kane is a representative on the

		Therapeutic Good Advertising Consultative Committee.
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	
Stock or stock options	None	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	None	

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
A personal relationship with another person (e.g., spouse, family member) involved in	Gabrielle O'Kane has a second degree family member who is a participant within the National Disability Insurance Scheme

the development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
Personal and/or family member experience of accessing therapies and/or support that may be covered in the guideline	None
Other	None

#### **Disclosure of Interests**

Date:	12/07/2022
First Name:	Jessica
Surname:	Paynter

## **Origin of Form**

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (<u>https://www.icmje.org/disclosure-of-interest/</u>)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form (<u>https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf</u>)

## Instructions

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Each person will be asked to complete their own form and you are responsible for the accuracy and completeness. In submitting this form, you certify that you have answered every question and have not altered the wording of any of the questions on this form.

If new interests arise during the project, you are required to submit an updated form.

#### 1. Support for your involvement in the development of the guideline.

Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	Autism CRC	Member of an organisation (Australian Society for Autism Research) that received an honorarium of \$1000 for membership of the Reference Group
Consulting fee or honorarium	None	None
Support for travel to meetings for the guideline or other purposes	None	None
Other	None	None

Please add more rows if necessary.

#### 2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the guideline, and up until the point it is submitted to Autism CRC (i.e., 2019-2022). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	Department of Social Services AEIOU Foundation (above funding)	Research funding (end 2019) via Autism Specific Early Learning and Care Centres including AEIOU Foundation to institution:
	Education Queensland	<ol> <li>Paynter, J., Keen, D., Trembath, D., Fordyce, K., Joosten, A., Hoppenbrouwers, G., DeBlassio, A., Ecker, U.,</li> </ol>

Australian Psychological	& Imms, C. (2016-2019).
Society (APS)	Debunking Autism
Society (III S)	Treatment Myths (Early
	Intervention Staff).
Autism CRC	Department of Social
	Services (DSS) Autism
	Specific Early Learning
	and Care Centre
Dlay Matters (Formarly	Research Funding,
Play Matters (Formerly	Department of Social
playgroup Queensland)	Security, \$89,445.43.
	2. Trembath, D., Tucker,
	M., <b>Paynter</b> ,
A 1	JDissanayake, C.
Advance	
Queensland/Queensland	(2017-2019). Supporting
Government	Best Practice in the
Government	Assessment and
	Treatment of Minimally
	Verbal Children with
	Autism. DSS Autism
	Specific Early Learning
	and Care Centre
	Research Funding,
	\$232,821.
	+ - )-
	E
	Funded consultancy for
	Education Queensland
	(presentations, workshops) to
	institution
	Funded consultancy to
	institution and personally
	× •
	(workshops paid to me
	personally)- APS
	1 37
	CI on fundad grants outside of
	CI on funded grants outside of
	guidelines, payments made to
	institution.
	1. Roberts, J., Keen, D.,
	Trembath, D.,
	Westerveld, M.,
	Simpson, K., Paynter, J.,
	Adams, D., Howlin, P.
	(2016-2021).
	Longitudinal Study of
	Australian Students with
	Autism (LASA). Autism
	Cooperative Research
	-
	Centre (Autism CRC),
	Strategic Project
	Funding, \$661,989.
	2. Westerveld, M.,
	McCartney, D., Paynter,
	<b>J.,</b> Simpson, K., Ward, I.,
	& Hurley, A. (2017-2020).
	Providing early literacy
	sessions in libraries to

	1	· · · · · · · · · · · · · · · · · · ·
		preschoolers on the
		autism spectrum and
		their parents. Autism
		CRC Utilisation Grant
		Application. \$77,350.
		Funded consultancy to
		institution from Playgroup
		Queensland
		1. <b>Paynter, J.</b> (2021-2022).
		Active Inclusion
		Evaluation. Playgroup
		Queensland Consultancy.
		\$39, 749.60.
		Funded research grant to
		institution from Queensland
		Government.
		1. <b>Paynter, J.</b> (2020-2022).
		Griffith University – Dr
		Jessica Paynter –
		Maternity Funding.
		Women's Research
		Assistance Program
		(Advance
		Queensland/Queensland
		Government). \$15, 600.
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for	Education	Payment for presentations from
lectures, presentations,	Queensland/Department of	2018 to present.
speakers bureaus, manuscript	Education	
writing or educational events	N7.	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	
Patents planned, issued or	None	
pending		
Participation on a Data Safety	None	
Monitoring Board or Advisory		
Board		
Leadership or fiduciary role in	Australian Society for Autism	Vice President (2021-present)
other board, society, committee	Research	Committee Member (2018-
or advocacy group, paid or		present). Unpaid position.
unpaid		
	Ameteolican Derry 1 - 1 1	Chain Cald Carat Day at
	Australian Psychological	Chair Gold Coast Branch
	Society	(2018-present)
		Committee Member
		Psychology of Intellectual
		Disability and Autism. Unpaid
Create on existing to C	News	positions.
Grants or contracts from any	None	
antity (if not indicated in it.		
entity (if not indicated in item		
entity (if not indicated in item #1 above). Royalties or licenses	None	

Consulting fees	None	
Payment or honoraria for	Children's Health Queensland	Payment for presentation at
lectures, presentations,		conference (2022) to
speakers bureaus, manuscript		institution.
writing or educational events		
Payment for expert testimony	None	
Support for attending meetings	None	
and/or travel		
Patents planned, issued or	None	
pending		
Participation on a Data Safety	None	
Monitoring Board or Advisory		
Board		
Leadership or fiduciary role in	None	
other board, society, committee		
or advocacy group, paid or		
unpaid		
Stock or stock options	None	
Receipt of equipment,	None	
materials, drugs, medical		
writing, gifts or other services		

## 3. Relevant other activities or relationships, including non-financial relationships (no time limit)

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	Jessica Paynter is a clinical psychologist who maintains her own private practice renting rooms from Griffith University operating out of the psychology clinic. She offers diagnostic and therapy services to clients on the autism spectrum. Interventions draw from behavioural and cognitive-behavioural strategies. She receives private fees paid directly by clients, NDIS funding, and/or medicare rebates.
	Jessica Paynter is an author on evaluations of Early Start Denver Model (ESDM)/La Trobe research and AEIOU Foundation program/AEIOU Foundation. She has published a number of articles on evidence-based practice in autism. For full list, please see: https://scholar.google.com.au/citations?user=9VT4bfQAAAAJ&hl=en&oi=ao
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None

Development and/or	Yes. Jessica Paynter is a senior lecturer in the School of Applied
delivery of professional	Psychology at Griffith University and she teaches into the clinical
preparation programs that	psychology and professional psychology masters programs.
may be relevant to the	
guideline (e.g., allied	
health professional	
preparation programs)	
A personal relationship	None
with another person (e.g.,	
spouse, family member)	
involved in the	
development and/or	
delivery of professional	
preparation programs that	
may be relevant to the	
guideline (e.g., allied	
health professional	
preparation programs)	
Personal and/or family	None
member experience of	
accessing therapies	
and/or support that may	
be covered in the	
guideline	
Other	None

#### Declaration

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than 'none' to any of the questions above, these will be reviewed by Dr Gary Allen, Senior Policy Officer Human Research Ethics and Research Integrity at Griffith University. In each case, appropriate processes will be put in place to management any conflicts arising. Team members should not be concerned about answering 'yes' to any of the questions. 'Yes' answers do not indicate good or bad, but are simply something to declare on the form and consider for inclusion in the declarations section of the guideline.

#### **Autism CRC National Practice Guideline**

#### **Disclosure of Interests**

Date:	11 July 2022
First Name:	Nicole
Surname:	Rogerson

#### Origin of Form

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (<u>https://www.icmje.org/disclosure-of-interest/</u>)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form (<u>https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf</u>)

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#### 1. Support for your involvement in the development of the guideline.

This section asks for information about your role in the development of the guideline. The time frame for this reporting is that of the work itself, from the initial conception and planning to the present. The requested information is about resources that you received, either directly or indirectly (via your institution), to enable you to complete the work. Writing "None" means that you did the work without receiving any financial support from any third party -- that is, the work was supported by funds from the same institution that pays your salary and that institution did not receive third-party funds with which to pay you. If you or your institution received funds from a third party to support the work, such as a government granting agency, charitable foundation or commercial sponsor, then provide the details. For example, if you received an honorarium from Autism CRC in relation to your involvement, you would name Autism CRC and then indicate the amount of funds received.

Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	None	
Consulting fee or	None	
honorarium		
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

Please add more rows if necessary.

#### 2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the guideline, and up until the point it is submitted to Autism CRC (i.e., 2019-2022). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	None	1.
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	
Patents planned, issued or pending	None	

Participation on a Data Safety	None
Monitoring Board or Advisory	
Board	
Leadership or fiduciary role in	None
other board, society, committee	
or advocacy group, paid or	
unpaid	
Grants or contracts from any	None
entity (if not indicated in item	
#1 above).	
Royalties or licenses	None
Consulting fees	None
Payment or honoraria for	None
lectures, presentations,	
speakers bureaus, manuscript	
writing or educational events	
Payment for expert testimony	None
Support for attending meetings	None
and/or travel	
Patents planned, issued or	None
pending	
Participation on a Data Safety	None
Monitoring Board or Advisory	
Board	
Leadership or fiduciary role in	None
other board, society, committee	
or advocacy group, paid or	
unpaid	
Stock or stock options	None
Receipt of equipment,	None
materials, drugs, medical	
writing, gifts or other services	

## 3. Relevant other activities or relationships, including non-financial relationships (no time limit)

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of	None

therapies and/or supports	
that may be covered	
within the scope of the	
guideline	
Development and/or	None
	None
delivery of professional	
preparation programs that	
may be relevant to the	
guideline (e.g., allied	
health professional	
preparation programs)	
A personal relationship	None
with another person (e.g.,	
spouse, family member)	
involved in the	
development and/or	
delivery of professional	
preparation programs that	
may be relevant to the	
guideline (e.g., allied	
health professional	
preparation programs)	
Personal and/or family	None
member experience of	
accessing therapies	
and/or support that may	
be covered in the	
guideline	
Other	None

#### Declaration

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than 'none' to any of the questions above, these will be reviewed by Dr Gary Allen, Senior Policy Officer Human Research Ethics and Research Integrity at Griffith University. In each case, appropriate processes will be put in place to management any conflicts arising. Team members should not be concerned about answering 'yes' to any of the questions. 'Yes' answers do not indicate good or bad, but are simply something to declare on the form and consider for inclusion in the declarations section of the guideline.

#### **Autism CRC National Practice Guideline**

#### **Disclosure of Interests**

Date:	21/06/2022
First Name:	Frances
Surname:	Scodellaro

#### Origin of Form

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (<u>https://www.icmje.org/disclosure-of-interest/</u>)
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#### 1. Support for your involvement in the development of the guideline.

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Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	None	NA
Consulting fee or honorarium	None	NA
Support for travel to meetings for the guideline or other purposes	None	NA
Other	None	NA
Member of an organisation that received an honorarium of \$1000 for membership of the Reference Group	None	NA

Please add more rows if necessary.

#### 2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the guideline, and up until the point it is submitted to Autism CRC (i.e., 2019-2022). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	

Payment for expert testimony	None	
Support for attending meetings and/or travel	Autism Qld	Ref group members' time to participate in meetings and related activities in undertaken whilst employed by AQ
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	
Stock or stock options	None	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	None	

## **3.** Relevant other activities or relationships, including non-financial relationships (no time limit)

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

	Specifications/comments (e.g., description of the	
	relationship/activity/organisations involved)	
Development, delivery, and/or	Autism Qld (employer) develops and delivers therapy services	
evaluation of therapies and/or	and supports for children and their parents and carers,	
supports that may be covered	Autism Qld has engaged in research independently and in	
within the scope of the	partnership with universities, the CRC and other institutions.	
guideline		

	Autism Qld provides information to parents, autistic people, professionals, schools, etc about autism supports and services.
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	AQ has a dedicated Professional Learning and Development services that develops and delivers professional and parent education throughout Qld and occasionally interstate and internationally. AQ also coordinates the national Early Days Workshop program.
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
Personal and/or family member experience of accessing therapies and/or support that may be covered in the guideline Other	None

#### Declaration

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than 'none' to any of the questions above, these will be reviewed by Dr Gary Allen, Senior Policy Officer Human Research Ethics and Research Integrity at Griffith University. In each case, appropriate processes will be put in place to management any conflicts arising. Team members should not be concerned about answering 'yes' to any of the questions. 'Yes' answers do not indicate good or bad, but are simply something to declare on the form and consider for inclusion in the declarations section of the guideline.

#### **Autism CRC National Practice Guideline**

#### **Disclosure of Interests**

Date:	21/06/2022
First Name:	Jess
Surname:	Styles

#### Origin of Form

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (<u>https://www.icmje.org/disclosure-of-interest/</u>)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form
   (<u>https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf</u>)

#### Instructions

The purpose of this form is to provide readers of your review with information about your other interests that could influence how they receive and understand your work. We ask you to disclose all relationships/activities/interests listed below that are related to your involvement in the development of the National Practice Guideline (herein referred to as the *guideline*). "Related" means any relation with for-profit or not-for-profit third parties whose interests may be affected by the content of the guideline. Disclosure represents a commitment to transparency and does not necessarily indicate a bias. Please think broadly when disclosing all relationships/activities/interests that may be relevant to your involvement in the guideline. If you are in doubt about whether to list a relationship/activity/interest, it is preferable that you do so.

Each person will be asked to complete their own form and you are responsible for the accuracy and completeness. In submitting this form, you certify that you have answered every question and have not altered the wording of any of the questions on this form.

If new interests arise during the project, you are required to submit an updated form.

#### 1. Support for your involvement in the development of the guideline.

This section asks for information about your role in the development of the guideline. The time frame for this reporting is that of the work itself, from the initial conception and planning to the present. The requested information is about resources that you received, either directly or indirectly (via your institution), to enable you to complete the work. Writing "None" means that you did the work without receiving any financial support from any third party -- that is, the work was supported by funds from the same institution that pays your salary and that institution did not receive third-party funds with which to pay you. If you or your institution received funds from a third party to support the work, such as a government granting agency, charitable foundation or commercial sponsor, then provide the details. For example, if you received an honorarium from Autism CRC in relation to your involvement, you would name Autism CRC and then indicate the amount of funds received.

Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	Autism CRC	Member of an organisation that received an honorarium of \$1000 for membership of the Reference Group
Consulting fee or honorarium	None	
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

Please add more rows if necessary.

#### 2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the guideline, and up until the point it is submitted to Autism CRC (i.e., 2019-2022). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	

Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	
Stock or stock options	None	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	None	

## 3. Relevant other activities or relationships, including non-financial relationships (no time limit)

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, and/or evaluation of therapies and/or supports that may be covered within the scope of the guideline	None
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, and/or evaluation of therapies	None

and/or supports that may be covered within the scope of the guideline	
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs)	None
Personal and/or family member experience of accessing therapies and/or support that may be covered in the guideline	None
Other	None

#### Declaration

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than 'none' to any of the questions above, these will be reviewed by Dr Gary Allen, Senior Policy Officer Human Research Ethics and Research Integrity at Griffith University. In each case, appropriate processes will be put in place to management any conflicts arising. Team members should not be concerned about answering 'yes' to any of the questions. 'Yes' answers do not indicate good or bad, but are simply something to declare on the form and consider for inclusion in the declarations section of the guideline.

National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia

 Appendix 4.1
 Existing Guidelines review - Included Guidelines

Academy of Medicine Singapore-Ministry of Health Clinical Practice Guidelines Workgroup on Autism Spectrum Disorders. (2010). Autism Spectrum Disorders in pre-school children. https://www.moh.gov.sg/hpp/all-healthcareprofessionals/guidelines

Barthélémy, C., Fuentes, J., Howlin, P., & and Jan van der Gaag, R. (2019). People with autism spectrum disorder: Identification, understanding, intervention (3rd ed.). Autism-Europe. https://www.autismeurope.org/blog/2019/09/16/people-with-autism-spectrum-disorder-identification-understanding-intervention-third-edition/

Dubai Health Authority (2021). Dubai Clinical Practice Guidelines for Autism Spectrum Disorder (ASD) in Children and Adolescents (from Birth to 18 Years of Age). https://www.dha.gov.ae/uploads/112021/f5d3aa75-37c3-4237-ba9ad9e4fba52531.pdf

Ministries of Health and Education. (2016). New Zealand Autism Spectrum Disorder Guideline (2nd ed.). New Zealand Ministries of Health.

https://www.health.govt.nz/publication/new-zealand-autism-spectrum-disorder-guideline

Ministry of Health Malaysia (2014). Clinical practice guidelines: management of autism spectrum disorder in children and adolescents.

https://www.moh.gov.my/moh/attachments/CPG%202014/CPG%20Management%2 0of%20Autism%20Spectrum%20Disofer%20in%20Children%20and%20Adolescents .pdf

Ministry of Public Health Qatar. (2019). National Clinical Guideline: The Diagnosis and Management of Autism Spectrum Disorder.

Missouri Autism Guidelines Initiative. (2012). Autism spectrum disorders: Guide to evidence-based interventions. https://autismguidelines.dmh.mo.gov/

National Institute for Health and Care Excellence (2021). Autism spectrum disorder in under 19s: support and management. https://www.nice.org.uk/guidance/cg170

New York State Department of Health, Bureau of Early Intervention. (2017). Clinical practice guideline on assessment and intervention services for young children with autism spectrum disorders (ASD): 2017 update report of recommendations. https://www.health.ny.gov/community/infants\_children/early\_intervention/disorders/a utism/

Roberts, J., & Williams, K. J. (2016). Autism spectrum disorder: Evidencebased/evidence-informed good practice for supports provided to preschool children, their families and carers. https://www.ndis.gov.au/media/863/download

Scottish Intercollegiate Guidelines Network (SIGN). (2016). Assessment, diagnosis and interventions for autism spectrum disorders: A national clinical guideline. https://www.sign.ac.uk/our-guidelines/assessment-diagnosis-and-interventions-for-autism-spectrum-disorders/

Subramanyam AA, Mukherjee A, Dave M, Chavda K. (2019). Clinical Practice Guidelines for Autism Spectrum Disorders. Indian Journal of Psychiatry. doi: 10.4103/psychiatry.IndianJPsychiatry\_542\_18.

Veereman, G., Holdt Henningsen, K., Eyssen, M., Benahmed, N., Christiaens, W., Bouchez, M-H., De Roeck, A., Deconinck, N., De ligne, G., Dewitte, G., Gheysen, T., Hendrix, M., Kagan, C., Magerotte, G., Moonen, M., Roeyers, H., Schelstraete, S., Soncarrieu, M-V., Steyaert, J., Tolfo, F., Vrancken, G., Willaye, E., Wintgens, A., Wouters, S., Croonenberghs, J. (2014). Management of autism in children and young people: A good clinical practice guideline. Belgian Health Care Knowledge Centre (KCE). https://kce.docressources.info/index.php?lvl=notice\_display&id=3465

Washington Department of Health. (2010, April 12). Defining Autism. In Autism guidebook for Washington State (Chapter 3). Retrieved April 16, 2011, from Autism Task Force website:

http://www.doh.wa.gov/cfh/mch/autism/Documents/Guidebook/Chapter3.pdf

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 Appendix 5.1
 Umbrella review - Outcomes included

### Appendix 5.1 - Umbrella review - Outcomes included

Outcome category Specific outcome	Operationalised definition	Examples of terms used to describe these outcomes in included systematic reviews.
Communication Overall communication	Please note the differentiation between 'social communication' and 'communication' categories described in the 'social communication' entry. 'Communication' was coded where: (a) the term was used to describe the outcome; and/or (b) The outcome refers to a set of behaviours that together enhance the child's capacity to understand, and/or be understood by others. This latter definition was based on that described in Volkmar (2013).	Child communication; communication; communication- language; communication and language skill; composite language; general language; gestures; joint language; language; qualitative impairment in communication;
Communication Social-communication	<ul> <li>The following definition was used to guide coding for measures of social communication (Volkmar, 2013):</li> <li>"Social communication is a broad term that describes the vast amount of verbal and nonverbal behaviors used to interact with other people. Examples of the verbal and nonverbal behaviors are (but are not limited to) speech, prosody, gestures, and facial expressions. These behaviors can be used to initiate or respond to joint attention, to share emotion with others, or to signal when an individual wants the attention of another person, along with many other uses."</li> <li>The term 'social communication' emphasises the pragmatic (functional) use of language. Accordingly, variables that relate primarily to children expressing a pragmatic function (e.g., requesting, commenting, sharing) were coded as 'social communication'. Measures were coded under other communication related categories ('communication', 'expressive language', 'receptive language'), where: (a) these terms were used explicitly and/or (b) the outcome emphasises the proficiency of expressive or receptive language (e.g., syntax, grammar, morphology) in comparison to other children of similar age.</li> </ul>	Child initiations; interpersonal; joint attention; non- verbal behaviours; pragmatic language; qualitative impairment in social interaction; reciprocity of social interaction towards others; shared engagement; socialisation; social-communication; social and emotional development; social adaptation; social skills.
Communication <i>Expressive language</i>	Please note the differentiation between 'social communication' and 'expressive language' categories described in the 'social communication' entry. 'Expressive language' was coded where: (a) the term was used to describe the outcome; and/or (b) The	Expression; expressive language; speech or vocalisation; speech outcomes; spoken language; words produced.

	outcome referred to a skill that enhances a child's capacity to be	
	understood by others via a range of modalities such as	
	vocalisations, speech, gesture, and augmentative communication.	
	This latter definition was based on that described in Volkmar	
	(2013).	
Communication	Please note the differentiation between 'social communication'	Comprehension; receptive language.
Receptive language	and 'receptive language' categories described in the 'social	
	communication' entry. 'Receptive language' was coded where: (a)	
	the term was used to describe the outcome; and/or (b) The	
	outcome referred to a skill that enhances a child's capacity to	
	understand others' vocalisations, speech, and gestures. This latter	
	definition was based on that described in Volkmar (2013).	
Sensory development	The following definition was used to guide coding for measures of	Sensory or emotion regulation; sensory skills; sensory-
	sensory behaviours (Volkmar, 2013):	related outcomes.
	Sensory seeking: "Sensation-seeking is the tendency to pursue	
	sensory stimulation and excitement.	
	Sensory avoiding: "Sensation avoiding is the tendency to avoid	
	sensory stimulation."	
Cognitive development	The following definition was used to guide coding for measures of	Child cognitive or educational strengths; cognition;
	cognition (Volkmar, 2013):	cognitive; cognitive development; developmental
		quotient; developmental/intellectual gains; full scale IQ;
	"The term "cognition" refers to mental processes or forms of	higher cognitive functioning; non-verbal cognitive
	information processing. These processes include attention,	skills; non-verbal IQ; visual reception.
	memory, learning, decision making, reasoning, and problem	
	solving. In the study of autism, a distinction often is drawn	
	between social and/or non-social forms of cognition "	
Social-emotional	The following definition was used to guide coding for measures of	Adaptive/maladaptive behaviour; behaviour;
development	social-emotional development:	behavioural skills; challenging/interfering behaviour;
		classroom behaviour; disruptive behaviour;
	Social-Emotional: "Behavioural and emotional strengths and	hyperactivity; maladaptive behaviour; problem
	ability to adapt and deal with daily challenges (resilience and	behaviour; self-regulation; social emotional/challenging
	coping skills) and respond positively to adversity while leading a	behaviour.
	fulfilling life" (AIHW 2012).	
	'Challenging behaviour': "Challenging behavior refers to certain	
	behaviors that a person engages in which negatively affect his/her	
	daily functioning. These behaviors are often recognized as being	
	culturally abnormal and occur at such an intensity, frequency, or	
	duration that the safety of the person and/or others is placed in	
	jeopardy. Challenging behaviors may be related to social,	

	academic, communicative, cognitive, vocational, or physical domains, may serve various functions, and should be examined systematically in order to identify these functions." (Volkmar, 2013)	
Motor development	The following definition was used to guide coding for measures of motor (Volkmar, 2013):	Fine motor; gross motor performance; motor; motor and fine motor; motor skills.
	"Fine motor skills are also termed hand skills, fine motor coordination, object manipulation, or dexterity. Components of fine motor development include reach, grasp, release, in-hand manipulation, and bimanual coordination"	
	"Gross motor abilities entail the use of large muscle groups that coordinate body movements to perform activities such as maintaining balance, walking, sitting upright, jumping, throwing objects, etc."	
Academic Skills	The following definition was used to guide coding for measures of academic skills (Volkmar, 2013):	Academic/s.
	"Academic skillsrefer to skills in subject areas that form the academic curriculum, available to all children in that country."	
School/Learning Readiness	The following definition was used to guide coding for measures of school/learning readiness (UNICEF, 2012):	Academic placement; learning readiness; placement; school readiness.
	"School readiness is a combination of three domains: learned behaviours such as knowing colours and shapes, counting numbers and saying letters of the alphabet; attitude and emotional competence, as in listening to directions, being interested in learning and behaving in a socially acceptable manner; and developmental maturation, including fine and gross motor development and sitting still for an appropriate period of time."	
Daily activities and participation	The following definition was used to guide coding for measures of adaptive behaviour (Volkmar, 2013):	Adaptive behaviour; adaptive/self-help; daily living skills; functional skills; personal responsibility.
Adaptive behaviour	"The collection of conceptual, social, and practical skills that have been learned by people in order to function in everyday lives. Adaptive behavior is best understood as the degree to which individuals are able to function and maintain themselves independently and meet cultural expectations for personal and social responsibility at various ages."	

Daily activities and participation <i>Play skills</i>	The following definition was used to guide coding for measures of play skills: A set of behaviours referred to as 'play' by the study authors and encompassing various characteristics including exploratory, functional, parallel, sensorimotor, and pretend.	Play.
	The investigators of the current review formulated this definition based on definitions for a range of play activities provided in Volkmar (2013).	
Daily activities and participation <i>Participation</i>	The following definition was used to guide coding for measures of participation: A child's ability to participate in activities within the community.	Academic placement (percentage of time spent with typical peers); functional participation.
General child outcomes	The investigators of the current review formulated this definition. This outcome was coded where authors did not specify a specific outcome, but provided a global measure of the effect of a support.	Condition specific outcomes; child behavioural functioning and development; efficacy outcomes; functioning and participation; outcomes.
Overall autism characteristics	This outcome was coded where authors provided a global measure of autism symptoms or characteristics.	ASD/autism symptom severity; autism general symptoms; diagnostic characteristics of autism; general symptoms; severity of autism; symptoms associated with autism/ASD.
Restricted and repetitive interests and behaviours	The following definition was used to guide coding for measures of restricted and repetitive interests and behaviours (Volkmar, 2013): <b>Repetitive behaviours:</b> "The term "repetitive behaviors" refers to abnormal behaviors that are characterized by repetition, rigidity, inappropriateness, and lack of adaptability. They include motor stereotyped behaviors, self-stimulatory behaviors, self-injurious behaviors, compulsive or sameness behaviors, and verbal repetitive behaviors such as echolalia." <b>Restricted interest:</b> "A limited set or limited number of interests and/or activities Restrictive interests may be repetitious (i.e., spinning a wheel) and/or limited in scope or range (i.e., a narrow or limited range of items that hold the individual's interest)." <b>Stereotypies:</b> "Stereotypies are repetitive, persistent, non-goal, and apparently purposeless motor actions and speech patterns which are carried out in a rhythmic and uniform way that serves no obvious adaptive functioning."	Repetitive behaviours; Repetitive and maladaptive behaviours; Restrictive and repetitive behaviours; Restricted, repetitive, non-functional patterns of behaviour, interests, or activity.

Family wellbeing and satisfaction <i>Child quality of life</i>	A separate category for social-emotional developments was also included in the current review. Measures were coded according to the context in which the authors of a systematic review used the term. The following definition was used to guide coding for measures of quality of life (WHO, : "An individual's perception of their position in life in the context	Joy; quality of life.
	of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."	
Family wellbeing and satisfaction <i>Child satisfaction with</i> support	The following definition was used to guide coding for measures of child satisfaction with support: Children's' views regarding the appropriateness and acceptability of support goals, methods, and/or outcomes. The investigators of the current review formulated this definition.	Child distress.
Family wellbeing and satisfaction Parent knowledge and skills	The following definition was used to guide coding for measures of caregiver communication and interaction strategies: Caregiver behaviour proposed by the authors to be beneficial to promoting communication and interaction abilities in children on the autism spectrum.	Fidelity; knowledge acquisition; parental responsiveness; parental synchrony; parents' use of intervention strategies
Family wellbeing and satisfaction Parent social emotional wellbeing	The investigators of the current review formulated this definition. The following definition was used to guide coding for measures of caregiver social emotional wellbeing (AIHW, 2012): "Behavioural and emotional strengths and ability to adapt and deal with daily challenges (resilience and coping skills) and respond positively to adversity while leading a fulfilling life".	Parent behaviours; Parenting efficacy; parental stress; parental distress; parental self-efficacy; parent-child relationship; parents' confidence; quality of family relationships.
Family wellbeing and satisfaction Parent financial wellbeing	The following definition was used to guide coding for measures of caregiver financial impact: Direct or indirect consequence to caregivers of accessing a support measured in monetary terms. The investigators of the current review formulated this definition.	Cost of intervention; reduced costs.
Family wellbeing and satisfaction Parent satisfaction with support	The following definition was used to guide coding for measures of caregiver financial impact: Caregivers' views regarding the appropriateness and acceptability of support goals, methods, and/or outcomes.	Customer satisfaction; satisfaction and acceptability; social validity.

	The investigators of the current review formulated this definition.	
Child related adverse effects	The following definition was used to guide coding for measures of	Adverse effects; deterioration; increases in stereotypy
	child-related adverse effects	and problem behaviour.
	Undesired and/or harmful effects of the support on the child. These	
	can be immediate effects or longer-term effects.	
	The investigators of the current review formulated this definition.	

#### **References:**

Australian Institute of Health and Welfare. Australia's children. Cat. no. CWS 69. Canberra: AIHW; 2020/ UNICEF. School readiness: A conceptual framework. New York: United Nations Children's Fund; 2012. Volkmar F. (Ed). Encyclopedia of Autism Spectrum Disorders. New York: Springer-Verlag; 2013. World Health Organisation. World Health Organisation Definition of Quality of Life. Accessed 1<sup>st</sup> July 2020 from: https://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/

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 Appendix 5.2
 Umbrella review - Database search strategy

### Appendix 5.2 - Umbrella review - Database search strategy

#### CINAHL

- S1 (MH"Asperger Syndrome") OR (MH"Autistic Disorder") OR (MH"Pervasive Development Disorder-Not Otherwise Specified")
- S2 Autis\* OR ASD\* OR Asperger\* OR "pervasive developmental disorder\*" OR PDD\* OR "pervasive child development disorder\*" OR "pervasive childhood developmental disorder\*" OR PCDD\* OR "disintegrative disorder\*"
- S3 intervention\* OR therap\* OR treat\* OR teach\* OR program\* OR package\*
- S4 "systematic review\*" OR "systematic literature review\*" OR "evidence synthes\*" OR "metaanaly\*" OR "meta-regression\*"

S5 S1 OR S2

S6 S3 AND S4 AND S5

S7 Limiters – Published Date: 20200107-20211119

#### Cochrane

- #1 MeSH descriptor: [Child Development Disorders, Pervasive] explode all trees
- #2 Autis\* OR ASD\* OR Asperger\* OR "pervasive developmental disorder\*" OR PDD\* OR "pervasive child development disorder\*" OR "pervasive childhood developmental disorder\*" OR PCDD\* OR "disintegrative disorder\*"

#3 #1 OR #2

- #4 intervention\* OR therap\* OR treat\* OR teach\* OR program\* OR package\*
- #5 "systematic review\*" OR "systematic literature review\*" OR "evidence synthes\*" OR "metaanaly\*" OR "meta-regression"

#6 #3 AND #4 AND #5

#7 Limit: Cochrane Library publication date from July 2020 to present

#### **Education Source**

- S1 Autis\* OR ASD\* OR Asperger\* OR "pervasive developmental disorder\*" OR PDD\* OR "pervasive child development disorder\*" OR "pervasive childhood developmental disorder\*" OR PCDD\* OR "disintegrative disorder\*"
- S2 intervention\* OR therap\* OR treat\* OR teach\* OR program\* OR package\*
- S3 "systematic review\*" OR "systematic literature review\*" OR "evidence synthes\*" OR "metaanaly\*" OR "meta-regression"

S4 S1 AND S2 AND S3

S5 Limiters – Published Date: 20200107-20211119

#### EMBASE

- #1 'autism'/exp
- #2 Autis\* OR ASD\* OR Asperger\* OR "pervasive developmental disorder\*" OR PDD\* OR "pervasive child development disorder\*" OR "pervasive childhood developmental disorder\*" OR PCDD\* OR "disintegrative disorder\*"

#3 #1 OR #2

#4 intervention\* OR therap\* OR treat\* OR teach\* OR program\* OR package\*

#5 "systematic review\*" OR "systematic literature review\*" OR "evidence synthes\*" OR "metaanaly\*" OR "meta-regression"

#6 #3 AND #4 AND #5

#7 #6 AND (2010:py OR 2011:py OR 2012:py OR 2013:py OR 2014:py OR 2015:py OR 2016:py OR 2017:py OR 2018:py OR 2019:py OR 2020:py)

#### Epistemonikos

(title:(Autis\* OR ASD\* OR Asperger\* OR "pervasive developmental disorder\*" OR PDD\* OR "pervasive child development disorder\*" OR "pervasive childhood developmental disorder\*" OR PCDD\* OR "disintegrative disorder\*") OR abstract:(Autis\* OR ASD\* OR Asperger\* OR "pervasive developmental disorder\*" OR PDD\* OR "pervasive child development disorder\*" OR "pervasive childhood developmental disorder\*" OR PCDD\* OR "disintegrative disorder\*")) AND (title:(intervention\* OR therap\* OR treat\* OR teach\* OR program\* OR package\*)) OR abstract:(intervention\* OR therap\* OR treat\* OR teach\* OR program\* OR package\*)) AND (title:("systematic review\*" OR "systematic literature review\*" OR "evidence synthes\*" OR meta-analy\* OR meta-regression\*) OR abstract:("systematic review\*" OR "systematic literature review\*" OR "evidence synthes\*" OR meta-analy\* OR meta-regression\*)) Limit: 2020 - 2021

#### ERIC

S1 su(autism)

S2 Autis\* OR ASD\* OR Asperger\* OR "pervasive developmental disorder\*" OR PDD\* OR "pervasive child development disorder\*" OR "pervasive childhood developmental disorder\*" OR PCDD\* OR "disintegrative disorder\*"

S3 S1 OR S2

S4 intervention\* OR therap\* OR treat\* OR teach\* OR program\* OR package\*

S5 "systematic review\*" OR "systematic literature review\*" OR "evidence synthes\*" OR "metaanaly\*" OR "meta-regression"

S6 S3 AND S4 AND S5

S7 Limits applied: 2020-07-01 - 2020

#### Medline

1. exp Child Development Disorders, Pervasive/

2. (Autis\* OR ASD\* OR Asperger\* OR "pervasive developmental disorder\*" OR PDD\* OR "pervasive child development disorder\*" OR "pervasive childhood developmental disorder\*" OR PCDD\* OR "disintegrative disorder\*").mp.[mp=title, abstract, original title, name of substance word, subject heading word, floating subheading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

3. 1 OR 2

4. (intervention\* OR therap\* OR treat\* OR teach\* OR program\* OR package\*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 5. ("systematic review\*" OR "systematic literature review\*" OR "evidence synthes\*" OR "meta-analy\*" OR "meta-regression").mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

6. 3 and 4 and 5

7. Limit 6 to yr="2020-current"

#### PsycInfo

1. exp autism spectrum disorders/

2. (Autis\* OR ASD\* OR Asperger\* OR "pervasive developmental disorder\*" OR PDD\* OR "pervasive child development disorder\*" OR "pervasive childhood developmental disorder\*" OR PCDD\* OR "disintegrative disorder\*").mp.[mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]

3. 1 or 2

4. (intervention\* OR therap\* OR treat\* OR teach\* OR program\* OR package\*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]

5. ("systematic review\*" OR "systematic literature review\*" OR "evidence synthes\*" OR "meta-analy\*" OR "meta-regression").mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]

6. 3 and 4 and 5

7. Limit 6 to yr="2020-current"

#### PubMed

(((child development disorders, pervasive[MeSH Terms] OR (Autis\* OR ASD\* OR Asperger\* OR "pervasive developmental disorder\*" OR PDD\* OR "pervasive child development disorder\*" OR "pervasive childhood developmental disorder\*" OR PCDD\* OR "disintegrative disorder\*")) AND (intervention\* OR therap\* OR treat\* OR teach\* OR program\* OR package\*)) AND ("systematic review\*" OR "systematic literature review\*" OR "evidence synthes\*" OR "meta-analy\*" OR "meta-regression") Filters: from 2020 - 2021

#### Scopus

(TITLE-ABS-KEY (Autis\* OR ASD\* OR Asperger\* OR "pervasive developmental disorder\*" OR PDD\* OR "pervasive child development disorder\*" OR "pervasive childhood developmental disorder\*" OR PCDD\* OR "disintegrative disorder\*") AND TITLE-ABS-KEY (intervention\* OR therap\* OR treat\* OR teach\* OR program\* OR package\*) AND TITLE-ABS-KEY ("systematic review\*" OR "systematic literature review\*" OR "evidence synthes\*" OR "metaanaly\*" OR "meta-regression")) AND (LIMIT-TO (PUBYEAR, 2020))

# National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia

# Appendix 5.3 - Umbrella review - Consensus on the eligibility of each type of support

Type of support	Explicitly listed for exclusion	Not an practice/ category of support i.e. assessment	Not a practice/ category of support i.e. technique	Does not meet eligibility criteria	Include
Acceptance and Commitment					Х
Therapy					
Acupuncture	Х				
Animal-assisted Therapy					X
Antecedent-Based Interventions			X		
Art therapy				X	
Auditory Integration Training					X
Augmentative and Alternative					Х
Communication (AAC)					
Behavioral intervention					Х
Behavioral Momentum			Х		
Intervention					
Behavioural skills training					Х
Chelation	Х				
Child-centred play therapy					Х
Chiropractic	Х				
Client Feedback			Х		
Cognitive bias modification				Х	
Cognitive Behavioral/					Х
Instructional Strategies					
Cognitive Orientation to Daily Occupational Performance (CO- OP)					Х
Cognitive					Х
Remediation/Cognitive training					
Comprehensive Behavioral					Х
Treatment for Young Children					
Computer-based intervention					Х
Concept Mapping			Х		
Creative arts programs				Х	
Dance	Х				
Developmental Relationship-					Х
based Treatment					

Differential Reinforcement of			X		
Alternative, Incompatible, or			21		
Other Behavior					
DIR/Floortime					X
Direct Instruction (DI)			X		Δ
Discrete Trial Training (DTT)			Λ		X
Emotion Recognition Training				X	Λ
Enhanced Milieu Training				Λ	X
Exercise and Movement	Х				Λ
Exposure Package	Λ				X
Exposure rackage			X		Λ
Facial Emotion Training/			Λ	X	
Emotion Recognition Training				Λ	
Facilitated Communication					X
Family therapy				X	Λ
Feeding				X	
Fluency intervention				Λ	v
Functional Communication					X X
					Λ
Training (FCT) Functional Behavioral		Х			
		Λ			
Assessment (FBA)					X
Gamification/Serious games Gluten-free/Casein-free diet	Х				Λ
	Λ				X
Holding therapy	V				Λ
Hydrotherapy	X X				
Hyperbaric oxygen therapy interventions	Х				
Imitation-based Intervention					v
			V		X
Inclusion of			Х		
circumscribed/special interests					V
Initiation Training					X
Intensive Interaction					X
'Interactive social interventions'			N/		Х
Joint control training/Joint			Х		
stimulus control	V				
Kinesiology	Х				V
Language Training (Production					Х
& Understanding)					v
Language Training (Production)					X
Lego therapy			v		X
Mand training	v		X		
Martial arts	X		+		
Massage Therapy	Х		v		
Matrix training			X		

Mind-body therapies	X			
(yoga, meditation, Nei Yang				
Gong, acceptance and				
<i>commitment therapy)</i>				
Mindfulness				X
Modelling		X		
Motivating Operations				
Multi-component Package				X
Music-Mediated Intervention				X
(MMI)				Λ
Narrative intervention			X	
Natural Language Paradigm			1	X
Naturalistic Intervention				X
Neurofeedback	X			
Neurostimulation	X			
Oral health	<u>A</u>		X	
Parent Child Interaction			Λ	X
Therapy				Λ
Parent verbal responsiveness		X		
Parent-Implemented				X
Intervention				Λ
Peer-Based Instruction and				X
Intervention (PBII)				Λ
Picture Exchange				X
Communication System				
Pivotal Response Treatment®				Х
Precision teaching				Х
Prompting (PP)		Х		
Psychodynamic psychotherapy			Х	
Psychomotor therapy				Х
Punishment		X		
Rapid Prompting Method				Х
(RPM)				
Reductive Package				Х
Reflexology	X			
Reinforcement		X		
Response		X		
Interruption/Redirection				
Responsivity interventions				X
Role play		Х		
Schedules		Х		
Scripting		X X		
Self-controlled technology				X
Self-Management (SM)		Х		
SENSE Theatre Intervention			Х	

Sensory Integration® (SI)				Х
Shared reading				Х
Shock Therapy	Х			
Sign Instruction				Х
Social Behavioral Learning				Х
Strategy				
Social Cognition Intervention				Х
Social communication				Х
intervention				
Social Narratives (SN)		Х		
Social Robots				Х
Social Skills Training (SST)				Х
Social Thinking Intervention-				Х
Speaker/Listener instruction				Х
Structured teaching				Х
Systemic therapy				Х
Task Analysis (TA)		Х		
Task interspersal		X		
Technology-Aided Instruction				Х
and Intervention (TAII)				
The listening programme				Х
Theory of Mind Training-				Х
Therapeutic surfing	Х			
Theraplay				Х
Time Delay (TD)		X		
Toileting			Х	
Transcranial magnetic	Х			
stimulation				
UCLA PEERS				Х
Verbal behaviour intervention				Х
Video Modeling		Х		
Video-based instruction		Х		
Virtual/augmented/mixed				Х
reality				
Visual Supports		Х		
Water Safety			Х	
Weighted vests				Х
Supports targeting inappropriate			Х	
masturbation				

Note: The names of these supports were taken verbatim from the articles.

 Appendix 5.4
 Umbrella review - Items for extraction

# Appendix 5.4 - Umbrella review - Items for extraction

#### Items for extraction at the systematic review level

- 1. Review title
- 2. Review authors
- 3. Year of publication
- 4. Type of review (meta-analysis or narrative synthesis)
- 5. Aims/objectives as stated in the review
- 6. Databases searched
- 7. Start and end year for search
- 8. Number of studies included
- 9. Number of autism-specific studies included
- 10. Design of eligible studies
  - Randomised controlled trial
  - Non-randomised with comparison
  - Non-randomised without comparison
  - Single case experimental designs
  - Other designs
- 11. Design of included studies
  - Randomised controlled trial
  - Non-randomised with comparison
  - Non-randomised without comparison
  - Single case experimental designs
  - Other designs
  - Designs not specified
- 12. Comparison groups for included studies
  - Wait list control
  - Treatment-as-usual
  - Another support (includes minimal support and eclectic)
  - The individual's own baseline (single case experimental designs)
  - Other comparison group
  - No comparison group
- 13. Continents in which included studies were conducted
  - Africa
  - Asia
  - Australia
  - Pacific
  - Europe
  - South America/Caribbean
  - North America
- 14. Eligible and included autism diagnoses

- Children diagnosed with autism were eligible for inclusion (yes/no)
- Children at increased likelihood for a diagnosis of autism were eligible for inclusion (yes/no)
- Children diagnosed with autism were included (yes/no)
- Children at increased likelihood for a diagnosis of autism were included (yes/no)
- Autism diagnoses of included children

15. Number of included participants

- Number of participants in the total sample
- Number of participants in the support group
- Number of participants in the comparison group
- 16. Eligible and included participant age
  - Minimum age of eligible participants
  - Maximum age of eligible participants
  - Minimum age of included participants
  - Maximum age of included participants
  - Mean age of participants in the total sample
  - Mean age of participants in the support group
  - Mean age of participants in the comparison group
- 17. Sex of included participants
  - Mean percentage male
  - Mean percentage female
  - Minimum percentage male
  - Maximum percentage male
  - Minimum percentage female
  - Maximum percentage female
- 18. Specified cooccurring conditions for included participants
  - ADHD
  - Sleep
  - Anxiety
  - Depression
  - Language delay
  - Minimal verbal (descriptive term, used with language delay)
  - Cognitive impairment (including ID, IQ <70)
  - Global developmental delay
  - Genetic syndrome (e.g. Down Syndrome, Fragile X)
  - Challenging behaviour
  - Physical disability
  - Other cooccurring conditions
- 19. Included categories and practices
- 20. Appraisal instrument used
- 21. Appraisal ratings
- 22. Sources of funding
- 23. Conflict(s) of interest reported by the author(s)

#### **Outcome-level data for extraction**

- 1. Review authors
- 2. Year of publication
- 3. Type of review (practice/category focussed, outcome focussed, delivery focussed
- 4. Name of category (Behavioural, Developmental, NDBI, Sensory, Technology, CBT, Animal-assisted, Other)
- 5. Name of practice
- 6. Name of delivery characteristic
- 7. Setting(s) for included studies
  - Clinic
  - Home
  - Educational settings (schools, early childhood)
  - Other settings
- 8. Format(s) for included studies
  - Delivered to individuals
  - Delivered to groups
- 9. Agent(s) (type of people delivering the support) for included studies
  - Parent(s)/caregiver(s)
  - Peer(s)/sibling(s)
  - School or early childhood staff (e.g. teacher, TA)
  - Clinician(s)/researcher(s)
  - Other agents
- 10. Mode(s) for included studies
  - Face-to-face
  - Telehealth
  - Other modes
- 11. Amount of support
- 12. Mean amount
- 13. Minimum amount
- 14. Maximum amount
- 15. Term used by SR to describe overall outcome
- 16. Outcomes that contributed to the overall effect measure
- 17. Specify the overall effect size including confidence intervals
- 18. Specify the types of effect size (e.g. Cohen's d or Hedge's g)
- 19. Meta-analysis direction of the therapeutic effect.
- 20. Effect size specified
- 21. Heterogeneity statistic type
- 22. Heterogeneity statistic value
- 23. For qualitative studies, copy the author's terminology to describe the summary of outcomes verbatim.
- 24. General child outcomes from meta-analyses
  - Term used by review to describe this outcome
  - Specific outcomes that contributed to the 'general outcomes' effect

- Number of studies evaluating this outcome
- Overall effect size and confidence intervals
- Type(s) of effect size (e.g., Cohen's d or Hedge's g)
- Direction of the effect (positive effect of support, negative effect of support, null effect of support)
- Heterogeneity statistic type
- Heterogeneity statistic value
- Verbatim summary of outcomes
- 25. Overall autism characteristics outcomes from meta-analyses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Overall effect size and confidence intervals
  - Type(s) of effect size (e.g., Cohen's d or Hedge's g)
  - Pooled direction of the effect (positive effect of support, negative effect of support, null effect of support)
  - Heterogeneity statistic type
  - Heterogeneity statistic value
  - Verbatim summary of outcomes
- 26. Social-communication outcomes from meta-analyses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Overall effect size and confidence intervals
  - Type(s) of effect size (e.g., Cohen's d or Hedge's g)
  - Pooled direction of the effect (positive effect of support, negative effect of support, null effect of support)
  - Heterogeneity statistic type
  - Heterogeneity statistic value
  - Verbatim summary of outcomes
- 27. Restricted and repetitive behaviour outcomes from meta-analyses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Overall effect size and confidence intervals
  - Type(s) of effect size (e.g., Cohen's d or Hedge's g)
  - Pooled direction of the effect (positive effect of support, negative effect of support, null effect of support)
  - Heterogeneity statistic type
  - Heterogeneity statistic value
  - Verbatim summary of outcomes
- 28. Sensory outcomes from meta-analyses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Overall effect size and confidence intervals
  - Type(s) of effect size (e.g., Cohen's d or Hedge's g)

- Pooled direction of the effect (positive effect of support, negative effect of support, null effect of support)
- Heterogeneity statistic type
- Heterogeneity statistic value
- Verbatim summary of outcomes
- 29. Overall communication outcomes from meta-analyses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Overall effect size and confidence intervals
  - Type(s) of effect size (e.g., Cohen's d or Hedge's g)
  - Pooled direction of the effect (positive effect of support, negative effect of support, null effect of support)
  - Heterogeneity statistic type
  - Heterogeneity statistic value
  - Verbatim summary of outcomes
- 30. Expressive language outcomes from meta-analyses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Overall effect size and confidence intervals
  - Type(s) of effect size (e.g., Cohen's d or Hedge's g)
  - Pooled direction of the effect (positive effect of support, negative effect of support, null effect of support)
  - Heterogeneity statistic type
  - Heterogeneity statistic value
  - Verbatim summary of outcomes
- 31. Receptive language outcomes from meta-analyses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Overall effect size and confidence intervals
  - Type(s) of effect size (e.g., Cohen's d or Hedge's g)
  - Pooled direction of the effect (positive effect of support, negative effect of support, null effect of support)
  - Heterogeneity statistic type
  - Heterogeneity statistic value
  - Verbatim summary of outcomes
- 32. Cognitive development outcomes from meta-analyses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Overall effect size and confidence intervals
  - Type(s) of effect size (e.g., Cohen's d or Hedge's g)
  - Pooled direction of the effect (positive effect of support, negative effect of support, null effect of support)
  - Heterogeneity statistic type

- Heterogeneity statistic value
- Verbatim summary of outcomes
- 33. Motor outcomes from meta-analyses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Overall effect size and confidence intervals
  - Type(s) of effect size (e.g., Cohen's d or Hedge's g)
  - Pooled direction of the effect (positive effect of support, negative effect of support, null effect of support)
  - Heterogeneity statistic type
  - Heterogeneity statistic value
  - Verbatim summary of outcomes
- 34. Social emotional development outcomes from meta-analyses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Overall effect size and confidence intervals
  - Type(s) of effect size (e.g., Cohen's d or Hedge's g)
  - Pooled direction of the effect (positive effect of support, negative effect of support, null effect of support)
  - Heterogeneity statistic type
  - Heterogeneity statistic value
  - Verbatim summary of outcomes
- 35. Play outcomes from meta-analyses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Overall effect size and confidence intervals
  - Type(s) of effect size (e.g., Cohen's d or Hedge's g)
  - Pooled direction of the effect (positive effect of support, negative effect of support, null effect of support)
  - Heterogeneity statistic type
  - Heterogeneity statistic value
  - Verbatim summary of outcomes
- 36. Adaptive behaviour outcomes from meta-analyses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Overall effect size and confidence intervals
  - Type(s) of effect size (e.g., Cohen's d or Hedge's g)
  - Pooled direction of the effect (positive effect of support, negative effect of support, null effect of support)
  - Heterogeneity statistic type
  - Heterogeneity statistic value
  - Verbatim summary of outcomes
- 37. School/learning readiness outcomes from meta-analyses

- Term used by review to describe this outcome
- Number of studies evaluating this outcome
- Overall effect size and confidence intervals
- Type(s) of effect size (e.g., Cohen's d or Hedge's g)
- Pooled direction of the effect (positive effect of support, negative effect of support, null effect of support)
- Heterogeneity statistic type
- Heterogeneity statistic value
- Verbatim summary of outcomes
- 38. Academic outcomes from meta-analyses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Overall effect size and confidence intervals
  - Type(s) of effect size (e.g., Cohen's d or Hedge's g)
  - Pooled direction of the effect (positive effect of support, negative effect of support, null effect of support)
  - Heterogeneity statistic type
  - Heterogeneity statistic value
  - Verbatim summary of outcomes
- 39. Child quality of life outcomes from meta-analyses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Overall effect size and confidence intervals
  - Type(s) of effect size (e.g., Cohen's d or Hedge's g)
  - Pooled direction of the effect (positive effect of support, negative effect of support, null effect of support)
  - Heterogeneity statistic type
  - Heterogeneity statistic value
  - Verbatim summary of outcomes
- 40. Community participation outcomes from meta-analyses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Overall effect size and confidence intervals
  - Type(s) of effect size (e.g., Cohen's d or Hedge's g)
  - Pooled direction of the effect (positive effect of support, negative effect of support, null effect of support)
  - Heterogeneity statistic type
  - Heterogeneity statistic value
  - Verbatim summary of outcomes
- 41. Parent knowledge and skill outcomes from meta-analyses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Overall effect size and confidence intervals

- Type(s) of effect size (e.g., Cohen's d or Hedge's g)
- Pooled direction of the effect (positive effect of support, negative effect of support, null effect of support)
- Heterogeneity statistic type
- Heterogeneity statistic value
- Verbatim summary of outcomes
- 42. Parent social-emotional wellbeing outcomes from meta-analyses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Overall effect size and confidence intervals
  - Type(s) of effect size (e.g., Cohen's d or Hedge's g)
  - Pooled direction of the effect (positive effect of support, negative effect of support, null effect of support)
  - Heterogeneity statistic type
  - Heterogeneity statistic value
  - Verbatim summary of outcomes
- 43. Parent financial wellbeing outcomes from meta-analyses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Overall effect size and confidence intervals
  - Type(s) of effect size (e.g., Cohen's d or Hedge's g)
  - Pooled direction of the effect (positive effect of support, negative effect of support, null effect of support)
  - Heterogeneity statistic type
  - Heterogeneity statistic value
  - Verbatim summary of outcomes
- 44. Parent satisfaction
  - Term used for the measure of parent satisfaction
  - Number of studies evaluating this outcome
  - Verbatim summary of outcomes
  - Summarised direction of the effect (consistent positive effect of support; consistently negative effect of support, consistently null effect of support, inconsistent effect of support)
- 45. Parent dissatisfaction
  - Term used for the measure of parent satisfaction
  - Number of studies evaluating this outcome
  - Verbatim summary of outcomes
  - Summarised direction of the effect (consistent positive effect of support; consistently negative effect of support, consistently null effect of support, inconsistent effect of support)
- 46. Child satisfaction
  - Term used for the measure of parent satisfaction
  - Number of studies evaluating this outcome
  - Verbatim summary of outcomes

- Summarised direction of the effect (consistent positive effect of support; consistently negative effect of support, consistently null effect of support, inconsistent effect of support)
- 47. Child dissatisfaction
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Verbatim summary of outcomes
  - Summarised direction of the effect (consistent positive effect of support; consistently negative effect of support, consistently null effect of support, inconsistent effect of support)
- 48. Child distress/harm related to the support (Adverse effects)
  - Evidence for child distress or harm
  - Description of type of harm/distress related to the support
- 49. General child outcomes from narrative syntheses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Verbatim summary of outcomes
  - Summarised direction of the effect (positive effect of support, negative effect of support, null effect of support, inconsistent effect of support)
- 50. Overall autism characteristics outcomes from narrative syntheses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Verbatim summary of outcomes
  - Summarised direction of the effect (positive effect of support, negative effect of support, null effect of support, inconsistent effect of support)
- 51. Social-communication outcomes from narrative syntheses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Verbatim summary of outcomes
  - Summarised direction of the effect (positive effect of support, negative effect of support, null effect of support, inconsistent effect of support)
- 52. Restricted and repetitive behaviour outcomes from narrative syntheses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Verbatim summary of outcomes
  - Summarised direction of the effect (positive effect of support, negative effect of support, null effect of support, inconsistent effect of support)
- 53. Sensory outcomes from narrative syntheses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Verbatim summary of outcomes
  - Summarised direction of the effect (positive effect of support, negative effect of support, null effect of support, inconsistent effect of support)
- 54. Overall communication outcomes from narrative syntheses
  - Term used by review to describe this outcome

- Number of studies evaluating this outcome
- Verbatim summary of outcomes
- Summarised direction of the effect (positive effect of support, negative effect of support, null effect of support, inconsistent effect of support)
- 55. Expressive language outcomes from narrative syntheses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Verbatim summary of outcomes
  - Summarised direction of the effect (positive effect of support, negative effect of support, null effect of support, inconsistent effect of support)
- 56. Receptive language outcomes from narrative syntheses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Verbatim summary of outcomes
  - Summarised direction of the effect (positive effect of support, negative effect of support, null effect of support, inconsistent effect of support)
- 57. Cognitive development outcomes from narrative syntheses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Verbatim summary of outcomes
  - Summarised direction of the effect (positive effect of support, negative effect of support, null effect of support, inconsistent effect of support)
- 58. Motor outcomes from narrative syntheses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Verbatim summary of outcomes
  - Summarised direction of the effect (positive effect of support, negative effect of support, null effect of support, inconsistent effect of support)
- 59. Social emotional development outcomes from narrative syntheses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Verbatim summary of outcomes
  - Summarised direction of the effect (positive effect of support, negative effect of support, null effect of support, inconsistent effect of support)
- 60. Play outcomes from narrative syntheses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Verbatim summary of outcomes
  - Summarised direction of the effect (positive effect of support, negative effect of support, null effect of support, inconsistent effect of support)
- 61. Adaptive behaviour outcomes from narrative syntheses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome

- Verbatim summary of outcomes
- Summarised direction of the effect (positive effect of support, negative effect of support, null effect of support, inconsistent effect of support)
- 62. School/learning readiness outcomes from narrative syntheses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Verbatim summary of outcomes
  - Summarised direction of the effect (positive effect of support, negative effect of support, null effect of support, inconsistent effect of support)
- 63. Academic outcomes from narrative syntheses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Verbatim summary of outcomes
  - Summarised direction of the effect (positive effect of support, negative effect of support, null effect of support, inconsistent effect of support)
- 64. Child quality of life outcomes from narrative syntheses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Verbatim summary of outcomes
  - Summarised direction of the effect (positive effect of support, negative effect of support, null effect of support, inconsistent effect of support)
- 65. Community participation outcomes from narrative syntheses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Verbatim summary of outcomes
  - Summarised direction of the effect (positive effect of support, negative effect of support, null effect of support, inconsistent effect of support)
- 66. Parent knowledge and skill outcomes from narrative syntheses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Verbatim summary of outcomes
  - Summarised direction of the effect (positive effect of support, negative effect of support, null effect of support, inconsistent effect of support)
- 67. Parent social-emotional wellbeing outcomes from narrative syntheses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Verbatim summary of outcomes
  - Summarised direction of the effect (positive effect of support, negative effect of support, null effect of support, inconsistent effect of support)
- 68. Parent financial wellbeing outcomes from narrative syntheses
  - Term used by review to describe this outcome
  - Number of studies evaluating this outcome
  - Verbatim summary of outcomes

• Summarised direction of the effect (positive effect of support, negative effect of support, null effect of support, inconsistent effect of support)

#### 69. Moderators

- Term used by review to describe the moderator
- Term used for moderator in the current umbrella review
- Term used by review to describe outcome
- Term used for the outcome in the current umbrella review
- Direction of moderation effect
- Verbatim summary of moderation effect
- Summary of moderation effect for the current umbrella review

Appendix 5.5Umbrella review - Quality appraisal form

# Appendix 5.5 - Umbrella review - Quality appraisal form

adapted from the Critical Appraisal Checklist for SRs and Research Syntheses created by the Joanna Briggs institute (2020)

NB: A 'Yes' decision requires all checkboxes under a single item to be met, unless the criteria specifically state otherwise (i.e., use an 'OR' qualifier). If all checkboxes are not met, a 'No' decision should be specified.

# 1. Is the review question clearly and explicitly stated?

 $\Box$  The review question(s) or aim(s)/objectives explicitly state(s) the population, intervention, and outcomes of interest PI(C)O.

# 2. Were the inclusion criteria appropriate for the review question?

- □ The PICO elements and design were clearly defined in the inclusion and/or exclusion criteria.
- $\hfill\square$  The PICO elements were relevant to the objectives of the review and/or the research questions

# 3. Was the search strategy appropriate?

- □ The search strategy included key words and/or index terms that specified PI(C)O
- $\hfill\square$  Date and language limits appropriate and/or justified

## 4. Were the sources and resources used for the study adequate?

- □ Included at least two major bibliographic databases relevant to the review question, from the following list: Medline, CINAHL, PsycINFO, PubMed, EMBASE, Scopus, Web of Science, and ERIC
- □ Attempt to search for grey literature (e.g. websites relevant to the review question, thesis repositories, trial registries)

# 5. Were criteria for appraising the studies appropriate?

- $\hfill\square$  Clear statement that critical appraisal was conducted
- □ Details of the items that were used to assess the included studies (within methods, appendix, or further reference) were outlined and appropriate for the relevant study design

# 6. Was critical appraisal conducted by two or more reviewers independently?

- □ Critical appraisal was conducted by two reviewers working independently from each other and conferring when needed to make a decision; OR
- $\Box$  Two reviewers conducted critical appraisal with at least 10% of eligible studies and achieved good agreement (at least 80% or Cohen's kappa = 0.6 or greater), with the remainder extracted by one reviewer.

## 7. Were there methods to minimise errors in data extraction?

- □ All data extraction was conducted by two reviewers working independently OR
- $\Box$  Two reviewers extracted data with a sample of eligible studies and achieved good agreement (at least 80% or Cohen's kappa = 0.6 or greater), with the remainder extracted by one reviewer.

## 8. Were the methods used to combine studies appropriate?

- Meta-analyses
  - $\Box$  A statement about the extent to which the studies were appropriate to be combined
  - □ Assessment of heterogeneity
  - □ Explanation for heterogeneity that may be present
- Narrative synthesis
  - $\Box$  Methods for data synthesis are congruent with the stated methodology
  - □ Adequate information is provided to support the synthesised findings
- Meta-analyses and narrative synthesis
  - □ Summary/extraction tables were structured to provide sufficient information to ascertain PICO elements and design for each included study.

## 9. Was the likelihood of publication bias assessed? (meta-analyses only)

- Publication bias was assessed (e.g. a funnel plot for 10 or more studies or Egger's test Begg test, Harbord test)
- $\square$  N/A

## 10. Were recommendations for policy and/or practice supported by the reported data?

- □ Clear link made between the results of the review and recommendations for policy and practice.
- □ The strengths of the findings and the quality of the research considered in the formulation of the review recommendations

## 11. Were the specific directives for new research appropriate?

 $\hfill\square$  Indication of directions for further research

 Appendix 5.6
 Umbrella review - Excluded articles

# Appendix 5.6 - Umbrella review - Excluded articles

#### Articles excluded during full-text screening with reasons

\*Indicates an article identified in the ancestral search

#### Exclusion reason: Duplicate (n = 4)

- Boster, J. B., Spitzley, A. M., Castle, T. W., Jewell, A. R., Corso, C. L., & McCarthy, J. W. (2021). Music Improves Social and Participation Outcomes for Individuals With Communication Disorders: A Systematic Review. *Journal of Music Therapy*, 58(1), 12-42.
- Moore, D. M., Baggett, K. M., & Barger, B. (2021). Measuring parent positive support of social communication among toddlers with autism: a systematic review. *Psychosocial Intervention*, *30*(1), 57-66.
- Sandgreen, H., Frederiksen, L. H., & Bilenberg, N. (2021). Digital interventions for autism spectrum disorder: a meta-analysis. *Journal of Autism and Developmental Disorders*, *51*(9), 3138-3152.
- Valentine, A. Z., Hall, S. S., Young, E., Brown, B. J., Groom, M. J., Hollis, C., & Hall, C. L. (2021).
   Implementation of telehealth services to assess, monitor, and treat neurodevelopmental disorders: systematic review. *Journal of Medical Internet Research*, 23(1), e22619.

#### Exclusion reason: Not systematic (n = 33)

- Aspiranti, K. B., Larwin, K. H., & Schade, B. P. (2020). iPads/tablets and students with autism: A metaanalysis of academic effects. *Assistive Technology*, *32*(1), 23-30.
- Bene, K., & Lapina, A. (2021). A Meta-Analysis of Sibling-Mediated Intervention for Brothers and Sisters Who Have Autism Spectrum Disorder. *Review Journal of Autism and Developmental Disorders*, 8, 186-194.
- Birnschein, A. M., Paisley, C. A., & Tomeny, T. S. (2021). Enhancing social interactions for youth with autism spectrum disorder through training programs for typically developing peers: A systematic review. *Research in Autism Spectrum Disorders*, *84*, e101784.
- Bottema-Beutel, K., Crowley, S., Sandbank, M., & Woynaroski, T. G. (2021). Adverse event reporting in intervention research for young autistic children. *Autism*, *25*(2), 322-335.
- \*Brelsford, V. L., Meints, K., Gee, N. R., & Pfeffer, K. (2017). Animal-Assisted Interventions in the Classroom—a systematic review. *International Journal of Environmental Research and Public Health*, 14(7), 669.
- \*Canoy, J. P., & Boholano, H. B. (2015). Early start DENVER model: A meta-analysis. *Journal of Education and Learning*, 9(4), 314-327.
- Damianidou, D., Eidels, A., & Arthur-Kelly, M. (2020). The use of robots in social communications and interactions for individuals with ASD: A systematic review. *Advances in Neurodevelopmental Disorders*, *4*(4), 357-388.
- \*Diehl, J. J., Schmitt, L. M., Villano, M., & Crowell, C. R. (2012). The clinical use of robots for individuals with autism spectrum disorders: A critical review. *Research in Autism Spectrum Disorders*, 6(1), 249-262.
- \*DiPietro, J., Kelemen, A., Liang, Y., & Sik-Lanyi, C. (2019). Computer-and robot-assisted therapies to aid social and intellectual functioning of children with autism spectrum disorder. *Medicina*, *55*(8), 440-458.

- Droboniku, M. J., & Mychailyszyn, M. P. (2021). Animal Interaction Affecting Core Deficit Domains Among Children with Autism: A Meta-Analysis. *Journal of Autism and Developmental Disorders*, *51*(12), 4605-4620.
- Farzana, W., Sarker, F., Chau, T., & Mamun, K. A. (2021). Technological evolvement in AAC modalities to Foster communications of verbally challenged ASD children: A systematic review. *IEEE Access*, advance online publication.
- Hussain, A., Mkpojiogu, E. O., & Okoroafor, P. C. (2021). Assisting Children with Autism Spectrum Disorder with Educational Mobile Apps to Acquire Language and Communication Skills: A Review. International Journal of Interactive Mobile Technologies, 15(6), 161-170.
- Karami, B., Koushki, R., Arabgol, F., Rahmani, M., & Vahabie, A. H. (2021). Effectiveness of Virtual/Augmented Reality-based therapeutic interventions on individuals with autism spectrum disorder: A comprehensive meta-analysis. *Frontiers in Psychiatry*, *12*, 887-912.
- \*Kokol, P., Vošner, H. B., Završnik, J., Vermeulen, J., Shohieb, S., & Peinemann, F. (2020). Serious gamebased intervention for children with developmental disabilities. *Current Pediatric Reviews*, 16(1), 26-32.
- Lorenzo, G., Lledó, A., Pérez-Vázquez, E., & Lorenzo-Lledó, A. (2021). Action protocol for the use of robotics in students with Autism Spectrum Disoders: A systematic-review. *Education and Information Technologies*, *26*(4), 4111-4126.
- Lu, Y., Douglas, S. N., Bagawan, A., & Hauck, J. L. (2021). Using neurotypical siblings as intervention agents to guide individuals with Autism Spectrum Disorders: A systematic review. *Research in Autism Spectrum Disorders*, *89*, e101868.
- MacKenzie, K. T., & Eack, S. M. (2021). Interventions to improve outcomes for parents of children with autism spectrum disorder: a meta-analysis. *Journal of Autism and Developmental Disorders*, advance online publication.
- Macmillan, C. M., Pecora, L. A., Ridgway, K., Hooley, M., Thomson, M., Dymond, S., ... & Stokes, M. A. (2021). An Evaluation of Education-Based Interventions for Students with Autism Spectrum Disorders Without Intellectual Disability: a Systematic Review. *Review Journal of Autism and Developmental Disorders*, advance online publication.
- Marino, L., & Lilienfeld, S. O. (2021). Third time's the charm or three strikes you're out? An updated review of the efficacy of dolphin-assisted therapy for autism and developmental disabilities. *Journal of Clinical Psychology*, 77(6), 1265-1279
- \*Meadan, H., & Daczewitz, M. E. (2015). Internet-based intervention training for parents of young children with disabilities: A promising service-delivery model. *Early Child Development and Care*, *185*(1), 155-169.
- Moore, D. M., Baggett, K. M., & Barger, B. (2021). Measuring parent positive support of social communication among toddlers with autism: a systematic review. *Psychosocial Intervention*, *30*(1), 57-66.
- Mostajo, S. T., Legaspi, O. M., Camarse, M. G., & Salva, R. A. (2021). Exploring the Potentials of Robotics in Supporting Children with Autism Spectrum Disorder. *IAFOR Journal of Education*, *9*(1), 77-93.
- Muharib, R., & Lang, R. (2020). Systematic review suggests social-communication interventions can be effective when implemented in inclusive schools with children with autism spectrum disorders. *Evidence-Based Communication Assessment and Intervention*, 14(3), 109-112.
- Nicolosi, M., & Dillenburger, K. (2021). The University of California at Los Angeles-Young Autism Project: A systematic review of replication studies. *Behavioral Interventions*, advance online publication.
- Pontikas, C. M., Tsoukalas, E., & Serdari, A. (2020). A map of assistive technology educative instruments in neurodevelopmental disorders. *Disability and Rehabilitation: Assistive Technology*, advance online publication.

Ratliff-Black, M., & Therrien, W. (2021). Parent-mediated interventions for school-age children with ASD: A meta-analysis. *Focus on Autism and Other Developmental Disabilities, 36*(1), 3-13.

- Saleh, M. A., Hanapiah, F. A., & Hashim, H. (2021). Robot applications for autism: A comprehensive review. *Disability and Rehabilitation: Assistive Technology*, *16*(6), 580-602.
- Sani-Bozkurt, S., & Bozkus-Genc, G. (2021). Social Robots for Joint Attention Development in Autism Spectrum Disorder: A Systematic Review. *International Journal of Disability, Development and Education*, advance online publication.
- \*Swan, A. J., Carper, M. M., & Kendall, P. C. (2016). In pursuit of generalization: An updated review. *Behavior Therapy*, *47*(5), 733-746.
- Syriopoulou-Delli, C. K., & Eleni, G. (2021). Effectiveness of Different Types of Augmentative and Alternative Communication (AAC) in Improving Communication Skills and in Enhancing the Vocabulary of Children with ASD: a Review. *Review Journal of Autism and Developmental Disorders*, advance online publication.
- Tárraga-Mínguez, R., Gómez-Marí, I., & Sanz-Cervera, P. (2021). Interventions for Improving Reading Comprehension in Children with ASD: A Systematic Review. *Behavioral Sciences*, 11(1), 3-15.
- \*Tonge, B. J., Bull, K., Brereton, A., & Wilson, R. (2014). A review of evidence-based early intervention for behavioural problems in children with autism spectrum disorder: the core components of effective programs, child-focused interventions and comprehensive treatment models. *Current Opinion in Psychiatry*, *27*(2), 158-165.
- Zilz, W., & Pang, Y. (2021). Application of assistive technology in inclusive classrooms. *Disability and Rehabilitation: Assistive Technology*, *16*(7), 684-686.

#### Exclusion reason: No relevant design (n = 9)

- Al-Rashaida, M., Amayra, I., López-Paz, J. F., Martínez, O., Lázaro, E., Berrocoso, S., ... & Caballero, P. (2021). Studying the Effects of Mobile Devices on Young Children with Autism Spectrum Disorder: a Systematic Literature Review. *Review Journal of Autism and Developmental Disorders*, advance online publication.
- Aldabas, R. (2020). Effectiveness of peer-mediated interventions (PMIs) on children with autism spectrum disorder (ASD): a systematic review. *Early Child Development and Care*, 190(10), 1586-1603.
- Alves, F. J., De Carvalho, E. A., Aguilar, J., De Brito, L. L., & Bastos, G. S. (2020). Applied behavior analysis for the treatment of autism: A systematic review of assistive technologies. *IEEE Access*, 8, 118664-118672.
- Brooks, R., & Bannigan, K. (2021). Occupational therapy interventions in child and adolescent mental health to increase participation: A mixed methods systematic review. *British Journal of Occupational Therapy*, *84*(8), 474-487.
- Haas, A., Vannest, K. J., Fuller, M. C., & Ganz, J. B. (2021). Understanding the Effect Size of Peer-Mediated Academic Instruction: A Meta-Analysis. *Focus on Autism and Other Developmental Disabilities*, 37(1), 3-12.
- Money, R., Wilde, S., & Dawson, D. (2021). The effectiveness of Theraplay for children under 12–a systematic literature review. *Child and Adolescent Mental Health*, *26*(3), 238-251.
- O'Donoghue, M., O'Dea, A., O'Leary, N., Kennedy, N., Forbes, J., & Murphy, C. A. (2021). Systematic review of peer-mediated intervention for children with autism who are minimally verbal. *Review Journal of Autism and Developmental Disorders*, 8(1), 51-66.
- Root, J. R., Ingelin, B., & Cox, S. K. (2021). Teaching Mathematical Word Problem Solving to Students with Autism Spectrum Disorder: A Best-Evidence Synthesis. *Education and Training in Autism* and Developmental Disabilities, 56(4), 420-436.

Wei, Q., Machalicek, W., Crowe, B., Kunze, M., & Rispoli, M. (2021). Restricted and Repetitive Patterns of Behavior and Interests in Children with Autism Spectrum Disorder: A Systematic Review of Behavioral Interventions. *Education and Training in Autism and Developmental Disabilities*, 56(2), 115-139.

#### Exclusion reason: No (separate analysis of) children diagnosed with autism (n = 8)

- Darling, S. J., Goods, M., Ryan, N. P., Chisholm, A. K., Haebich, K., & Payne, J. M. (2021). Behavioral intervention for social challenges in children and adolescents: a systematic review and meta-analysis. *JAMA Pediatrics*, *175*(12), e213982-e213982.
- Hampton, L. H., & Rodriguez, E. M. (2021). Preemptive interventions for infants and toddlers with a high likelihood for autism: A systematic review and meta-analysis. *Autism*, advance online publication.
- Law, M. L., Singh, J., Mastroianni, M., & Santosh, P. (2021). Parent-Mediated Interventions for Infants under 24 Months at Risk for Autism Spectrum Disorder: A Systematic Review of Randomized Controlled Trials. *Journal of Autism and Developmental Disorders*, advance online publication.
- Lynam, A., & Smith, M. M. (2021). Sibling involvement in interventions for children with a disability: a systematic review. *Disability and Rehabilitation*, advance online publication.
- Melbye, S., Kessing, L. V., Bardram, J. E., & Faurholt-Jepsen, M. (2020). Smartphone-based selfmonitoring, treatment, and automatically generated data in children, adolescents, and young adults with psychiatric disorders: systematic review. *JMIR Mental Health*, 7(10), e17453e17470.
- Sun, X. (2020). Behavior skills training for family caregivers of people with intellectual or developmental disabilities: a systematic review of literature. *International Journal of Developmental Disabilities*, advance online publication.
- Stiles-Shields, C., Potthoff, L. M., Bounds, D. T., Burns, M. T., Draxler, J. M., Otwell, C. H., ... & Karnik, N. S. (2020). Harnessing phones to target pediatric populations with socially complex needs: Systematic review. *JMIR Pediatrics and Parenting*, 3(2), e19269.
- Yakubova, G., Defayette, M. A., Chen, B. B., & Proulx, A. L. (2021). The Use of Augmented Reality Interventions to Provide Academic Instruction for Children with Autism, Intellectual, and Developmental Disabilities: an Evidence-Based Systematic Review. *Review Journal of Autism* and Developmental Disorders, advance online publication.

#### Exclusion reason: No relevant (useable summary of) outcomes (n = 11)

- Berenguer, C., Baixauli, I., Gómez, S., Andrés, M. D. E. P., & De Stasio, S. (2020). Exploring the impact of augmented reality in children and adolescents with autism spectrum disorder: A systematic review. *International Journal of Environmental Research and Public Health*, 17(17), 6143-6157.
- Boster, J. B., Spitzley, A. M., Castle, T. W., Jewell, A. R., Corso, C. L., & McCarthy, J. W. (2021). Music Improves Social and Participation Outcomes for Individuals With Communication Disorders: A Systematic Review. *Journal of Music Therapy*, 58(1), 12-42.
- Dean, M., & Chang, Y. C. (2021). A systematic review of school-based social skills interventions and observed social outcomes for students with autism spectrum disorder in inclusive settings. *Autism*, 25(7), 1828-1843.
- Hernandez-Ruiz, E. (2021). Parent-mediated music interventions with children with ASD: A systematic review. *Review Journal of Autism and Developmental Disorders*, 8(4), 403-420.
- Holbrook, S., & Israelsen, M. (2020). Speech prosody interventions for persons with Autism Spectrum Disorders: A systematic review. *American Journal of Speech-Language Pathology*, *29*(4), 2189-2205.

- \*Mapes, A. R., & Rosén, L. A. (2016). Equine-assisted therapy for children with autism spectrum disorder: A comprehensive literature review. *Review Journal of Autism and Developmental Disorders*, 3(4), 377-386.
- Marquez-Garcia, A. V., Magnuson, J., Morris, J., Iarocci, G., Doesburg, S., & Moreno, S. (2021). Music Therapy in Autism Spectrum Disorder: a Systematic Review. *Review Journal of Autism and Developmental Disorders*, advance online publication.
- Narzisi, A., Sesso, G., Berloffa, S., Fantozzi, P., Muccio, R., Valente, E., ... & Masi, G. (2021). Could You Give Me the Blue Brick? LEGO<sup>®</sup>-Based Therapy as a Social Development Program for Children with Autism Spectrum Disorder: A Systematic Review. *Brain Sciences*, *11*(6), 702-714.
- Rojas-Torres, L. P., Alonso-Esteban, Y., & Alcantud-Marín, F. (2020). Early Intervention with Parents of Children with Autism Spectrum Disorders: A Review of Programs. *Children*, 7(12), 294-321.
- Salimi, Z., Jenabi, E., & Bashirian, S. (2021). Are Social Robots Ready Yet to be Used in Care and Therapy of Autism Spectrum Disorder: A Systematic Review of Randomized Controlled Trials. *Neuroscience & Biobehavioral Reviews*, *129*, 1-16.
- White, E. N., Ayres, K. M., Snyder, S. K., Cagliani, R. R., & Ledford, J. R. (2021). Augmentative and Alternative Communication and Speech Production for Individuals with ASD: A Systematic Review. *Journal of Autism and Developmental Disorders*, *51*(11), 4199-4212.

#### Exclusion reason: Excluded publication type (n = 10)

- Brock, M. E., Shawbitz, K. N., Anderson, E. J., Criss, C. J., Sun, X., & Alasmari, A. (2021). Recess Should Include Everyone: a Scoping Review of Interventions Designed to Improve Social and Play Outcomes for Elementary Students with Developmental Disabilities at Recess. *Review Journal of Autism and Developmental Disorders*, advance online publication.
- Comas-González, Z., Sánchez-Comas, A., De-La-Hoz-Franco, E., Synnes, K., Sánchez, J. F., & Collazos-Morales, C. (2020, October). Technology Contribution to Improve Autistic Children Life Quality.

In International Conference on Brain Function Assessment in Learning (pp. 176-185). Springer, Cham.

- Correll, C. U., Cortese, S., Croatto, G., Monaco, F., Krinitski, D., Arrondo, G., ... & Solmi, M. (2021). Efficacy and acceptability of pharmacological, psychosocial, and brain stimulation interventions in children and adolescents with mental disorders: an umbrella review. World Psychiatry, 20(2), 244-275.
- Doney, E. (2021). *Animal-Assisted Interventions with Dogs: A Review of the Current Literature* (Doctoral dissertation, Azusa Pacific University).
- Ghumman, U., Conrad, C., Ghumman, M. Z., & Alvarado, C. (2020, October). Review of Randomized Controlled Trials Studying the Benefits of Equine-Assisted Activities and Therapy in Children with Autism Spectrum Disorder. In *2020 Virtual Meeting*. AACAP.
- Lehtimaki, S., Martic, J., Wahl, B., Foster, K. T., & Schwalbe, N. (2021). Evidence on Digital Mental Health Interventions for Adolescents and Young People: Systematic Overview. *JMIR Mental Health, 8*(4), e25847, 1-20.
- Ogourtsova, T., O'Donnell, M., Boychuck, Z., Ahmed, S., Osman, G., & Majnemer, A. (2021). Telerehabilitation for children and youth with brain-based developmental disabilities and their families: Systematic review. *Developmental Medicine and Child Neurology, 63*(SUPPL 3), 9-10.
- Pritzker, E. (2020). *Pragmatic language and behavioral and emotional functioning-a systematic review: Implications for research and interprofessional practice* (Doctoral dissertation, James Madison University).
- Myriam, S., & Valerie, C. (2021). Verbal behavior for school-aged children with autism spectrum disorder: What does the literature say? 65(8), 704.

Zhang, D., Lee, E. K., Mak, E. C., Ho, C. Y., & Wong, S. Y. (2021). Mindfulness-based interventions: an overall review. *British Medical Bulletin*, *138*(1), 41-57.

#### Exclusion reason: No (separate analysis of) relevant age range (n = 11)

- Bailey, B., Bryant, L., & Hemsley, B. (2021). Virtual Reality and Augmented Reality for Children,
   Adolescents, and Adults with Communication Disability and Neurodevelopmental Disorders:
   a Systematic Review. *Review Journal of Autism and Developmental Disorders*, advance online publication.
- Dandil, Y., Smith, K., Kinnaird, E., Toloza, C., & Tchanturia, K. (2020). Cognitive remediation interventions in autism spectrum condition: A systematic review. *Frontiers in Psychiatry*, *11*(722), 1-12.
- Elliott, S. J., Marshall, D., Morley, K., Uphoff, E., Kumar, M., & Meader, N. (2021). Behavioural and cognitive behavioural therapy for obsessive compulsive disorder (OCD) in individuals with autism spectrum disorder (ASD). *Cochrane Database of Systematic Reviews*, *9*, CD013173.
- Garcia, Y., Keller-Collins, A., Andrews, M., Kurumiya, Y., Imlay, K., Umphrey, B., & Foster, E. (2021). Systematic Review of Acceptance and Commitment Therapy in Individuals with Neurodevelopmental Disorders, Caregivers, and Staff. *Behavior Modification*, advance online publication.
- Healy, S., Obrusnikova, I., & Getchell, N. (2021). Fundamental Motor Skill Interventions in Children with Autism Spectrum Disorder: A Systematic Review of the Literature Including a Methodological Quality Assessment. *Research in Autism Spectrum Disorders*, *81*, advance online publication.
- Lian, X., & Sunar, M. S. (2021). Mobile Augmented Reality Technologies for Autism Spectrum Disorder Interventions: A Systematic Literature Review. *Applied Sciences*, *11*(10), 4550-4770.
- Lichtlé, J., Downes, N., Engelberg, A., & Cappe, E. (2020). The effects of parent training programs on the quality of life and stress levels of parents raising a child with autism spectrum disorder: A systematic review of the literature. *Review Journal of Autism and Developmental Disorders*, 7(3), 242-262.
- Mosher, M. A., & Carreon, A. C. (2021). Teaching social skills to students with autism spectrum disorder through augmented, virtual and mixed reality. *Research in Learning Technology*, *29*, 1-22.
- Mosher, M. A., Carreon, A. C., Craig, S. L., & Ruhter, L. C. (2021). Immersive Technology to Teach Social Skills to Students with Autism Spectrum Disorder: a Literature Review. *Review Journal of Autism and Developmental Disorders*, advance online publication.
- Nieforth, L. O., Schwichtenberg, A. J., & O'Haire, M. E. (2021). Animal-Assisted Interventions for Autism Spectrum Disorder: A Systematic Review of the Literature from 2016 to 2020. *Review Journal of Autism and Developmental Disorders*, advance online publication.
- Silva, G. M., Souto, J. J. D. S., Fernandes, T. P., Bolis, I., & Santos, N. A. (2021). Interventions with Serious Games and Entertainment Games in Autism Spectrum Disorder: A Systematic Review. *Developmental Neuropsychology*, 46(7), 463-485.

#### Exclusion reason: No relevant intervention (n = 5)

- Akers, J. S., Davis, T. N., Gerow, S., & Avery, S. (2020). Decreasing motor stereotypy in individuals with autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders*, 77, advance online publication.
- Byrne, G., Ghráda, Á. N., O'Mahony, T., & Brennan, E. (2021). A systematic review of the use of acceptance and commitment therapy in supporting parents. *Psychology and Psychotherapy: Theory, Research and Practice, 94*, 378-407.

- Chua, J. Y. X., & Shorey, S. (2021). The Effect of Mindfulness-Based and Acceptance Commitment Therapy-Based Interventions to Improve the Mental Well-Being Among Parents of Children with Developmental Disabilities: A Systematic Review and Meta-Analysis. *Journal of Autism and Developmental Disorders*, advance online publication.
- Juvin, J., Sadeg, S., Julien-Sweerts, S., & Zebdi, R. (2021). A Systematic Review: Acceptance and Commitment Therapy for the Parents of Children and Adolescents with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *52*, 124–141.
- Osborn, R., Dorstyn, D., Roberts, L., & Kneebone, I. (2021). Mindfulness therapies for improving mental health in parents of children with a developmental disability: a systematic review. *Journal of Developmental and Physical Disabilities*, *33*(3), 373-389.

#### Exclusion reason: No full-text in English (n = 5)

- da Costa Carneiro, A. C., Brassolatti, I. M., Nunes, L. F. S., Damasceno, F. C. A., & Cortez, M. D. (2020). Ensino de Pais via Telessaúde para a Implementação de Procedimentos Baseados em ABA: Uma Revisão de Literatura e Recomendações em Tempos de COVID-19. *Revista Brasileira de Análise do Comportamento, 16*(2), 148-173.
- Jung, S. I., Lim, S., Jo, E., Sim, H. S., Sung, J. E., & Kim, Y. T. (2020). The efficacy of telepractice intervention for children & adolescents with speech, language & hearing impairments: a metaanalysis. *Communication Sciences & Disorders*, 25(4), 976-986.
- Moral Pérez, M. E. D., & López Bouzas, N. (2021). Augmented reality and stimulation of social and communicative abilities in people with ASD: research review. *RED-Revista de Educación a Distancia*, 22(66), 1-13.
- Rojas Torres, L., Alonso Esteban, Y., & Alcantud-Marín, F. (2020). Revisión de evidencias de las técnicas de DIR/Floortime™ para la intervención en niños y niñas con Trastornos del Espectro del Autismo. *Siglo Cero, 51*(2), 7-32
- Shiri, E., Pouratemad, H., Fathabadi, J., & Narimani, M. (2021). Parent-mediated behavioural intervention for treatment behavioural excesses in children with autism spectrum disorder. *Journal of Arak University of Medical Sciences (JAMS), 24*(4), 422-437.

#### Exclusion reason: Did not name all practices and categories (n = 2)

- \*Beaudoin, A. J., Sébire, G., & Couture, M. (2014). Parent training interventions for toddlers with autism spectrum disorder. *Autism Research and Treatment*, 2014, 1-15.
- Musetti, A., Manari, T., Dioni, B., Raffin, C., Bravo, G., Mariani, R., ... & Corsano, P. (2021). Parental Quality of Life and Involvement in Intervention for Children or Adolescents with Autism Spectrum Disorders: A Systematic Review. *Journal of Personalized Medicine*, *11*(9), 894-910.

#### Exclusion reason: No useable combination of practices and categories (n = 3)

- \*Ledbetter-Cho, K., Lang, R., Watkins, L., O'Reilly, M., & Zamora, C. (2017). Systematic review of collateral effects of focused interventions for children with autism spectrum disorder. *Autism & Developmental Language Impairments*, 2, 1-22.
- McDaniel, J., Brady, N. C., & Warren, S. F. (2021). Effectiveness of Responsivity Intervention Strategies on Prelinguistic and Language Outcomes for Children with Autism Spectrum Disorder: A Systematic Review and Meta-Analysis of Group and Single Case Studies. *Journal* of Autism and Developmental Disorders, advance online publication.
- O'Keeffe, C., & McNally, S. (2021). A systematic review of play-based interventions targeting the social communication skills of children with Autism Spectrum Disorder in educational contexts. *Review Journal of Autism and Developmental Disorders*, advance online publication.

#### Articles excluded during extraction with reasons

#### Exclusion reason: No relevant (useable summary of) outcomes (n = 7)

- de Nocker, Y. L., & Toolan, C. K. (2021). Using Telehealth to Provide Interventions for Children with ASD: a Systematic Review. *Review Journal of Autism and Developmental Disorders*, 1-31.
- Ellison, K. S., Guidry, J., Picou, P., Adenuga, P., & Davis, T. E. (2021). Telehealth and autism prior to and in the age of COVID-19: a systematic and critical review of the last decade. *Clinical Child and Family Psychology Review*, 24(3), 599-630.
- Gassner, L., Geretsegger, M., & Mayer-Ferbas, J. (2022). Effectiveness of music therapy for autism spectrum disorder, dementia, depression, insomnia and schizophrenia: update of systematic reviews. *European Journal of Public Health*, *32*(1), 27-34.
- Pacia, C., Holloway, J., Gunning, C., & Lee, H. (2021). A systematic review of family-mediated social communication interventions for young children with autism. *Review Journal of Autism and Developmental Disorders*, advance online publication.
- Pasqualotto, A., Mazzoni, N., Bentenuto, A., Mulè, A., Benso, F., & Venuti, P. (2021). Effects of cognitive training programs on executive function in children and adolescents with Autism Spectrum Disorder: A systematic review. *Brain Sciences*, *11*(10), 1280.
- Short, C. A., & Vital, P. (2021). A Systematic Review of Social Maintenance Behavior Outcomes of Interactive Social Interventions for Children With Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities*, *36*(2), 108-120.
- Valentine, A. Z., Hall, S. S., Young, E., Brown, B. J., Groom, M. J., Hollis, C., & Hall, C. L. (2021).
   Implementation of telehealth services to assess, monitor, and treat neurodevelopmental disorders: Systematic review. *Journal of Medical Internet Research*, 23(1), e22619.

#### Exclusion reason: Publication corresponding to included report (n = 1; excluded during extraction)

Hume, K., Steinbrenner, J. R., Odom, S. L., Morin, K. L., Nowell, S. W., Tomaszewski, B., ... & Savage, M. N. (2021). Evidence-based practices for children, youth, and young adults with autism: Third generation review. *Journal of Autism and Developmental Disorders*, *51*, 4013–4032.

#### Articles excluded from the original umbrella review with reasons (n = 28)

#### Exclusion reason: Final literature search conducted > 10 years ago (n = 6)

- Flippin, M., Reszka, S., & Watson, L. R. (2010). Effectiveness of the picture exchange communication system (PECS) on communication and speech for children with autism spectrum disorders: a meta-analysis. *American Journal of Speech-Language Pathology*, 19(2), 178-195. doi:10.1044/1058-0360(2010/09-0022)
- Lang, R., O'Reilly, M., Healy, O., Rispoli, M., Lydon, H., Streusand, W., . . . Giesbers, S. (2012). Sensory integration therapy for autism spectrum disorders: A systematic review. *Research in Autism Spectrum Disorders, 6*(3), 1004-1018. doi:10.1016/j.rasd.2012.01.006
- Makrygianni, M. K., & Reed, P. (2010). A meta-analytic review of the effectiveness of behavioural early intervention programs for children with autistic spectrum disorders. *Research in Autism Spectrum Disorders*, 4(4), 577-593. doi:10.1016/j.rasd.2010.01.014
- Peters-Scheffer, N., Didden, R., Korzilius, H., & Sturmey, P. (2011). A meta-analytic study on the effectiveness of comprehensive ABA-based early intervention programs for children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 5*(1), 60-69. doi:10.1016/j.rasd.2010.03.011

- Treurnicht Naylor, K., Kingsnorth, S., Lamont, A., McKeever, P., & Macarthur, C. (2011). The effectiveness of music in pediatric healthcare: a systematic review of randomized controlled trials. *Evidence-Based Complementary and Alternative Medicine, 2011*, 464759. doi:10.1155/2011/464759
- Virués-Ortega, J. (2010). Applied behavior analytic intervention for autism in early childhood: Metaanalysis, meta-regression and dose-response meta-analysis of multiple outcomes. *Clinical Psychology Review*, *30*(4), 387-399. doi:10.1016/j.cpr.2010.01.008

#### Exclusion reason: No relevant (useable summary of) outcomes (n = 17)

- Akemoglu, Y., Muharib, R., & Meadan, H. (2020). A systematic and quality review of parentimplemented language and communication interventions conducted via telepractice. *Journal* of Behavioral Education, 29(2), 282-316.
- Boshoff, K., Bowen, H., Paton, H., Cameron-Smith, S., Graetz, S., Young, A., & Lane, K. (2020). Child development outcomes of DIR/Floortime TM-based programs: a systematic review. *Canadian Journal of Occupational Therapy*, 87(2), 153-164. doi:10.1177/0008417419899224
- Chang, Y. C., & Locke, J. (2016). A systematic review of peer-mediated interventions for children with autism spectrum disorder. *Research in Autism Spectrum Disorders, 27*, 1-10. doi:10.1016/j.rasd.2016.03.010
- Hill, J., Ziviani, J., Driscoll, C., & Cawdell-Smith, J. (2019). Can canine-assisted interventions affect the social behaviours of children on the autism spectrum? a systematic review. *Review Journal of Autism and Developmental Disorders*, 6(1), 13-25. doi:10.1007/s40489-018-0151-7
- Knight, V., McKissick, B., & Saunders, A. (2013). A review of technology-based interventions to teach academic skills to students with autism spectrum disorder. *Journal of Autism & Developmental Disorders*, 43(11), 2628-2648. doi:10.1007/s10803-013-1814-y
- Logan, K., Iacono, T., & Trembath, D. (2017). A systematic review of research into aided AAC to increase social-communication functions in children with autism spectrum disorder. *Augmentative & Alternative Communication, 33*(1), 51-64. doi:10.1080/07434618.2016.1267795
- McCoy, A., Holloway, J., Healy, O., Rispoli, M., & Neely, L. (2016). A systematic review and evaluation of video modeling, role-play and computer-based instruction as social skills interventions for children and adolescents with high-functioning autism. *Review Journal of Autism and Developmental Disorders*, *3*(1), 48-67. doi:10.1007/s40489-015-0065-6
- Miguel Cruz, A., R os Rinc n, A. M., Rodr guez Due as, W. R., Quiroga Torres, D. A., & Bohrquez-Heredia, A. F. (2017). What does the literature say about using robots on children with disabilities? *Disability and Rehabilitation: Assistive Technology*, 12(5), 429-440. doi:10.1080/17483107.2017.1318308
- National Autism Center. (2015). Findings and conclusions: National standards project, phase 2. https://www.nationalautismcenter.org/national-standards-project/phase-2/
- Schaaf, R. C., Dumont, R. L., Arbesman, M., & May-Benson, T. A. (2018). Efficacy of occupational therapy using Ayres Sensory Integration: A Systematic Review. *The American Journal of Occupational Therapy*, 72(1), 7201190010p7201190011-7201190010p7201190010. https://dx.doi.org/10.5014/ajot.2018.028431
- Schoen, S. A., Lane, S. J., Mailloux, Z., May-Benson, T., Parham, L. D., Smith Roley, S., & Schaaf,
   R. C. (2019). A systematic review of Ayres Sensory Integration intervention for children with autism. *Autism Research*, 12(1), 6-19. doi:10.1002/aur.2046
- Srinivasan, S. M., Cavagnino, D. T., & Bhat, A. N. (2018). Effects of equine therapy on individuals with autism spectrum disorder: a systematic review. *Review Journal of Autism and Developmental Disorders*, 5(2), 156-175. doi:10.1007/s40489-018-0130-z

Steinbrenner, J. R., Hume, K., Odom, S. L., Morin, K. L., Nowell, S. W., Tomaszewski, B., ... & Savage, M. N. (2020). Evidence-Based Practices for Children, Youth, and Young Adults with Autism. National Clearinghouse on Autism Evidence and Practice. <u>https://ncaep.fpg.unc.edu/sites/ncaep.fpg.unc.edu/files/imce/documents/EBP%20Report%2</u> 02020.pdf

- Waddington, H., van der Meer, L., & Sigafoos, J. (2016). Effectiveness of the Early Start Denver Model: a systematic review. *Review Journal of Autism and Developmental Disorders*, *3*(2), 93-106. doi:10.1007/s40489-015-0068-3
- Watkins, L., Ledbetter-Cho, K., O'Reilly, M., Barnard-Brak, L., & Garcia-Grau, P. (2019). Interventions for students with autism in inclusive settings: A best-evidence synthesis and meta-analysis. *Psychological Bulletin*, *145*(5), 490-507.
- Weitlauf, A. S., Sathe, N., McPheeters, M. L., & Warren, Z. E. (2017). Interventions targeting sensory challenges in autism spectrum disorder: a systematic review. *Pediatrics*, *139*(6), 41-54. doi:10.1542/peds.2017-0347
- Wiese, C., Simpson, R., & Kumar, S. (2016). The effectiveness of equine-based therapy in the treatment of social and behavioural aspects of children with autism spectrum disorder: a systematic review. *Internet Journal of Allied Health Sciences and Practice*, *14*(3), 12.

#### Exclusion reason: Did not name all practices and categories (n = 3)

- Fuller, E. A., & Kaiser, A. P. (2020). The effects of early intervention on social communication outcomes for children with autism spectrum disorder: a meta-analysis. *Journal of Autism* and Developmental Disorders, 50(5), 1683-1700. doi:10.1007/s10803-019-03927-z
- Sandbank, M., Bottema-Beutel, K., Crowley, S., Cassidy, M., Feldman, J. I., Canihuante, M., & Woynaroski, T. (2020). Intervention Effects on Language in Children With Autism: A Project AIM Meta-Analysis. *Journal of speech, language, and hearing research : JSLHR, 63*(5), 1537-1560. doi:10.1044/2020\_JSLHR-19-00167
- Zagona, A. L., & Mastergeorge, A. M. (2018). An empirical review of peer-mediated interventions: implications for young children with autism spectrum disorders. *Focus on Autism & Other Developmental Disabilities*, 33(3), 131-141. doi:10.1177/1088357616671295

#### Exclusion reason: No (separate analysis of) relevant age range (n = 1)

Weston, L., Hodgekins, J., & Langdon, P. E. (2016). Effectiveness of cognitive behavioural therapy with people who have autistic spectrum disorders: A systematic review and meta-analysis. *Clinical Psychology Review*, 49, 41-54. doi:10.1016/j.cpr.2016.08.001

#### Exclusion reason: No relevant design (n = 1)

Case, L., & Yun, J. (2019). The effect of different intervention approaches on gross motor outcomes of children with autism spectrum disorder: a meta-analysis. *Adapted Physical Activity Quarterly*, *36*(4), 501-526. doi:10.1123/apaq.2018-0174

 Appendix 5.7
 Umbrella review - Included articles

# Appendix 5.7 - Umbrella review - Included articles

#### Articles excluded during full-text screening with reasons

\*Indicates an article from the original 2020 umbrella review

- \*Bejarano-Martín, Á., Canal-Bedia, R., Magán-Maganto, M., Fernández-Álvarez, C., Lóa-Jónsdóttir, S., Saemundsen, E., ... & Posada, M. (2020). Efficacy of focused social and communication practices for young children with autism spectrum disorder: A meta-analysis. *Early Childhood Research Quarterly*, *51*, 430-445.
- \*Binns, A. V., & Oram Cardy, J. (2019). Developmental social pragmatic interventions for preschoolers with autism spectrum disorder: A systematic review. *Autism & Developmental Language Impairments, 4*(1), 1-18.
- Crank, J. E., Sandbank, M., Dunham, K., Crowley, S., Bottema-Beutel, K., Feldman, J., & Woynaroski,
   T. G. (2021). Understanding the Effects of Naturalistic Developmental Behavioral Interventions:
   A Project AIM Meta-analysis. *Autism Research*, 14(4), 817-834.
- Deb, S. S., Retzer, A., Roy, M., Acharya, R., Limbu, B., & Roy, A. (2020). The effectiveness of parent training for children with autism spectrum disorder: a systematic review and meta-analyses. *BMC Psychiatry*, 20(1), 1-24.
- Dimolareva, M., & Dunn, T. J. (2021). Animal-assisted interventions for school-aged children with autism spectrum disorder: A meta-analysis. *Journal of Autism and Developmental Disorders*, *51*(7), 2436-2449.
- \*Ferguson, J., Craig, E. A., & Dounavi, K. (2019). Telehealth as a model for providing behaviour analytic interventions to individuals with autism spectrum disorder: a systematic review. *Journal of Autism and Developmental Disorders, 49*(2), 582-616.
- \* Fuller, E. A., Oliver, K., Vejnoska, S. F., & Rogers, S. J. (2020). The effects of the early start Denver model for children with autism spectrum disorder: a meta-analysis. *Brain Sciences*, 10(6), 368-384.
- \*Geretsegger, M., Elefant, C., Mossler, K. A., & Gold, C. (2014). Music therapy for people with autism spectrum disorder. *The Cochrane Database of Systematic Reviews (6),* CD004381.
- \* Griffith, S. F., Hagan, M. B., Heymann, P., Heflin, B. H., & Bagner, D. M. (2020). Apps as learning tools: a systematic review. *Pediatrics*, 145(1), 1-14.
- \* Hampton, L. H., & Kaiser, A. P. (2016). Intervention effects on spoken-language outcomes for children with autism: a systematic review and meta-analysis. *Journal of Intellectual Disability Research*, 60(5), 444-463.
- \*Hardy, K. K., & Weston, R. N. (2020). Canine-assisted therapy for children with autism spectrum disorder: a systematic Review. *Review Journal of Autism and Developmental Disorders, 7*(2), 197-204.
- \*Ho, B. P. V., Stephenson, J., & Carter, M. (2014). Cognitive-behavioral approach for children with autism spectrum disorders: a meta-analysis. *Review Journal of Autism and Developmental Disorders*, 1(1), 18-33.
- Jiménez-Muñoz, L., Peñuelas-Calvo, I., Calvo-Rivera, P., Díaz-Oliván, I., Moreno, M., Baca-García, E., & Porras-Segovia, A. (2021). Video games for the treatment of autism spectrum disorder: A systematic review. *Journal of Autism and Developmental Disorders*, advance online publication.

- \* Kent, C., Cordier, R., Joosten, A., Wilkes-Gillan, S., Bundy, A., & Speyer, R. (2020). A systematic review and meta-analysis of interventions to improve play skills in children with autism spectrum disorder. *Review Journal of Autism and Developmental Disorders*, 7(1), 91-118.
- \* Khan, K., Hall, C. L., Davies, E. B., Hollis, C., & Glazebrook, C. (2019). The effectiveness of web-based interventions delivered to children and young people with neurodevelopmental disorders: systematic review and meta-analysis. *Journal of Medical Internet Research*, *21*(11), e13478.
- Leung, P. W. S., Li, S. X., Tsang, C. S. O., Chow, B. L. C., & Wong, W. C. W. (2021). Effectiveness of using mobile technology to improve cognitive and social skills among individuals with autism spectrum disorder: Systematic literature review. JMIR Mental Health, 8(9), e20892.
- Mayer-Benarous, H., Benarous, X., Vonthron, F., & Cohen, D. (2021). Music therapy for children with autistic spectrum disorder and/or other neurodevelopmental disorders: a systematic review. *Frontiers in Psychiatry*, *12*, 643234.
- \* Mazon, C., Fage, C., & Sauzéon, H. (2019). Effectiveness and usability of technology-based interventions for children and adolescents with ASD: A systematic review of reliability, consistency, generalization and durability related to the effects of intervention. *Computers in Human Behavior, 93*, 235-251.
- \* Moon, S. J., Hwang, J., Hill, H. S., Kervin, R., Birtwell, K. B., Torous, J., . . . Kim, J. W. (2020). Mobile device applications and treatment of autism spectrum disorder: A systematic review and metaanalysis of effectiveness. *Archives of Disease in Childhood, 105*(5), 458-462.
- \* Murza, K. A., Schwartz, J. B., Hahs-Vaughn, D. L., & Nye, C. (2016). Joint attention interventions for children with autism spectrum disorder: a systematic review and meta-analysis. *International Journal of Language & Communication Disorders*, *51*(3), 236-251.
- \* Naveed, S., Waqas, A., Amray, A. N., Memon, R. I., Javed, N., Tahir, M. A., . . . Rahman, A. (2019). Implementation and effectiveness of non-specialist mediated interventions for children with Autism Spectrum Disorder: A systematic review and meta-analysis. *PLoS ONE*, 14(11), e0224362.
- \* Nevill, R. E., Lecavalier, L., & Stratis, E. A. (2018). Meta-analysis of parent-mediated interventions for young children with autism spectrum disorder. *Autism: The International Journal of Research & Practice, 22*(2), 84-98.
- O'Donovan, K. L., Armitage, S., Featherstone, J., McQuillin, L., Longley, S., & Pollard, N. (2019). Groupbased parent training interventions for parents of children with autism Spectrum disorders: A literature review. *Review Journal of Autism and Developmental Disorders, 6*(1), 85-95.
- \* Ona, H. N., Larsen, K., Nordheim, L. V., & Brurberg, K. G. (2020). Effects of pivotal response treatment (PRT) for children with autism spectrum disorders (ASD): a systematic review. *Review Journal of Autism and Developmental Disorders*, 7(1), 78-90.
- \* Oono, I. P., Honey, E. J., & McConachie, H. (2013). Parent-mediated early intervention for young children with autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews (4).*
- \* Parsons, D., Cordier, R., Vaz, S., & Lee, H. C. (2017). Parent-mediated intervention training delivered remotely for children with autism spectrum disorder living outside of urban areas: systematic review. *Journal of Medical Internet Research*, *19*(8), e6651.
- \* Parsons, L., Cordier, R., Munro, N., Joosten, A., & Speyer, R. (2017). A systematic review of pragmatic language interventions for children with autism spectrum disorder. *PLoS ONE*, *12*(4), e0172242.
- Pi, H. J., Kallapiran, K., Munivenkatappa, S., Kandasamy, P., Kirubakaran, R., Russell, P., & Eapen, V.
   (2021). Meta-Analysis of RCTs of Technology-Assisted Parent-Mediated Interventions for Children with ASD. *Journal of Autism and Developmental Disorders*, advance online publication.
- \* Postorino, V., Sharp, W., McCracken, C., Bearss, K., Burrell, T., Evans, A., . . . Evans, A. N. (2017). A systematic review and meta-analysis of parent training for disruptive behavior in children with autism spectrum disorder. *Clinical Child & Family Psychology Review, 20*(4), 391-402.
- \* Reichow, B., Hume, K., Barton, E. E., & Boyd, B. A. (2018). Early intensive behavioral intervention (EIBI)

for young children with autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews* (5). doi:10.1002/14651858.CD009260.pub3

- Rodgers, M., Marshall, D., Simmonds, M., Le Couteur, A., Biswas, M., Wright, K., ... & Hodgson, R. (2020). Interventions based on early intensive applied behaviour analysis for autistic children: a systematic review and cost-effectiveness analysis. *Health Technology Assessment*, 24(35), 1-342.
- \* Sandbank, M., Bottema-Beutel, K., Crowley, S., Cassidy, M., Dunham, K., Feldman, J. I., . . . Woynaroski, T. G. (2020). Project AIM: Autism intervention meta-analysis for studies of young children. *Psychological Bulletin*, 146(1), 1-29.
- Sandgreen, H., Frederiksen, L. H., & Bilenberg, N. (2021). Digital interventions for autism spectrum disorder: a meta-analysis. *Journal of Autism and Developmental Disorders*, *51*(9), 3138-3152.
- Shi, B., Wu, W., Dai, M., Zeng, J., Luo, J., Cai, L., ... & Jing, J. (2021). Cognitive, language, and behavioral outcomes in children with autism spectrum disorders exposed to early comprehensive treatment models: a meta-analysis and meta-regression. *Frontiers in Psychiatry*, *12*, e691148.
- Soares, E. E., Bausback, K., Beard, C. L., Higinbotham, M., Bunge, E. L., & Gengoux, G. W. (2021). Social skills training for autism spectrum disorder: A meta-analysis of in-person and technological interventions. *Journal of Technology in Behavioral Science*, 6(1), 166-180.
- \* Sutherland, R., Trembath, D., & Roberts, J. (2018). Telehealth and autism: A systematic search and review of the literature. *International Journal of Speech-Language Pathology*, *20*(3), 324-336.
- Tachibana, Y., Miyazaki, C., Mikami, M., Ota, E., Mori, R., Hwang, Y., ... & Kamio, Y. (2018). Metaanalyses of individual versus group interventions for pre-school children with autism spectrum disorder (ASD). *PloS ONE*, *13*(5), e0196272.
- Tan-MacNeill, K. M., Smith, I. M., Johnson, S. A., Chorney, J., & Corkum, P. (2021). A systematic review of online parent-implemented interventions for children with neurodevelopmental disorders. *Children's Health Care*, *50*(3), 239-277.
- \* Tarver, J., Palmer, M., Webb, S., Scott, S., Slonims, V., Simonoff, E., & Charman, T. (2019). Child and parent outcomes following parent interventions for child emotional and behavioral problems in autism spectrum disorders: A systematic review and meta-analysis. *Autism*, 23(7), 1630-1644.
- \* Tiede, G., & Walton, K. M. (2019). Meta-analysis of naturalistic developmental behavioral interventions for young children with autism spectrum disorder. *Autism*, 23(8), 2080-2095.
- \* Trzmiel, T., Purandare, B., Michalak, M., Zasadzka, E., & Pawlaczyk, M. (2019). Equine assisted activities and therapies in children with autism spectrum disorder: A systematic review and a meta-analysis. *Complementary Therapies in Medicine*, *42*, 104-113.
- \* Tupou, J., van Der Meer, L., Waddington, H., & Sigafoos, J. (2019). Preschool interventions for children with autism spectrum disorder: A review of effectiveness studies. *Review Journal of Autism and Developmental Disorders*, 6(4), 381-402.
- Valentine, A. Z., Brown, B. J., Groom, M. J., Young, E., Hollis, C., & Hall, C. L. (2020). A systematic review evaluating the implementation of technologies to assess, monitor and treat neurodevelopmental disorders: A map of the current evidence. *Clinical psychology review*, 80, 101870.
- \* Verschuur, R., Didden, R., Lang, R., Sigafoos, J., & Huskens, B. (2014). Pivotal response treatment for children with autism spectrum disorders: A systematic review. *Review Journal of Autism and Developmental Disorders*, 1(1), 34-61.
- Waddington, H., Reynolds, J. E., Macaskill, E., Curtis, S., Taylor, L. J., & Whitehouse, A. J. (2021). The effects of JASPER intervention for children with autism spectrum disorder: A systematic review. *Autism*, *25*(8), 2370-2385.
- Wang, Z., Loh, S. C., Tian, J., & Chen, Q. J. (2020). A meta-analysis of the effect of the early start Denver model in children with autism spectrum disorder. *International Journal of Developmental Disabilities*, advance online publication.

Wang, X., Zhao, J., Huang, S., Chen, S., Zhou, T., Li, Q., ... & Hao, Y. (2021). Cognitive behavioral therapy for autism spectrum disorders: A systematic review. *Pediatrics*, *147*(5), e2020049880.

Zheng, S., Kim, H., Salzman, E., Ankenman, K., & Bent, S. (2021). Improving social knowledge and skills among adolescents with autism: systematic review and meta-analysis of UCLA PEERS<sup>®</sup> for adolescents. *Journal of Autism and Developmental Disorders*, *51*(12), 4488-4503.

Appendix 5.8	Umbrella review - Characteristics of included systematic
Appendix 5.0	reviews

# Appendix 5.8 - Umbrella review - Characteristics of included systematic reviews

Author (year)	Characteristics of Systematic Review	Characteristics of Included Studies
Bejarano-Martín et	Type: Meta-analysis	Participant characteristics
al. (2020)	Objectives: "to ascertain the overall effectiveness of [focused	Number of participating children: 1402 (785 support,
	practices] in children with [autism spectrum disorder] 6 years of	617 comparison)
	age and younger."	Age: $25 - 72$ months, M = 41.6 months
	Number of included studies: 43	<b>Sex</b> : 75 – 91.7% male
	<b>Search limit (years):</b> 2000 – 2018	Description: Autism spectrum disorder (inclusion criteria)
	Locations of included studies: Not specified	Increased likelihood of ASD: Not eligible (inclusion criteria)
	Study designs: Randomised controlled trials, non-randomised	Other conditions: None
	with comparison, single-case experimental designs (inclusion	Support(s): Focused practices - Discrete trial training (DTT); Pivotal
	criteria).	Response Training (PRT), Contingent imitation; discrete trial training
	Quality (systematic review): High (9/11)	(DTT) plus social interaction, mediated learning with active
	Quality appraisal tool (included studies): EBP Update	engagement; picture exchange communication system (PECS); video
	Workgroup Reviewer Training criteria (Wong et al., 2015) of the	modelling; prompting and reinforcement; physical and verbal cues;
	National Professional Development Centre on Autism Spectrum	token economy and prompting; photographic schedules.
	Disorders.	Comparison: Not specified
	Quality (included studies): Included high quality/low risk of	Outcomes: Social-communication (social-communication, imitation,
	bias only.	joint attention, play).
	Sources of funding: Specified - Funded	
	Conflict of interest: Specified - No conflicts	
Binns & Oram	Type: Narrative synthesis	Participant characteristics
Cardy	<b>Objectives:</b> to "systematically review studies examining the	Number of participating children: 716
(2019)	impact of developmental social pragmatic interventions in	Age: 1 year, 3 months - 6 years, $M = 37.8$ months
	supporting (a) foundational social communication and language	Sex: Not specified
	skills of preschool children with autism spectrum disorder and (b)	Description: Autism spectrum disorder
	caregiver interaction style."	Increased likelihood of ASD: Not included
	Number of included studies: 10	Other conditions: None
	Search limit (years): Database inception – 2018	<b>Support(s):</b> Developmental social pragmatic interventions - Child Talk;
	Locations of included studies: Not specified	Hanen More than Words; Developmental Individual-Difference
	Study designs: Randomised controlled trials	Relationship-Based (DIR); Milton and Ethel Harris Research Initiative
	Quality (systematic review): High (9/10)	Treatment (MEHRIT) - DIR based; Pediatric Autism and
	Quality appraisal tool (included studies): Critical Appraisal	Communication Therapy (PACT); Joint attention mediated learning;
	Skills Programme tool (CASP, 2018); Dollaghan's (2007) scale.	Play and Language for Autistic Youngsters (PLAY) project - DIR
	Quality (included studies): Included low quality/high risk of	based; Social communication, emotion regulation, transactional support
	bias.	(SCERTS).

	Sources of funding: Specified - Funded	<b>Comparison:</b> Wait list, treatment as usual, another support.
	Conflict of interest: Specified - No conflicts	Outcomes: Social communication (social interaction and social
		communication);
		Communication (language capacities).
Crank et al. (2021)	Type: Meta-analysis	Participant characteristics
	<b>Objectives:</b> "We examined the quality of evidence supporting	Number of participating children: Not specified
	the effects of Naturalistic Developmental Behavioral	<b>Age:</b> $18.2 - 75.4$ months (M = 39 months)
	Interventions (NBDIs) for facilitating change in young children	Sex: Not specified
	with autism. We also investigated whether effects varied as a	Description: Autism spectrum disorder (inclusion criteria)
	function of specific features of the intervention, samples, and	Increased likelihood of autism: Not specified
	outcomes measured."	Other conditions: Not specified
	Number of included studies: 27	Support(s): Naturalistic developmental behavioural interventions -
	Search limit (years): 1970-2018	Advancing Social Communication and Play (ASAP); Caregiver-based
	Locations of included studies: Not specified	intervention program in community day-care centers; Denver Model;
	Study designs: Randomised controlled trials, non-randomised	Early Social Interaction Project (SCERTS); Early Start Denver Mode
	with comparison	(ESDM); Home-based Building Blocks Program; home-based
	Quality (systematic review): Low (8/11)	intervention program; ImPACT Online; Interpersonal Synchrony; Joint
	Quality appraisal tool (included studies): Quality indicators,	Attention Intervention; Joint Attention Symbolic Play Engagement
	including their risk of selection bias, detection bias, and attrition	Regulation (JASPER); Joint Engagement Intervention; Joint
	bias, as well as their proximity to intervention targets, their	Engagement Intervention with Creative Movement Therapy; Parent-
	boundedness to the context of intervention, and their risk of	Early Start Denver Model (P-ESDM); Parent-training intervention;
	parent/teacher training CME.	Pivotal Response Treatment (PRT); Reciprocal Imitation Training;
	Quality (included studies): Not specified	Social ABCs Cognitive behaviour therapy (CBT).
	Sources of funding: Not specified	Comparison: Not specified
	Conflict of interest: Not specified	Outcomes: General outcomes.
Deb et al. (2020)	Type: Meta-analysis	Participant characteristics
	<b>Objectives:</b> "We carried out a systematic review and meta-	Number of participating children: 975
	analyses to assess effectiveness of parental training for children	Age: 20 months $-10$ years
	with autism on their symptoms and parental stress."	Sex: $M = 84\%$ male
	Number of included studies: 17	Description: Autism spectrum disorder
	Search limit (years): Database inception – 2020	Increased likelihood of autism: Not included
	Locations of included studies: Not specified	Other conditions: Co-occurring sleep difficulties, cognitive
	Study designs: Randomised controlled trials	impairment
	Quality (systematic review): High (9/11)	Support(s): Parent-mediated support - Social pragmatic joint attention
	Quality appraisal tool (included studies): Cochrane Risk of	parent training; Pivotal Response Treatment; Developmental,
	Bias (RoB)	Individualised, Relationship oriented DIR/Floor Time intervention;
	Quality (included studies): Not specified	parent focussed training; Early start denver model (ESDM); Parent
	Contraction of the second se	r
	Sources of funding: Specified - Funded	education and behaviour management (PEBM) training; Sleep study

Dimolareva & Dunn (2021)	Type: Meta-analysis Objectives: "The current meta-analysis assesses the effectiveness of Animal Assisted Interventions (AAIs) on social interaction, communication and global autism symptoms." Number of included studies: 16 Search limit (years): Database inception – 2020 Locations of included studies: Not specified Study designs: Non-randomised without comparison, other designs not specified Quality (systematic review): Low (8/11) Quality appraisal tool (included studies): Cochrane collaboration tool for assessing risk of bias (Higgins and Green 2014). Quality (included studies): Not specified Sources of funding: Not specified Conflict of interest: Not specified	Training to manage behaviours; generic parent training; Autism Preschool Programme. Comparison: Wait list, treatment as usual, another support Outcomes: General outcomes (treatment effect). Participant characteristics Number of participating children: 489 Age: 4 – 18 years (inclusion criteria) Sex: Not specified Description: Autism spectrum disorder Increased likelihood of autism: Not included Other conditions: Not specified Support(s): Equine therapy Comparison: Wait list, treatment as usual, another support, no comparison Outcomes: Overall autism characteristics (global measures of ASD); Social-communication (social interaction); Language (communication).
Ferguson et al. (2019)	<ul> <li>Type: Narrative synthesis</li> <li>Objectives: "to systematically review the literature researching telehealth and [applied behaviour analysis to individuals with autism spectrum disorder]."</li> <li>Number of included studies: 28</li> <li>Search limit (years): Not specified – 2018</li> <li>Locations of included studies: Not specified</li> <li>Study designs: Randomised controlled trials, non-randomised with comparison, non-randomised without comparison, single-case experimental designs, other</li> <li>Quality (systematic review): High (9/10)</li> <li>Quality appraisal tool (included studies): Evaluative method for evaluating and determining evidence-based practices in autism (Reichow et al., 2008).</li> <li>Quality (included studies): Included low quality/high risk of bias</li> <li>Sources of funding: Specified – Funded</li> <li>Conflict of interest: Specified – No conflicts</li> </ul>	Participant characteristics         Number of participating children: 307 (231 support, 76 comparison)         Age: 1.75 - 16 years, M = 4.73 years (of studies reporting age)         Sex: Not specified         Description: Autism spectrum disorder, pervasive         developmental disorder not otherwise specified         Increased likelihood of ASD: Not included         Other conditions: None         Support(s): Telehealth interventions with behavioural principle -         functional analysis (FA); functional communication training (FCT);         naturalistic and incidental teaching; behaviour support strategies (e.g.,         positive behaviour support); preference assessments; Early Start Denver         Model (ESDM); Improving Parents as Communication Teachers         (imPACT).         Comparison: Wait list, treatment as usual, another support, the         individual's own baseline, no comparison group         Outcomes: General outcomes (efficacy outcomes).

Fuller et al. (2020)	Type: Meta-analysis	Participant characteristics
1 miler et mi (2020)	<b>Objectives:</b> to examine "the effects of the Early Start Denver	Number of participating children: 640 (286 support, 354
	Model (ESDM) for young children with autism on developmental	comparison)
	outcome measures."	Age: 9 months $-5$ years, M = 2.51 years
	Number of included studies: 12	Sex: $65.63 - 100\%$ male, M = $80.6\%$ male
	Search limit (years): Not specified – 2019	<b>Description:</b> Autism spectrum disorder (inclusion criteria)
	<b>Locations of included studies:</b> Asia, Australia, Europe, North	<b>Increased likelihood of ASD:</b> Eligible (inclusion criteria)
	America	Other conditions: None
	Study designs: Randomised controlled trials, non-randomised	Support(s): Early Start Denver Model (ESDM).
	with comparison	<b>Comparison:</b> Wait list, treatment as usual, another support
	Quality (systematic review): High (10/11)	<b>Outcomes:</b> General outcomes (child outcomes); overall autism
	Quality appraisal tool (included studies): Study quality	characteristics (autism symptoms); Social-communication; Restricted
	indicators (random assignment, use of assessors who were blind	and repetitive interests and behaviours (repetitive behaviours);
	or naïve of the group assignment). Measurement–quality	Communication (language); Cognitive development; Adaptive
	variables were coded based on Sandbank et al. (2020).	behaviour (adaptive functioning).
	Quality (included studies): Not specified	ochaviour (adaptive functioning).
	Sources of funding: Specified – Funded	
	<b>Conflict of interest:</b> Specified – Conflicts	
Geretsegger et al.	Type: Meta-analysis	Participant characteristics
(2014)	<b>Objectives:</b> "to review the effects of music therapy, or music	Number of participating children: 165
(2011)	therapy added to standard care, for individuals with [autism	Age: 2 – 12 years
	spectrum disorder]."	Sex: 80 – 100%
	Number of included studies: 10	<b>Description:</b> Autism spectrum disorder
	Search limit (years): Database inception – 2013	Increased likelihood of ASD: Not included
	Locations of included studies: Australia, South	Other conditions: None
	America/Caribbean, North America	Support(s): Music therapy.
	Study designs: Randomised controlled trials, non-randomised	<b>Comparison:</b> Treatment as usual, another support, other comparison
	with comparison (inclusion criteria)	group
	Quality (systematic review): High (11/11)	<b>Outcomes:</b> Social-communication (social adaptation); Communication
	Quality appraisal tool (included studies): Cochrane risk of bias	(non-verbal, verbal); Caregiver social emotional wellbeing (quality of
	tool (Higgins, 2011).	family relationships).
	Quality (included studies): Not specified	ranny relationships).
	Sources of funding: Specified – Funded	
	<b>Conflict of interest:</b> Specified – No conflicts	
Griffith et al.	Type: Narrative synthesis	Participant characteristics
(2020)	<b>Objectives:</b> to "present a narrative synthesis of studies	Number of participating children: 4639 (164 ASD)
(2020)	examining whether children < 6 years can learn from interactive	Age range (mean age): 0 - 71 months (inclusion criteria)
	apps."	Sex: $40 - 90\%$ male
	Number of included studies: 35 (3 autism-specific)	<b>Description:</b> Autism spectrum disorder
	Search limit (years): 2008 – 2019	Description. Autom spectrum disorder
	Scarch mint (years): 2000 – 2019	I

	Locations of included studies: Asia, Australia, Europe, North America Study designs: Randomised controlled trials, non-randomised with comparison Quality (systematic review): High (8/10) Quality appraisal tool (included studies): Adapted Cochrane risk of bias tool. Quality (included studies): Included low quality/high risk of bias Sources of funding: Specified – Not funded Conflict of interest: Specified – No conflicts	Increased likelihood of ASD: Not included Other conditions: Not specified Support(s): Interactive apps. Comparison: Treatment as usual, another support Outcomes: Social-communication.
Hampton & Kaiser (2016)	<ul> <li>Type: Meta-analysis</li> <li>Objectives: to examine "the effects of early interventions on spoken language in children with [autism spectrum disorder]."</li> <li>Number of included studies: 26</li> <li>Search limit (years): Not specified – 2014</li> <li>Locations of included studies: Australia, Europe, North America</li> <li>Study designs: Randomised controlled trials, non-randomised with comparison</li> <li>Quality (systematic review): High (10/11)</li> <li>Quality appraisal tool (included studies): Cochrane</li> <li>Collaboration (Higgins et al., 2011).</li> <li>Quality (included studies): Included low quality/high risk of bias</li> <li>Sources of funding: Not specified</li> <li>Conflict of interest: Not specified</li> </ul>	<ul> <li>Participant characteristics         <ul> <li>Number of participating children: 1738</li> <li>Age: 1.75 – 4.18 years, M = 3.33 years</li> <li>Sex: 69 – 91% male</li> <li>Description: Autism spectrum disorder</li> <li>Increased likelihood of ASD: Not included</li> <li>Other conditions: None</li> </ul> </li> <li>Support(s): Early interventions - Early Intensive Behavioural</li> <li>Intervention (EIBI); Early Intervention Preschool (EIP); Early Start</li> <li>Denver Model (ESDM); Joint Attention Mediated Learning (JAML);</li> <li>Joint Attention; Structured Play Engagement; and Regulation (JAML);</li> <li>Learning Experiences and Alternative Program (LEAP); Milton and</li> <li>Ethel Harris Research Initiative Treatment (MEHRIT); More Than</li> <li>Words (MTW); Pediatric Autism and Communication Therapy (PACT);</li> <li>Play and Language for Autistic Youngsters; PRT, Pivotal Response</li> <li>Training (Play and Language for Autistic Youngsters); Treatment and</li> <li>Education of Autistic and Related Communication Handicapped</li> <li>Children (TEACCH); Scottish Early Intervention Preschool; Parent</li> <li>training model (PSwA); Focused playtime (FPI); Speech remediation;</li> <li>Teach Town basics; Early Social Interaction (ESI); Parent training,</li> <li>Behaviour analytic.</li> <li>Comparison: Not specified</li> <li>Outcomes: Expressive language (spoken language).</li> </ul>
Hardy & Weston (2020)	Type: Narrative synthesis Objectives: to examine "the current state of literature on canine- assisted therapy (CAT) for children with [autism spectrum disorder] based on peer-reviewed articles." Number of included studies: 5 Search limit (years): Not specified – 2017	Participant characteristics         Number of participating children: 66         Age: 3 – 14 years         Sex: 66.7 - 87.5% male         Description: Autism spectrum disorder         Increased likelihood of ASD: Not included

	Locations of included studies: Not specified Study designs: Not specified Quality (systematic review): Low (6/10) Quality appraisal tool (included studies): Adapted from Jarde et al. (2013). Quality (included studies): Not specified Sources of funding: Not specified Conflict of interest: Specified – No conflicts	Other conditions: None Support(s): Canine-assisted therapy. Comparison: Not specified Outcomes: Social-communication (social behaviour).
Ho et al. (2014)	Type: Meta-analysis Objectives: to examine "studies reporting on randomised controlled trials of the use of cognitive-behavioural approaches to intervention for children with autism spectrum disorder." Number of included studies: 10 Search limit (years): Not specified – 2012 Locations of included studies: Not specified Study designs: Randomised controlled trials Quality (systematic review): Low (7/11) Quality appraisal tool (included studies): Gersten et al. (2005). Quality (included studies): Not specified Sources of funding: Not specified Conflict of interest: Not specified	Participant characteristics         Number of participating children: 402 (199/372 completed support, 173/372 comparison)         Age: 4.5 – 16 years, M = 10.5 years         Sex: Not specified         Description: Asperger's syndrome, high functioning autistic disorder/autism spectrum disorder, pervasive developmental disorder not otherwise specified, portion of sample without sub-type diagnoses specified         Increased likelihood of ASD: Not included         Other conditions: None         Support(s): Cognitive behavioural intervention - Cool Kids; Building Confidence Family Cognitive Behaviour Therapy (FCBT); Social Skills Training for Children and Adolescents with Asperger Syndrome and Social-Communications Problems; Thinking about you, thinking about me; Coping Cat CBT program; Facing your fears; Group Cognitive Behaviour Therapy (CBT).         Comparison: Not specified         Outcomes: Social-communication (social skills).
Jiménez-Muñoz et al. (2022)	Type: Narrative synthesis Objectives: "The aim of the present study is to systematically review the evidence about the use of video games as therapeutic tools in children diagnosed with ASD." Number of included studies: 24 Locations of included studies: Asia, Australia, Europe, South America/Caribbean, North America Search limit (years): Database inception - 2021 Study designs: Randomised controlled trial, non-randomised with comparison non-randomised without comparison, other study designs. Quality (systematic review): Low (7/10) Quality appraisal tool (included studies): Cochrane	Participant characteristics         Number of participating children: 803         Age: M = 6.8 – 17.7 years         Sex: 60 – 100% male         Description: Autism spectrum disorder, Asperger syndrome         Increased likelihood of autism: Not included         Other conditions: Attention deficit hyperactivity disorder, other conditions not specified.         Support(s): Video games.         Comparison: Treatment as usual, another support, no comparison, other comparisons not specified         Outcomes: General outcomes (main findings).

	Collaboration's tool for assessing risk of bias. Quality (included studies): Not specified Sources of funding: Specified - Funded Conflict of interest: Specified – No conflicts	
Kent et al. (2020)	Type: Meta-analysis Objectives: to examine "the efficacy of play-based interventions to address the play skills of children with [autism spectrum disorder] [and] to summarize key characteristics of a range of play-based interventions for children with [autism spectrum disorder] and assess the quality of published [randomised controlled trials]." Number of included studies: 19 narrative synthesis; 11 meta- analysis Search limit (years): Not specified – 2017 Locations of included studies: Not specified Study designs: Randomised controlled trials Quality (systematic review): High (10/11) Quality appraisal tool (included studies): The QualSyst critical appraisal tool (Kmet et al., 2004). Quality (included studies): Included moderate quality/moderate risk of bias Sources of funding: Specified – Funded Conflict of interest: Specified – No conflicts	Participant characteristics         Number of participating children: 1149         Age: 2 – 12 years         Sex: Not specified         Description: Autism spectrum disorder         Increased likelihood of ASD: Not included         Other conditions: None         Support(s): Play-based interventions - [Generic] play intervention;         Joint Attention, Symbolic Play, Engagement, and Regulation (JASPER);         Lego therapy; Social stories; behavioural approaches; peer training;         teacher training; Social Emotional NeuroScience Endocrinology         (SENSE) Theater principles; video modelling.         Comparison: Wait list, another support         Outcomes: Play.
Khan et al. (2019)	Type: Meta-analysis Objectives: "to review the effectiveness of randomized controlled trials (RCTs) of Web-based interventions delivered to children and young people with neurodevelopmental disorders." Number of included studies: 10 narrative review (5 autism- specific); 5 meta-analysis (3 autism-specific) Search limit (years): 2000 – 2018	Participant characteristicsNumber of participating children: 523 in analysis (545 in review, of which 289 were diagnosed with ASD)Age: 2 - 17 years, M range= 3.32 - 12.16 yearsSex: 62.5 - 94% maleDescription: Autism spectrum disorder Increased likelihood of ASD: Not included

	Locations of included studies: Australia, Europe, South	Other conditions: Tic disorders or chronic tic disorders,
	America/Caribbean, North America	attention
	Study designs: Randomised controlled trials	deficit hyperactivity disorder, specific learning disorder,
	Quality (systematic review): High (9/11)	dyscalculia
	Quality appraisal tool (included studies): Joanna Briggs	Support(s): Web-based interventions - apps; serious games;
	Institute Critical Appraisal Checklist for RCTs.	videoconferencing; virtual environment with playable games; Web-
	Quality (included studies): Included moderate quality/moderate	based cognitive behavioural therapy (CBT) intervention.
	risk of bias	Comparison: Wait list, treatment as usual, another support
	Sources of funding: Specified – Funded	Outcomes: General outcomes (condition-specific outcomes or reducing
	Conflict of interest: Specified – No conflicts	comorbid psychological symptoms).
Leung et al. (2021)	Type: Narrative synthesis	Participant characteristics
6 ( )	Objectives: "The objective of this review was to evaluate	Number of participating children: Not specified
	previous evidence, obtained in randomized controlled trials	Age: Not specified
	(RCTs), on the effectiveness of using mobile devices as the	Sex: Not specified
	medium of intervention targeting social and cognitive skills	Description: Autism spectrum disorder
	among individuals with ASD."	Increased likelihood of autism: Not included
	Number of included studies: 10	Other conditions: Not specified
	<b>Search limit (years):</b> 2000 – 2019	Support(s): Mobile technology.
	Locations of included studies: Not specified	<b>Comparison:</b> Wait list, treatment as usual, another support
	Study designs: Randomised controlled trials	Outcomes: General outcomes (effectiveness).
	Quality (systematic review): Low (7/10)	
	Quality appraisal tool (included studies): Cochrane risk of bias	
	tool	
	Quality (included studies): Not specified	
	Sources of funding: Not specified	
	Conflict of interest: Specified – No conflicts	
Mayer-Benarous et	Type: Narrative synthesis	Participant characteristics
al. (2021)	<b>Objectives:</b> "We aimed to review the evidence examining the	Number of participating children: Not specified
	use of music therapy in youths with ASD and/or other NDDs."	Age: $1-20$ years
	Number of included studies: 39 (22 autism specific)	
		Sex: Not specified
		Sex: Not specified Description: Autism spectrum disorder
	<b>Search limit (years):</b> 1970 – 2020	Description: Autism spectrum disorder
	Search limit (years): 1970 – 2020 Locations of included studies: Not specified	<b>Description:</b> Autism spectrum disorder <b>Increased likelihood of autism:</b> Not included
	Search limit (years): 1970 – 2020 Locations of included studies: Not specified Study designs: Randomised controlled trial, non-randomised	<b>Description:</b> Autism spectrum disorder <b>Increased likelihood of autism:</b> Not included <b>Other conditions:</b> Attention deficit hyperactivity disorder,
	Search limit (years): 1970 – 2020 Locations of included studies: Not specified Study designs: Randomised controlled trial, non-randomised with comparison, non-randomised without comparison, other	<b>Description:</b> Autism spectrum disorder <b>Increased likelihood of autism:</b> Not included <b>Other conditions:</b> Attention deficit hyperactivity disorder, anxiety, language delay, minimally verbal, cognitive
	Search limit (years): 1970 – 2020 Locations of included studies: Not specified Study designs: Randomised controlled trial, non-randomised with comparison, non-randomised without comparison, other study designs	<b>Description:</b> Autism spectrum disorder <b>Increased likelihood of autism:</b> Not included <b>Other conditions:</b> Attention deficit hyperactivity disorder, anxiety, language delay, minimally verbal, cognitive impairment, global developmental delay, dyslexia, severe and
	Search limit (years): 1970 – 2020 Locations of included studies: Not specified Study designs: Randomised controlled trial, non-randomised with comparison, non-randomised without comparison, other study designs Quality (systematic review): High (8/10)	<b>Description:</b> Autism spectrum disorder <b>Increased likelihood of autism:</b> Not included <b>Other conditions:</b> Attention deficit hyperactivity disorder, anxiety, language delay, minimally verbal, cognitive impairment, global developmental delay, dyslexia, severe and multiple disabilities, sensory impairment and neurological
	Search limit (years): 1970 – 2020 Locations of included studies: Not specified Study designs: Randomised controlled trial, non-randomised with comparison, non-randomised without comparison, other study designs Quality (systematic review): High (8/10) Quality appraisal tool (included studies): Risk of Bias In Non	<b>Description:</b> Autism spectrum disorder <b>Increased likelihood of autism:</b> Not included <b>Other conditions:</b> Attention deficit hyperactivity disorder, anxiety, language delay, minimally verbal, cognitive impairment, global developmental delay, dyslexia, severe and multiple disabilities, sensory impairment and neurological disorders, specific learning disorders/disabilities, emotional
	Search limit (years): 1970 – 2020 Locations of included studies: Not specified Study designs: Randomised controlled trial, non-randomised with comparison, non-randomised without comparison, other study designs Quality (systematic review): High (8/10)	<b>Description:</b> Autism spectrum disorder <b>Increased likelihood of autism:</b> Not included <b>Other conditions:</b> Attention deficit hyperactivity disorder, anxiety, language delay, minimally verbal, cognitive impairment, global developmental delay, dyslexia, severe and multiple disabilities, sensory impairment and neurological

	bias.	comparison
	Sources of funding: Specified - Funded	Outcomes: Social-communication (joint attention).
	Conflict of interest: Specified – No conflicts	
Mazon et al.	Type: Narrative synthesis	Participant characteristics
(2019)	<b>Objectives:</b> "to update the previous [reviews of technology-	<b>Number of participating children:</b> 796 (576 with ASD)
	based interventions] with a focus on clinical-quality studies; to	<b>Age:</b> 3 – 18 years
	examine reliability, consistency, durability and generalisation of	Sex: $M = 82\%$ male
	measurements; and to compare the methodology of two cores of	Description: Autism spectrum disorder
	studies according to two dimensions: Therapeutic Effectiveness	Increased likelihood of ASD: Not included
	(TE) and Technology Usability (TU)."	Other conditions: Down Syndrome, Speech and Language
	Number of included studies: 31	impairment (also included typically developing children)
	Search limit (years): 2000 – 2016	Support(s): Technology based interventions including (but not limited
	Locations of included studies: Not specified	to) computer and robot-based interventions.
	Study designs: Randomised controlled trials, non-randomised	Comparison: Not specified
	with comparison	Outcomes: General outcomes (statistical significance).
	Quality (systematic review): Low (6/10)	
	Quality appraisal tool (included studies): SIGN ratings for	
	levels of evidence (SIGN, 2008); Jadad Score for methodological	
	quality (Jadad et al., 1996).	
	Quality (included studies): Not specified	
	Sources of funding: Specified – Funded	
	Conflict of interest: Specified – No conflicts	
Moon et al. (2020)	Type: Meta-analysis	Participant characteristics
	<b>Objectives:</b> "to assess the evidence for effects of therapeutic	Number of participating children: 328
	intervention with mobile device applications (apps) for	<b>Age:</b> 39 – 120 months
	individuals with autism spectrum disorder (ASD)."	Sex: Not specified
	Number of included studies: 7	<b>Description:</b> Autism spectrum disorder (inclusion criteria)
	Search limit (years): 2009 – 2019	Increased likelihood of ASD: Not eligible (inclusion criteria)
	Study designs: Randomised controlled trials	Other conditions: None
	Locations of included studies: Australia, Europe, North	<b>Support(s):</b> Mobile device applications - including (but not limited to)
	America	FindMe game app, Therapy Outcomes By You (TOBY), Camp
	Quality (systematic review): Cochrane risk of bias (RoB)-2	Discovery.
	tool.	<b>Comparison:</b> Wait list, treatment as usual, other comparison group
	Quality appraisal tool (included studies): High (10/11)	Outcomes: Social-communication; Communication (gestures,
	Quality (included studies): Included low quality/high risk of	symbolic); Expressive language (expressive language, words produced);
	bias	Receptive language; Cognitive development (visual reception); Motor
	Sources of funding: Specified – Not funded	(fine motor).
	Conflict of interest: Specified – No conflicts	
Murza et al. (2016)	Type: Meta-analysis	Participant characteristics
. ,	<b>Objectives:</b> "to provide a quantitative assessment of the	Number of participating children: 694 (410 support; 284

	effectiveness of joint attention interventions aimed at improving joint attention abilities in children with [autism spectrum]	comparison) Age: $11 - 152$ months, M = 55 months
	disorder]."	Sex: Not specified
	Number of included studies: 16 narrative synthesis, 12 meta-	<b>Description:</b> Autism spectrum disorder
	analysis	<b>Increased likelihood of ASD:</b> Not eligible (inclusion criteria)
	Search limit (years): Database inception – 2015	Other conditions: None
	Locations of included studies: Not specified	Support(s): Joint attention interventions - Assessment, Evaluation and
	Study designs: Randomised controlled trials (inclusion criteria)	Programming System (AEPS) for Infants and Children; Caregiver
	Quality (systematic review): High (9/11)	Education Model (CEM); Caregiver Mediated Model (CMM); Hanen
	Quality appraisal tool (included studies): Cochrane	More Than Words (HMTW); Joint Attention Mediated Learning
	Collaboration's Tool for Assessing Risk of Bias (Higgins et al.,	(JAML); Joint Attention Symbolic Play Engagement and Regulation
	2011).	(JASPER); Milton and Ethel Harris Research Initiative (MEHRI);
	Quality (included studies): Included low quality/high risk of	Preschool Autism Communication Trial (PACT); parent training
	bias	modules; and workshop training.
	Sources of funding: Not specified	Comparison: Not specified
	Conflict of interest: Specified – No conflicts	Outcomes: Social-communication (joint attention).
Naveed et al.	Type: Meta-analysis	Participant Characteristics
(2019)	Objectives: to "a) assess the effectiveness of non-specialist	Number of participating children: Not specified
	delivered or mediated interventions in autism spectrum disorder	Age: 16 months – 17 years
	(ASD); b) systematically evaluate relevant implementation	Sex: Not specified
	processes involved in these non-specialists	Description: autism spectrum disorder, Asperger's syndrome,
	delivered interventions for autism spectrum disorder, and c) and	childhood disintegrative disorder (inclusion criteria)
	to rate the quality of evidence across different outcomes using	Increased likelihood of ASD: Not included
	the World Health Organization's recommended Grading of	Other conditions: None
	Recommendations	Support(s): Cognitive behavioural strategies (CBT); Social emotional
	Assessment, Development and Evaluation (GRADE) criteria."	NeuroScience Endocrinology (SENSE) theatre; Preschool Autism
	Number of included studies: 33	Communication Trial (PACT); Parent mediated intervention for Autism
	Search limit (years): Database inception - 2018	Spectrum Disorders in South Asia (PASS); Project Impact; Peer
	Locations of included studies: Asia, Australia, Europe, North	interventions; Qigong
	America	Sensory Treatment (QST); Qigong massage; Joint Attention, Symbolic
	Study designs: Randomised controlled trials	Play, Engagement, and Regulation programme (JASPER); Play project;
	Quality (systematic review): High (9/11)	LEAP project i.e. Learning Experiences and Alternative Program
	Quality appraisal tool (included studies): Cochrane	for Preschoolers and Their Parents; Hanen's more than
	Collaboration tool for randomized controlled trials (Higgins et	words (HMTW) intervention program; Peer network intervention
	al., 2011).	procedure; family centered music therapy; The Managing Repetitive
	<b>Quality (included studies):</b> Included low quality/high risk of bias	Behaviours Programme; psychoeducation program; autism preschool
	Sources of funding: Specified – Not funded	program; Video-feedback Intervention to promote Positive Parenting
	<b>Conflict of interest:</b> Specified – No conflicts	adapted for Autism; Social ABCs; Parent mediated intervention for
		Autism Spectrum Disorders in South Asia (PASS) plus; enhancing

		interactions tutorial; Social Tools And Rules for Teens socialization (START); COMPASS for Hope; Program for the Education and Enrichment of Relational Skills (PEERS) curriculum; Therapeutic Out- come By You (TOBY) application. <b>Comparison:</b> Not specified <b>Outcomes:</b> General outcomes; overall autism characteristics (autism symptom severity); social-communication (social skills, joint engagement, joint attention); Restricted and repetitive interests and behaviours (repetitive behaviours); Communication; Expressive language; Receptive language; Cognitive developement (visual reception); Motor (motor skills); Social emotional/challenging behaviour (self-regulation); Adaptive behaviour; Caregiver social emotional wellbeing (parent distress, parental self-efficacy, parent-child relationship); Child satisfaction (child distress).
Nevill et al. (2018)	Type: Meta-analysis Objectives: to review "randomised clinical trials of parent- mediated interventions for children with autism spectrum disorder between the ages of 1 and 6 years and [conduct] a meta-analysis on their efficacy." Number of included studies: 19 Search limit (years): 2000 – 2015 Locations of included studies: Asia, Australia, Europe, North America Study designs: Randomised controlled trials Quality (systematic review): Low (7/11) Quality appraisal tool (included studies): Grading of Recommendations Assessment, Development and Evaluation (Guyatt et al., 2011). Quality (included studies): Not specified Sources of funding: Specified – Not funded Conflict of interest: Not specified	Participant CharacteristicsNumber of participating children: 1205 (608 support, 597 comparison)Age: 15 – 72 months, M = 42 monthsSex: Not specifiedDescription: Autism spectrum disorder Increased likelihood of ASD: Not included Other conditions: NoneSupport(s): Parent-mediated interventions - Child's Talk Project; Hanen's More than Words (HMTW); DIR/Floortime; Parent Focus Training; Joint Attention Symbolic Play Engagement and Regulation (JASPER); Pivotal Response Training (PRT); Video Intervention to promote Positive Parenting for children with Autism (VIPP-AUTI); Home-based program; Building Blocks; Focused Playtime Intervention; Play and Language for Autistic Youngsters (PLAY) Project; Preschoolers with Autism; Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH); Social Communication, Emotion Regulation, and Transactional Supports (SCERTS); Parent-mediated Communication- focused Treatment (PACT).Comparison: Treatment as usual, another support Outcomes: Overall autism characteristics (autism symptom severity); Social-communication (socialisation); Communication (language); Cognitive developement.
O'Donovan et al.,	Type: Narrative synthesis	Participant characteristics
2019	<b>Objectives:</b> "This literature review examines the existing	Number of participating children: Not specified

	evidence for group-based parent training interventions that support parents of children with autism." Number of included studies: 13 Search limit (years): Database inception – 2016 Locations of included studies: Not specified Study designs: Randomised controlled trial, non-randomised with comparison, non-randomised without comparison, other study designs Quality (systematic review): Low (6/10) Quality appraisal tool (included studies): The Scientific Merit Rating Scale (SMRS) (Green et al. 2009). Quality (included studies): Included low quality/high risk of	Age: 3 – 18 years (inclusion criteria)         Sex: Not specified         Description: Autism         Increased likelihood of autism: Not included (inclusion criteria)         Other conditions: Sleep issues, other conditions not specified         Support(s): Group-based parent training interventions - The National         Autistic Society (NAS) EarlyBird and EarlyBird Plus Programme         (EBPP); 'Understanding autism and understanding my child with         autism' (UA); TEACCH-based; Incredible Years; Generic support         group; Parent management training (PMT); Sleep education workshops;         'Riding the Rapids: Living with Autism or Disability'; Psychoeducation
	bias Sources of funding: Not specified Conflict of interest: Specified - No conflicts	groups; 'Riding the Rapids: Living with Autism or Disability'; Parent Education and Behaviour Management (PEBM). <b>Comparison:</b> Wait list, treatment as usual, another support, no comparison <b>Outcomes:</b> Social emotional/ challenging behaviour (problematic behaviours); Caregiver communication and interaction (parental skills).
Ona et al. (2020)	Type: Meta-analysis Objectives: "to compile evidence examining the effectiveness of [pivotal response treatment] (PRT) on social communication, social interaction, and repetitive behaviour for children with autism spectrum disorder." Number of included studies: 5 Search limit (years): Database inception - 2017 Study designs: Randomised controlled trials Locations of included studies: Not specified Quality (systematic review): Low (8/11) Quality appraisal tool (included studies): Modified version of the guidelines from the Cochrane Consumers and Communication Review Group (Ryan et al., 2007). Quality (included studies): Included low quality/high risk of bias Sources of funding: Not specified Conflict of interest: Specified – No conflicts	Participant Characteristics         Number of participating children: 181 (91 support, 90 comparison)         Age: 2.4 - 9.2 years, M = 5.3 years         Sex: Not specified         Description: Autism spectrum disorder         Increased likelihood of ASD: Not included         Other conditions: None         Support(s): Pivotal Response Treatment (PRT).         Comparison: Wait list, treatment as usual, another support         Outcomes: Communication; Expressive language.
Oono et al. (2013)	<b>Type:</b> Meta-analysis <b>Objectives:</b> "To assess the effectiveness of parent-mediated early interventions in terms of the benefits for both children with autism spectrum disorder (ASD) and their parents and to explore some potential moderators of treatment effect."	Participant Characteristics Number of participating children: 919 Age: 17 months – 6 years Sex: Not specified Description: Autism, autism spectrum disorder

	Number of included studies: 17 narrative synthesis; 10 meta-	Increased likelihood of ASD: Not included
	analysis.	Other conditions: None
	Search limit (years): 2002 – 2012	Support(s): Parent mediated interventions – Developmental Individual-
	Locations of included studies: Asia, Australia, Europe, North	Difference Relationship-Based (DIR) techniques; massage intervention;
	America	management of challenging behaviour; early intensive behavioural
	Study designs: Randomised controlled trials	intervention; Pivotal Response Treatment (PRT).
	Quality (systematic review): High (11/11)	<b>Comparison:</b> Wait list, treatment as usual, another support,
	Quality appraisal tool (included studies): Cochrane	other comparison group
	Collaboration tool for assessing risk of bias (Higgins 2011).	Outcomes: Overall autism characteristics (severity of autism
	Quality (included studies): Not specified	characteristics); Social-communication (shared or joint attention, child
	Sources of funding: Specified – Funded	initiations); Communication (communication, joint language);
	Conflict of interest: Specified – No conflicts	Expressive language (expression); Receptive language (comprehension);
		Cognitive (developmental/intellectual gains); Social-emotional
		development (maladaptive behaviour); Adaptive behaviour; Caregiver
		communication and interaction (parental synchrony); Caregiver social
		emotional wellbeing (parents' level of stress, parental confidence).
Parsons, Cordier,	Type: Meta-analysis	Participant Characteristics
Munro et al. (2017)	<b>Objectives:</b> "to conduct a systematic review and meta-analysis	Number of participating children: 925
	of pragmatic language interventions for children with autism	Age: 21 months – 14 years
	spectrum disorder (ASD)."	Sex: Not specified
	Number of included studies: 21 narrative synthesis; 15 meta-	Description: Autism spectrum disorder
	analysis	Increased likelihood of ASD: Not included
	Search limit (years): Database inception - 2016	Other conditions: None
	Locations of included studies: Asia, Australia, Europe, North	Support(s): Pragmatic language interventions - The Junior detective
	America	Program; Milton and Ethel Harris Research Initiative Treatment
	Study designs: Randomised controlled trials	(MEHRIT); Building Blocks Program; Social Emotional NeuroScience
	Quality (systematic review): Low (7/10)	Endocrinology (SENSE) theatre; Social Skills Group Intervention- High
	Quality appraisal tool (included studies): Standard quality	Functioning Autism; FindMe App; Therapeutic Horse
	assessment (Kmet et al. 2004).	Riding; FaceSay; Joint Attention, Symbolic Play, Engagement, and
	Quality (included studies): Included low quality/high risk of	Regulation (JASPER); Improvisational music
	bias	therapy; SummerMAX; Mind Reading; Skillstreaming; Emotion
	Sources of funding: Specified – Not funded	Recognition Training; Seaver-NETT.
	Conflict of interest: Specified – No conflicts	Comparison: Wait list, treatment as usual, another support
		Outcomes: Social-communication (pragmatic language).
Parsons, Cordier,	Type: Narrative synthesis	Participant Characteristics
Vaz	<b>Objectives:</b> "to (1) systematically review the existing evidence	Number of participating children: Not specified
et al. (2017)	presented by studies on parent-mediated intervention training,	Age: 0 - < 18 years (inclusion criteria)
	delivered remotely for parents having children with autism	Sex: Not specified
	spectrum disorder and living outside of urban areas; (2) provide	Description: Autism spectrum disorder
	an overview of current parent training interventions used with	Increased likelihood of ASD: Not included

	<ul> <li>this population; (3) and provide an overview of the method of delivery of the parent training interventions used with this population."</li> <li>Number of included studies: 7</li> <li>Search limit (years): 2014 – 2016</li> <li>Locations of included studies: Australia, North America</li> <li>Study designs: Randomised controlled trials, non-randomised with comparison, non-randomised without comparison, single-case experimental designs</li> <li>Quality (systematic review): High (9/11)</li> <li>Quality appraisal tool (included studies): Standard quality assessment (Kmet et al. 2004).</li> <li>Quality (included studies): Included moderate quality/moderate risk of bias</li> <li>Sources of funding: Specified – Not funded</li> <li>Conflict of interest: Specified – No conflicts</li> </ul>	Other conditions: None Support(s): Parent-mediated interventions delivered remotely - Web- based training in behavioural interventions; Online and Applied System for Intervention Skills (OASIS) training intervention Research-to- practice; Improving Parents as Communication Teachers (ImPACT) on the Web; Implementation discrete-trial instructions using video training materials; Parent Early Start Denver Model (P-EDSM) training; Functional communication training. Comparison: Another support, the individual's own baseline, no comparison group Outcomes: Caregiver communication and interaction (parental knowledge acquisition).
Pi et al. (2021)	Type: Meta-analysis         Objectives: "This meta-analysis aimed to examine the effectiveness of technology-based interventions in assisting parents to deliver interventions for their children with ASD based only on RCTs."         Number of included studies: 16         Search limit (years): Database inception – 2021         Locations of included studies: Asia, Australia, Europe, North America         Study designs: Randomised controlled trials         Quality (systematic review): Low (8/11)         Quality appraisal tool (included studies): Standards set by Reichow et al. (Reichow et al., 2008).         Quality (included studies): Included low quality/high risk of bias         Sources of funding: Specified - Not funded         Conflict of interest: Specified – No conflicts	Participant characteristics         Number of participating children: 748         Age: 0 – 12 years (inclusion criteria)         Sex: 68 – 100% male         Description: Autism spectrum disorder, high-functioning autism spectrum disorder         Increased likelihood of autism: Not included         Other conditions: Not specified         Support(s): Technology assisted parent-mediated intervention - Appbased interventions, online/web based, computer based, DVD-based.         Comparison: Wait list, treatment as usual, another support         Outcomes: Social-communication (social-communication; socialisation); Language (language total score, gestures); Expressive language (expressive speech); Receptive language.
Postorino et al. (2017)	Connect of interest: Specified = 100 connects         Type: Meta-analysis         Objectives: to summarise "the essential elements of parent training (PT) for disruptive behaviour in children with autism spectrum disorder (ASD) and [evaluate] the available evidence for parent training using both descriptive and meta-analytic procedures."	Participant CharacteristicsNumber of participating children: 653 (343 support, 310 comparison)Age: 2 - 14 yearsSex: 76.9 - 87.8% maleDescription: Autism spectrum disorder

	Number of included studies: 8Search limit (years): 1980 – 2016Locations of included studies: Australia, North AmericaStudy designs: Randomised controlled trials, non-randomisedwith comparisonQuality (systematic review): Low (7/11)Quality appraisal tool (included studies): Cochrane risk of biasassessment tool (Higgins 2013).Quality (included studies): Included low quality/high risk ofbiasSources of funding: Not specifiedConflict of interest: Specified – Conflict	Increased likelihood of ASD: Not included Other conditions: None Support(s): Parent training for disruptive behaviour. Comparison: Wait list, treatment as usual, another support, other comparison group Outcomes: Social-emotional development (disruptive behaviour).
Reichow et al. (2018)	Type: Meta-analysis Objectives: "to systematically review the evidence for the effectiveness of early intensive behavioural intervention (EIBI) in increasing functional behaviours and skills, decreasing autism severity, and improving intelligence and communication skills for young children with autism spectrum disorder (ASD)." Number of included studies: 5 Search limit (years): Database inception - 2017 Locations of included studies: Europe, North America Study designs: Randomised controlled trials, non-randomised with comparison Quality (systematic review): High (11/11) Quality appraisal tool (included studies): Cochrane Collaboration's tool for assessing risk of bias (Higgins, 2017). Quality (included studies): Not specified Sources of funding: Specified – Funded Conflict of interest: Specified – Conflict	Participant Characteristics         Number of participating children: 219 (116 support, 103 comparison)         Age: 0 - <6 years (inclusion criteria), M range = 30.2 - 42.5 months
Rodgers et al. (2020)	Type: Meta-analysisObjectives: "To evaluate the clinical effectiveness and cost- effectiveness of early intensive applied behaviour analysis-based interventions for autistic children based on current evidence."Number of included studies: 20Search limit (years): Database inception – 2017 Locations of included studies: Asia, Australia, Europe, North America	Participant characteristics         Number of participating children: 669         Age: Med. = 37.4 months         Sex: M = 86% male         Description: autism, autism spectrum disorder,         pervasive developmental disorder not otherwise specified         Increased likelihood of autism: Not included         Other conditions: Cognitive impairment

	<ul> <li>Study designs: Randomised controlled trial; non-randomised with comparison</li> <li>Quality (systematic review): High (10/11)</li> <li>Quality appraisal tool (included studies): Cochrane Risk of Bias 2.0 tool; Risk Of Bias In Non-randomised Studies – of Interventions (ROBINS-I) tool.</li> <li>Quality (included studies): Not specified</li> <li>Sources of funding: Specified - Funded</li> <li>Conflict of interest: Specified – No conflicts</li> </ul>	Support(s): Early intensive applied behaviour analysis. Comparison: Treatment as usual, another support Outcomes: Overall autism characteristics (autism symptom severity); Cognitive development (cognitive ability); Adaptive behaviour.
Sandbank et al. (2020)	Type: Meta-analysis Objectives: to review "group design studies of non- pharmacological early interventions designed for young children with autism spectrum disorder (ASD)." Number of included studies: 130 Search limit (years): Not specified Locations of included studies: Not specified Study designs: Randomised controlled trials, non-randomised with comparison Quality (systematic review): High (10/11) Quality appraisal tool (included studies): Cochrane Collaboration's tool for assessing risk of bias (Higgins, 2011), plus additional indicators proposed by Yoder et al. (2013). Quality of studies: Not specified Sources of funding: Specified – Funded Conflict of interest: Specified – Conflict	Participant Characteristics         Number of participating children: 6240         Age: 0 – 8 years, M = 54.21 months         Sex: M = 84% male         Description: Autism spectrum disorder (inclusion criteria)         Increased likelihood of ASD: Not included         Other conditions: None         Support(s): Animal-assisted therapy - Canine Assistance; Presence of a         Therapeutic Service Dog; Therapeutic Horseback Riding.         Behavioural - Behavioral Parent Training; Discrete Trial Training with         Motor Vocal Imitation Assessment; Early Intensive Behavioral         Treatment; Functional Behavior Skills Training; Home-based behavioral         treatment; Home-based Early Intensive Behavioral; Intervention (EIBI);         Intervention; Low Intensity Behavioral Treatment; Managing Repetitive         Behaviors; Picture Exchange Communication System (PECS); Peer-         Mediated Intervention; Rapid Motor Imitation Antecedent; Regular         Intensive Learning for Young Children with Autism; Schedules, Tools,         and Activities for Transitions (STAT); Social Skills Group; Stepping         Stones Triple P Positive Parenting Program; Strategies for Teaching         Based on Autism Research (STAR).         Developmental - Adapted Hanen More Than Words; Developmental,         Individual-Difference, Relationship-Based (DIR)-Floortime; Hanen         More Than Words; Joint Attention Mediated Learning (JAML); </td

adapted to autism (VIPP-AUTI).
Naturalistic developmental behavioural intervention (NDBI) -
Advancing Social-Communication and Play (ASAP); Caregiver-based
intervention program in community day-care centers; Denver Model;
Early Social Interaction Project (SCERTS); Early Start Denver Mode
(ESDM); Home-based Building Blocks Program; home-based
intervention program; ImPACT Online; Interpersonal Synchrony; Joint
Attention Intervention Joint Attention Symbolic Play Engagement
Regulation (JASPER); Joint Engagement Intervention; Joint
Engagement Intervention with Creative Movement Therapy; Parent-
Early Start Denver Model (P-ESDM); Parent-training intervention;
Pivotal Response Treatment (PRT); Reciprocal Imitation Training;
Social ABCs
Cognitive behaviour therapy (CBT).
Sensory based - Developmental Speech and Language Training through
Music; Family-Centered Music Therapy; Improvisational Music
Therapy; Music Therapy; Qigong (QST) Massage Treatment; Qigong
Massage Treatment; Rhythm Intervention Sensorimotor Enrichment;
Sensory Enrichment; Thai Traditional Massage; Tomatis Sound
Therapy; Vestibular Stimulation via a Platform Swing.
<u>Technology based</u> - ABRACADABRA; Emotiplay Serious Game;
FaceSay; FindMe iPad App; Gaming Open Library for Intervention in
Autism at Home (GOLIAH); Gaze-contingent attention training; Social
Skills Training using a robotic behavioral intervention system; The
Transporters animated series; Therapy Outcomes By You (TOBY) App;
Transporters DVD; Transporters Program for Children with Autism.
Treatment and Education of Autistic and related Communications
Handicapped Children (TEACCH)
Other - "Autism 123"; Balance Training Intervention; Circle of Friends;
Cognitive Method; Colloborative Model for Promoting Competence and
Success (COMPASS); Comprehensive Inclusion Program; Group
Psychoeducational Program for Mothers; Home-based intervention;
Hyperbaric Oxygen Therapy; Individual Parent Sleep Education;
Interactive Book Reading; LEAP (Learning Experiences and Alternative
Program for Preschoolers); NeuroModulation Technique (NMT);
Outdoor Adventure Program; Parent Education and Counselling
(PEAC); Parent-Child Interaction Therapy (PCIT) or Child-directed
interaction therapy (CDIT); Positive Family Intervention (Positive
Behavior Support +parent optimism training); Primary Care Stepping
Stones Triple P; Professionally supported intervention; Psychoeducation

		Intervention; Psychomotor Intervention Program; Reading Mastery; Sleep Education Pamphlet; Sung computer-based intervention; Thought- bubble Training for Theory of Mind; Water Exercise Swimming Program. <b>Comparison:</b> Not specified <b>Outcomes:</b> Overall autism characteristics (diagnostic characteristics); Restricted and repetitive interests and behaviours; Social- Communication; Communication (language); Cognitive development; Motor; Social-emotional development; Adaptive behaviour; Play.
Sandgreen et al. (2021)	<ul> <li>Type: Meta-analysis</li> <li>Objectives: "This study aimed to review digital interventions in the treatment of autism spectrum disorder (ASD)."</li> <li>Number of included studies: 19</li> <li>Search limit (years): Not specified – 2019</li> <li>Locations of included studies: Not specified</li> <li>Study designs: Randomised controlled trials, non-randomised with comparison</li> <li>Quality (systematic review): Low (8/11)</li> <li>Quality appraisal tool (included studies): Revised Cochrane risk-of-bias tool for randomized trials (RoB 2) (Sterne et al. 2019).</li> <li>Quality (included studies): Included low quality/high risk of bias</li> <li>Sources of funding: Specified - Not funded</li> <li>Conflict of interest: Specified - No conflicts</li> </ul>	Participant characteristics         Number of participating children: 815         Age: No age limit (inclusion criteria)         Sex: M = 19.5% female         Description: Autism spectrum disorder         Increased likelihood of autism: Not included         Other conditions: Cognitive impairment         Support(s): Technology-based supports - computer programs, tablet         apps, robots, interactive DVD.         Comparison: Wait list, treatment as usual, another support         Outcomes: General outcomes.
Shi et al. (2021)	Connect of interest: opecanded into connectsType: Meta-analysisObjectives: "The current meta-analysis reviewed studiesreporting broader outcomes in children with ASD who had everparticipated in a [comprehensive treatment model] CTM andexamined the predictors of developmental gains."Number of included studies: 18Search limit (years): Database inception – 2019Locations of included studies: Australia, Europe, NorthAmericaStudy designs: Randomised controlled trial, non-randomisedwith comparison, non-randomised without comparison, otherdesignsQuality (systematic review): High (11/11)Quality appraisal tool (included studies): Evaluative Methodfor Determining Evidence-Based Practices in Autism (Reichow	Participant characteristics         Number of participating children: 495         Age: M = 24 - 49 months         Sex: 71 - 95% male         Description: autism, autism spectrum disorder, autism disorder, pervasive developmental disorder pervasive developmental disorder pervasive developmental disorder not otherwise specified         Increased likelihood of autism: Not included         Other conditions: Cognitive impairment         Support(s): Early intensive behavioural intervention - UCLA, early start Denver model, "other" interventions.         Comparison: Treatment as usual, another support, no comparison, other comparisons not specified         Outcomes: Social-communication (VABS Social); Communication (VABS communication); Expressive language; Receptive language;

	et al., 2008).	Cognitive development (IQ); Adaptive behaviour (VABS composite);
	Quality (included studies): Included low quality/high risk of	Adaptive behaviour (daily living skills).
	bias	
	Sources of funding: Specified - Funded	
	Conflict of interest: Specified - No conflicts	
Soares et al. (2021)	Type: Meta-analysis	Participant characteristics
	<b>Objectives:</b> "The aim of this study is to conduct a meta-analysis	Number of participating children: 1266
	comparing RCTs of [face-to-face social skills training] and	Age: $4 - 19$ years
	[behavioural intervention technologies social skills training]	<b>Sex</b> : 69 – 100% male
	interventions for children and adolescents with ASD to compare	<b>Description:</b> autism spectrum disorder
	their efficacy."	Increased likelihood of autism: Not included (inclusion
	Number of included studies: 18	criteria)
	Locations of included studies: Asia, Australia, Europe, North	Other conditions: Not specified
	America	Support(s): Technology-based - Social skills training
	Search limit (years): Database inception - 2020	<b>Comparison:</b> Wait list, treatment as usual, another support
	Study designs: Randomised controlled trials	Outcomes: Social-communication (social functioning).
	Quality (systematic review): High (9/11)	outcomest social communication (social functioning).
	Quality appraisal tool (included studies): Revised Cochrane	
	Risk-of-Bias Tool for Randomized Trials (Sterne et al. 2019).	
	Quality (included studies): Included moderate quality/moderate	
	risk of bias	
	Sources of funding: Not specified	
	<b>Conflict of interest:</b> Specified – No conflicts	
Sutherland et al.	Type: Narrative synthesis	Participant Characteristics
(2018)	<b>Objectives:</b> "to examine the nature and outcomes of studies	Number of participating individuals: 284
(2018)	examining telehealth assessment and/or intervention in autism	Age: 19 months – upper age not specified
	spectrum disorder (ASD)."	Sex: Not specified
	Number of included studies: 14	<b>Description:</b> Autism, autism spectrum disorder, pervasive
	Search limit (years): Database inception - 2016	developmental disorder not otherwise specified
	Locations of included studies: North America	Increased likelihood of ASD: Not included
	Study designs: Randomised controlled trials, single-case	Other conditions: None
	experimental designs, other	Support(s): Telehealth - Program Improving Parents as Communication
	Quality (systematic review): Low (7/10)	Teachers (imPACT); internet-based Parent Implemented
	Quality appraisal tool (included studies): Scientific Merit	Communication Strategies (iPICS); general communication
	Rating Scale (SMRS; National Autism Center, 2015).	intervention; imitation training; Telehealth diagnostic services;
	Quality (included studies): Included low quality/high risk of	'Telehealth Facing Your Fears' Intervention'; functional behaviour
	bias	assessment and functional communication training; school age
	Sources of funding: Not specified	intervention using web-based education; language intervention.
	Conflict of interest: Specified – No conflicts	Comparison: Wait list, treatment as usual, another support, the
		individual's own baseline, no comparison group

		Outcomes: Caregiver satisfaction (satisfaction and acceptability);
		Caregiver communication and interaction (fidelity).
Tachibana et al.	Type: Meta-analysis	Participant Characteristics
(2018)	<b>Objectives:</b> "to investigate the effectiveness of individual and	Number of participating children: 1220
	group interventions for children with autism spectrum disorder	Age: $1-6$ years
	(ASD) and to compare the effectiveness of these two types if	Sex: Not specified
	possible."	Description: Autism, autism spectrum disorder
	Number of included studies: 30 studies analysis II, IV; 14	Increased likelihood of ASD: Not included
	studies Analysis I and III	Other conditions: None
	Search limit (years): Not Specified – 2014	Support(s): Social communication supports - Hanen's More Than
	Study designs: Randomised controlled trials	Words; Early Start Denver Model (ESDM); Parent training; Joint
	Locations of included studies: Asia, Australia, Europe, North	Attention Symbolic Play Engagement and Regulation (JASPER);
	America	Preschool Autism Communication Trial (PACT); Treatment and
	Quality (systematic review): High (11/11)	Education of Autistic and related Communications Handicapped
	Quality appraisal tool (included studies): Cochrane	Children (TEACCH)-based group social skills; Reciprocal Imitation
	Collaboration's Tool for Assessing Risk of Bias (Higgins et al.,	Training; Caregiver-based intervention program in community day-
	2011).	care centers; Preschool-based joint attention intervention; Caregiver
	Quality (included studies): Included moderate quality/moderate	Mediated Joint Engagement Intervention; Improvisational music
	risk of bias	therapy; intervention targeting development of socially synchronous
	Sources of funding: Specified – Funded	engagement; Developmental, Individual-Difference, Relationship-
	Conflict of interest: Specified – No conflicts	Based(DIR)/ Floortime intervention; Functional Behavior Skills
		Training (FBST); Building Blocks; Parent delivery of the Early Start
		Denver Model (P-ESDM); Joint Attention Mediated Learning (JAML)
		intervention; Focused Playtime Intervention (FPI); Education and Skills
		Training Program for Parents; Parent education and behaviour
		management (PEBM) Skills training intervention or comparison for
		the non-specific aspects of the PEBM parent education and counselling
		intervention; Home TEACCHing Program.
		<b>Comparison:</b> Wait list, treatment as usual, another support
		<b>Outcomes:</b> Overall autism characteristics (autism general symptoms);
		Social-communication (qualitative impairment in social interaction,
		reciprocity of social interaction towards others, responding to joint
		attention, initiating joint attention; imitation); Restricted and repetitive
		interests and behaviours (restricted repetitive and stereotyped patterns,
		behaviours, interests and activities); Communication (qualitative
		impairment in communication); Expressive language; Receptive
		language; Cognitive development (developmental quotient); Adaptive
		behaviour; Caregiver communication and interaction (parental
		synchrony); Caregiver social emotional wellbeing (parenting stress).

Tan-MacNeill et	Type: Narrative synthesis	Participant characteristics
al. (2021)	<b>Objectives:</b> This systematic review identified and evaluated the	Number of participating children: Not specified
	quality of evidence for the efficacy of online parent-implemented	Age: 20 months – 16 years
	interventions for children with Autism Spectrum Disorder	Sex: Not specified
	(ASD), Attention-Deficit/Hyperactivity Disorder (ADHD),	Description: Autism spectrum disorder
	Cerebral Palsy (CP), and Fetal Alcohol Spectrum Disorder	Increased likelihood of autism: Not specified
	(FASD).	Other conditions: Attention deficit hyperactivity disorder,
	Number of included studies: 17 (9 autism-specific)	sleep issues, anxiety, language delay, cognitive impairment,
	Search limit (years): Database inception – 2020	sensory processing, learning disability, epilepsy, oppositional
	Locations of included studies: Not specified	defiant disorder, disruptive behaviour disorder, Tourette
	Study designs: Randomised controlled trial, non-randomised	Syndrome, conduct disorder.
	with comparison, non-randomised without comparison, single	<b>Support(s):</b> Online parent implemented interventions - ImPACT online,
	case experimental design	POWR Online Communication Training; Pivotal response treament
	Quality (systematic review): High (8/10)	(PRT); enhancing interactions; reciprocal imitation training (RIT); ABA
	Quality appraisal tool (included studies): Quality index for	Web-Based Training; Enhancing Interactions; FASD Education and
	randomized and non-randomized studies proposed by Downs and	Training; Triple P online (TPOL); Project CHASE (children with autism
	Black (1998).	supported to exercise); parent sleep education intervention; promoting
	Quality (included studies): Not specified	engagement for ADHD pre-Kindergarteners (PEAK), blended
	Sources of funding: Specified - Funded	behavioural parent training (BPT).
	Conflict of interest: Specified – No conflicts	Comparison: Wait list, another support, the individual's own baseline,
		no comparison, other comparisons not specified
		Outcomes: Social-communication (communication behaviours and
<b>—</b>		language targets).
Tarver et al. (2019)	Type: Meta-analysis	Participant Characteristics
	<b>Objectives:</b> to assess the "evidence for the efficacy of	Number of participating children: 764 (396 supports,
	behavioural parent interventions for disruptive and hyperactive	368 comparison)
	child behaviour in autism spectrum disorders, as well as	Age: $2 - 14$ years
	parenting efficacy and stress."	Sex: 21 – 100% male
	Number of included studies: 11	<b>Description:</b> Autism spectrum disorder, Asperger's
	Search limit (years): Database inception - 2017	Increased likelihood of ASD: Not included
	Locations of included studies: Australia, North America	Other conditions: None
	<b>Study designs:</b> Randomised controlled trials	Support(s): Behavioural parent interventions – Research Units in
	Quality (systematic review): Low (8/11)	Behavioural Intervention (RUBI) Parent Training Manual; Child
	Quality appraisal tool (included studies): Cochrane risk of bias	directed interaction therapy (CDIT); Compass for help (C-
	tool (Higgins et al., 2011).	HOPE); Parent management training; parent-child interaction therapy
	Quality (included studies): Included low quality/high risk of	(PCIT); Primary care stepping stones Tripe P (PCSSTP); Stepping
	bias	stones triple P (SSTP).
	Sources of funding: Specified – Funded	Comparison: Wait list, treatment as usual, another support, other
	Conflict of interest: Not specified	comparison group

		Outcomes: Social-emotional development; Caregiver social emotional
		wellbeing (parenting stress, parenting efficacy).
Tiede & Walton	Type: Meta-analysis	Participant characteristics
(2019)	Objectives: to conduct "a meta-analysis of outcomes of group-	Number of participating children: Not specified
	design studies testing interventions using naturalistic	<b>Age:</b> Mean age < 6 (inclusion criteria)
	developmental behavioural intervention strategies [for children	Sex: Not specified
	with autism spectrum disorder]."	Description: Autism spectrum disorder (inclusion criteria)
	Unique included studies: 27	Increased likelihood of ASD: Eligible (inclusion criteria)
	Search limit (years): Not Specified – 2018	Other conditions: None
	Locations of included studies: Not specified	Support(s): Naturalistic Developmental Behavioural Interventions -
	Study designs: Randomised controlled trials, non-randomised	Early Start Denver Model (ESDM); Early Social Interaction Project
	with comparison (inclusion criteria)	(ESI); intervention emphasizing joint attention and imitation skill-
	Quality (systematic review): High (10/11)	building (JA/Imitation); Joint Attention, Symbolic Play, Engagement,
	Quality appraisal tool (included studies): Evaluative Method	and Regulation (JASPER); Learning Experiences Alternative Program
	for Determining Evidence-Based Practice in Autism (Reichow et	(LEAP); Pivotal Response Treatment (PRT); Reciprocal Imitation
	al., 2008).	Training (RIT); Focus parent training program; parent training.
	Quality (included studies): Included low quality/high risk of	Comparison: Not specified
	bias	Outcomes: Overall autism characteristics (symptoms of ASD); Social-
	Sources of funding: Specified – Not funded	communication (joint attention, social engagement); Expressive
	Conflict of interest: Not specified	language; Receptive language; Cognitive development (cognitive
		development, non-verbal IQ); Play; Adaptive behaviour.
Trzmiel et al.	Type: Meta-analysis	Participant Characteristics
(2019)	<b>Objectives:</b> "to assess the effectiveness of Equine-Assisted	Number of participating children: 390
	Activities and Therapies (EAAT) in autism spectrum	<b>Age:</b> $3 - 16$ years, M range = $5.14 - 10.2$ years
	disorder (ASD) patients."	Sex: $M = 79\%$ male, 21% female
	Number of included studies: 15 narrative synthesis; 3 meta-	Description: Autism spectrum disorder
	analysis	Increased likelihood of ASD: Not included
	Search limit (years): 2000 – 2017	Other conditions: None
	Locations of included studies: Not specified	<b>Support(s):</b> Equine-assisted therapy - hippotherapy, therapeutic riding.
	Study designs: Not specified	Comparison: Not specified
	Quality (systematic review): Low (7/11)	Outcomes: Social-communication (social); Communication; Adaptive
	Quality appraisal tool (included studies): Quality Assessment	behaviour.
	Tool for Quantitative Studies (QATQS; National Collaborating	
	Centre for Methods and Tools, 2008).	
	Quality (included studies): Included low quality/high risk of	
	bias	
	Sources of funding: Not specified	
	<b>Conflict of interest:</b> Specified – No conflicts	
Tupou et al. (2019)	Type: Narrative synthesis	Participant characteristics

		202 : )
	intervention to children with autism spectrum disorder (ASD)	292 comparison)
	who were attending inclusive preschool settings. We also sought	Age: $12 - 72$ months (inclusion criteria), M = 46 months
	to appraise the quality of the identified studies and evaluate their	Sex: Not specified
	effects on child outcomes. The strategies used in training	Description: Autism/autism spectrum disorder, pervasive
	teaching staff to implement these interventions with fidelity were	developmental disorder not otherwise specified, Asperger's
	a particular focus of the review as well."	syndrome
	Number of included studies: 16	Increased likelihood of ASD: Included
	<b>Search limit (years):</b> 2000 – 2017	Other conditions: None
	Locations of included studies: Not specified	<pre>Support(s): Comprehensive treatment programmes - Developmentally</pre>
	Study designs: Randomised controlled trials, non-randomised	Appropriate Treatment for Autism (DATA); Treatment and Education
	with comparison, non-randomised without comparison, single-	of Autistic and Related Communication Handicapped Children
	case experimental designs	(TEACCH); Early Intensive Behavioural Intervention (EIBI); Learning
	Quality (systematic review): High (9/10)	Experiences and Alternative Program for Preschoolers (LEAP);
	Quality appraisal tool (included studies): Modified version of	Comprehensive Autism Program (CAP); EIBI intervention described as
	Goldstein et al.'s (2014) framework.	being based on Lovaas' UCLA model.
	Quality (included studies): Included low quality/high risk of	Skills focused interventions targeting - communication, play skills, peer
	bias	interaction, and reading skills.
	Sources of funding: Specified – Funded	Comparison: Not specified
	<b>Conflict of interest:</b> Specified – No conflicts	<b>Outcomes:</b> Overall autism characteristics (autism severity and/or
		symptoms); Social-communication (social skills); Communication
		(communication and/or language); Social-emotional development
		(adaptive/maladaptive behaviour); Adaptive behaviour (functional
		skills).
Valentine et al.	Type: Narrative synthesis	Participant characteristics
(2020)	<b>Objectives:</b> "This review provides an evidence map describing	Number of participating children: Not specified
()	how technology is implemented in the assessment/diagnosis and	Age: 17 months – 44 years
	monitoring/ treatment of NDD."	Sex: Not specified
	Number of included studies: 47 (32 autism-specific)	<b>Description:</b> All autism spectrum disorders included pervasive
	Search limit (years): $2014 - 2019$	Developmental delay not otherwise specified and Retts
	Locations of included studies: Not specified	Increased likelihood of autism: Not specified
	Study designs: Randomised controlled trial, non-randomised	Other conditions: Attention deficit hyperactivity disorder,
	with comparison, single case experimental designs, other designs	anxiety, cognitive impairment, communication disorders,
	Quality (systematic review): High (9/10)	specific learning disorder, oppositional defiance
	Quality appraisal tool (included studies): Oxford Centre for	disorder/conduct disorder
	Evidence Based Medicine (OCEBM)	Support(s): Technology-assisted - tablet, Mobile App, Gaming,
	Quality (included studies): Included low quality/high risk of	Video/DVD/Video modelling, Robots, Virtual Reality.
	bias	<b>Comparison:</b> Wait list, treatment as usual, the individual's own
	Sources of funding: Specified – Funded	baseline, no comparison, other comparisons not specified
	Conflict of interest: Specified – Conflicts	Outcomes: General outcomes (clinical effectiveness).

Verschuur et al. (2014)	<b>Type:</b> Narrative synthesis <b>Objectives:</b> "to analyse the research on [Pivotal Responses Treatment] (PRT) in order to (a) document the range of skills that have been targeted for improvement with PRT, (b) assess the success of PRT for improving the skills of children with autism spectrum disorder (i.e., pivotal skills and untargeted skills), (c)	Participant characteristicsNumber of participating children: 420Age: 1 – 12 years, 7 months, M = 4 years, 7 monthsSex: M = 71% male, 15.4% female, remainder not reportedDescription: Autism spectrum disorder, autism, pervasive developmental disorder not otherwise specified, Asperger's
	assess the success of PRT for improving the skills of caregivers and staff, (d) evaluate the certainty of evidence arising from these studies, (e) identify limitations of the existing evidence base, and (f) suggest directions for future research." <b>Number of included studies:</b> 43 <b>Search limit (years):</b> Database inception – 2013	Syndrome.         Increased likelihood of ASD: Included         Other conditions: None         Support(s): Pivotal Response Treatment (PRT); Natural Language         Paradigm; facilitated social play training; and socio-dramatic play         training.
	Locations of included studies: Not specified Study designs: Randomised controlled trials, non-randomised with comparison, non-randomised without comparison, single- case experimental designs, other Quality (systematic review): Low (6/10)	Comparison: Wait list, another support, the individual's own baseline, no comparison group Outcomes: General outcomes (child behaviours); Caregiver social emotional wellbeing (caregiver behaviours).
	Quality appraisal tool (included studies): Certainty of evidence rated using the classification system described by Lang et al. (2012), Palmen et al. (2012), Ramdoss et al. (2011) and Ramdoss et al. (2012). Quality (included studies): Included low quality/high risk of bias	
	Sources of funding: Not specified Conflict of interest: Specified – No conflicts	
Waddington et al. (2021)	Type: Narrative synthesis Objectives: "This systematic literature review examined the effects of Joint Attention, Symbolic Play, Engagement, and Regulation (JASPER) intervention and its components on child, parent and educator outcomes." Number of included studies: 19 Search limit (years): 2006 – 2020 Locations of included studies: Europe, North America Study designs: Randomised controlled trials Quality (systematic review): High (9/10) Quality appraisal tool (included studies): Quality indicators outlined by the Council of Exceptional Children (Cook et al., 2015).	Participant characteristics         Number of participating children: 619 (346 support, 273 comparison)         Age: M = 30 - 60 months         Sex: Not specified         Description: Autism spectrum disorder, pervasive developmental disorder not otherwise specified         Increased likelihood of autism: Included         Other conditions: Minimally verbal, other conditions not specified         Support(s): Joint Attention, Symbolic Play, Engagement, and Regulation (JASPER) intervention.         Comparison: Wait list, treatment as usual, another support
	Quality (included studies): Not specified	<b>Outcomes:</b> Overall autism characteristics (core characteristics of ASD); Social-communication (joint attention and engagement);

	Sources of funding: Specified – Funded	Communication (child communication skills); Expressive language
	Conflict of interest: Specified – No conflicts	(overall expressive language); Receptive language; Play.
Wang et al.	Type: Meta-analysis	Participant characteristics
(2021a)	<b>Objectives:</b> "To examine and analyse the intervention effects of	Number of participating children: 624
. ,	the Early Start Denver Model (ESDM) on children with autism	<b>Age:</b> $M = 1.72 - 3.96$ years
	spectrum disorder (ASD)."	Sex: Not specified
	Number of included studies: 11	Description: Not specified
	Search limit (years): Not specified – 2020	Increased likelihood of autism: Not specified
	Locations of included studies: Asia, Australia, North America	Other conditions: Not specified
	Study designs: Randomised controlled trials	Support(s): Early Start Denver Model.
	Quality (systematic review): Low (8/11)	Comparison: Not specified
	Quality appraisal tool (included studies): Cochrane risk of bias	Outcomes: Overall autism characteristics (autism symptoms); Social-
	Quality (included studies): Included high quality	communication; Communication (language); Cognitive development
	Sources of funding: Specified - Funded	(cognition).
	Conflict of interest: Specified - No conflicts	
Wang et al.	Type: Meta-analysis	Participant characteristics
(2021b)	<b>Objectives:</b> To evaluate the effectiveness of [cognitive	Number of participating children: 2485
	behavioural therapy] on the symptoms of ASD and social-	Age: $0 - 17$ years (inclusion criteria)
	emotional problems in children or adolescents with ASD by	Sex: Not specified
	using a meta-analytic approach.	Description: Autism spectrum disorder
	Number of included studies: 51	Increased likelihood of autism: Not included
	Search limit (years): Database inception – 2019	Other conditions: Not specified
	Locations of included studies: Asia, Australia, Europe, North	Support(s): Cognitive behavioural therapy.
	America	Comparison: Not specified
	Study designs: Randomised controlled trials, other designs	<b>Outcomes:</b> Overall autism characteristics (symptoms related to ASD);
	Quality (systematic review): High (9/11)	Social emotional/challenging behaviour (symptoms of social-emotional
	Quality appraisal tool (included studies): the Jadad scale	problems).
	(Jadad et al., 1996)	
	Quality (included studies): Included low quality/high risk of	
	bias	
	Sources of funding: Specified – Not funded	
	Conflict of interest: Specified – No conflicts	
Zheng et al. (2021)	Type: Meta-analysis	Participant characteristics
<b>U U</b>	<b>Objectives:</b> "We synthesized current research evidence on the	Number of participating children: 441 (245 intervention, 196
	PEERS program to evaluate the treatment effect on four	comparison)
	commonly used outcome measures."	Age: $11 - 21$ years (M = $12.9 - 18.8$ years)
	Number of included studies: 12	Sex: 64 – 93% male
	<b>Search limit (years):</b> 2000 – 2020	<b>Description:</b> Autism spectrum disorder
		Increased likelihood of autism: Not included
		Other conditions: Cognitive impairment, other conditions not

Locations of included studies: Asia, North Ame	erica specified
Study designs: Randomised controlled trials, nor	n-randomised <b>Support(s):</b> UCLA Program for the Education and Enrichment of
without comparison	Relational Skills (PEERS).
Quality (systematic review): Low (8/11)	Comparison: Wait list, another support, no comparison
Quality appraisal tool (included studies): an ad	lapted version of <b>Outcomes:</b> Social-communication.
Risk of Bias In Non-Randomized Studies-of Inter	rventions
(ROBINS-I)	
Quality (included studies): Included low quality	/high risk of
bias	
Sources of funding: Not specified	
<b>Conflict of interest:</b> Specified – No conflicts	

Footnote: "(inclusion criteria)" indicates that the given information was taken from the SR inclusion criteria as it was not possible to determine based on the included studies; "number of included studies" refers to the number of studies included in overall analysis within each SR; "quality of included studies" refers to the overall quality of all studies included in the SR; "M" indicates mean age; M range indicates the range of mean ages (minimum – maximum) reported by SR authors; "increased likelihood of autism" refers to whether or not individuals with an increased likelihood of autism, but without an autism diagnosis, were eligible for included, in the SR; the names of all supports were taken verbatim from each SR; "Outcomes ()" the first term refers to the outcome categories defined for this umbrella review, the term in parenthesis refers to the author's term(s) for the outcome, where there is no term in brackets, the systematic review author's outcome classification matched that of the current umbrella review.

National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia

Appendix 5.9	Umbrella review - Summary of findings from practice/category-focused systematic reviews
	practice/category-locused systematic reviews

# Appendix 5.9 - Umbrella review - Summary of findings from practice/category-focused systematic reviews

## **Behavioural Supports**

		review)
Overall autism characteristics (diagnostic characteristics): Positive pooled effect*. Social-communication: Positive pooled effect*. Communication (language): Positive pooled effect*. Cognitive development: Positive pooled effect*. Motor: Positive pooled effect*. Social-emotional development: Positive pooled effect*. Adaptive behaviour: Positive pooled effect*. Adaptive behaviour: Positive pooled effect*.	RCTs, non- randomised with comparison	High (10/11)
	Social-communication: Positive pooled effect*. Communication (language): Positive pooled effect*. Cognitive development: Positive pooled effect*. Motor: Positive pooled effect*. Social-emotional development: Positive pooled effect*. Adaptive behaviour: Positive pooled effect*.	Social-communication: Positive pooled effect*.withCommunication (language): Positive pooled effect*.comparisonCognitive development: Positive pooled effect*.comparisonMotor: Positive pooled effect*.social-emotional development: Positive pooled effect*.Adaptive behaviour: Positive pooled effect*.development: Positive pooled effect*.

	Intensive Learning for Young Children with Autism; Schedules, Tools, and Activities for Transitions (STAT); Social Skills Group; Stepping Stones Triple P Positive Parenting Program; Strategies for Teaching Based on Autism Research (STAR). Eviews at the practice level or Behavioural Intervention (EIBI)			
Reichow et al. (2018)	Setting: Not specified. Format: Individual. Agent: Not specified. Mode: Face-to-face. Amount of support: Not specified.	Overall autism characteristics (autism symptoms): Null pooled effect*. Social-Communication (social competence): Positive pooled effect. Communication: Positive pooled effect. Expressive language: Positive pooled effect. Receptive language: Positive pooled effect. Cognitive development (intelligence quotient): Positive pooled effect. Social-emotional development (problem behaviour): Null pooled effect*. Adaptive behaviour: Positive pooled effect. Adaptive behaviour (daily living skills): Positive pooled effect.	RCTs, non- randomised with comparison	High (11/11)
Rodgers et al. (2020)	Setting: Clinics, homes, educational settings, other. Format: Individuals, groups. Agent: Parents/caregivers, early childhood staff, clinicians/researchers, other. Mode: Face-to-face. Amount of support: Not specified.	Adverse effects: Considered, and none identified.Overall autism characteristics (autism symptom severity):Null pooled effect*.Cognitive development (cognitive ability – 1 year):Positive pooled effect.Cognitive development (cognitive ability – 2 years):Positive pooled effect.Adaptive behaviour (1 year): Null pooled effect.Adaptive behaviour (2 years): Positive pooled effect.	RCTs; non- randomised with comparison	High (10/11)

		<ul> <li>Child age: The child's age (age at recruitment) was not related to the effect of support on cognitive development or adaptive behaviour.</li> <li>Cognitive development: The child's cognitive development (IQ at baseline) was not related to the effect of support on cognitive development or adaptive behaviour.</li> <li>Adaptive behaviour: The child's adaptive behaviour (VABS at baseline) was not related to the effect of support on Cognitive development or adaptive behaviour.</li> <li>Adaptive behaviour: The child's adaptive behaviour (VABS at baseline) was not related to the effect of support on Cognitive development or adaptive behaviour.</li> <li>Adverse effects: Not reported.</li> </ul>		
Shi et al. (2021)	Setting: Not specified. Format: Not specified. Agent: Parents/caregivers, clinicians/researchers. Mode: Face-to-face. Amount of support: Not specified.	Social-communication (VABS Social): Positive pooled effect*. Communication (VABS communication): Positive pooled effect*. Expressive language: Null pooled effect*. Receptive language: Null pooled effect*. Cognitive development (IQ): Positive pooled effect*. Adaptive behaviour (VABS composite): Positive pooled effect*. Adaptive behaviour (daily living skills): Null pooled effect*. Adverse effects: Not reported.	RCTs, non- randomised with comparison, non- randomised without comparison, other designs	High (11/11)

\* This effect is presented in the summary table in Appendix 6.13 (Effect of type of support on child and family outcomes).

# **Developmental Supports**

Characteristics of supp	ts Findings form the systematic review	Study	Quality
included in the system	ic	designs	(systematic
review			review)

Systematic re	views at the category level			
Binns &	Label: Developmental social	Social-communication (social interaction and social-	RCTs only	High (9/10)
Oram Cardy	pragmatic supports.	communication): Positive summarised effect.		
(2019)	Setting: Clinic, home.	Communication (language capacities): Inconsistent		
	Format: Individual, group.	summarised effect.		
	Agent: Parents/caregivers,			
	educators, clinicians/researchers.	Adverse effects: Not reported.		
	Mode: Face-to-face.			
	Amount of support: Not			
	specified.			
	Practices: Child Talk; Hanen More			
	than Words; Developmental			
	Individual-Difference			
	Relationship-Based (DIR); Milton			
	and Ethel Harris Research			
	Initiative Treatment (MEHRIT)-			
	DIR based; Pediatric Autism and			
	Communication Therapy (PACT);			
	Joint attention mediated			
	learning; Play and Language for			
	Autistic Youngsters (PLAY) project			
	- DIR based; Social			
	communication, emotion			
	regulation, transactional support			
	(SCERTS).			
Sandbank et	Label: Developmental supports.	Social-communication: Positive pooled effect*.	RCTs, non-	High
al. (2020)	Setting: Not specified.	Communication (language): Null pooled effect*.	randomised	(10/11)
	Format: Not specified.		with	
	Agent: Not specified.	Adverse effects: Not reported.	comparison	
	Mode: Not specified.			
	Amount of support: Not			
	specified.			
	Practices: Adapted Hanen More			
	Than Words; DIR-Floortime;			

effect. RCTs	High (9/1
effect. RCTs	High (9/1
effect. RCTs	High (9/1

<sup>1</sup> This summary of findings is also presented within the 'Delivery Characteristics table' (Appendix 6.11) under 'Agent (parent-mediated, DIR/Floortime)'

#### Naturalistic Developmental Behavioural Interventions

	Characteristics of supports included in the systematic review	Findings form the systematic review	Study designs	Quality (systematic review)
Systematic	reviews at the category level			-
Tiede & Walton (2019)	Label: Naturalisticdevelopmental behaviouralinterventions.Setting: Clinic, home,educational, community.Format: Individual.Agent: Parents/caregivers,educators,clinicians/researchers.Mode: Face-to-face.	Overall autism characteristics (symptoms of ASD): Positive pooled effect*. Social-communication (joint attention): Null pooled effect*. Social-communication (social engagement): Positive pooled effect*. Expressive language: Positive pooled effect*. Receptive language: Positive pooled effect*. Cognitive development: Positive pooled effect*. Play: Positive pooled effect*. Adaptive behaviour: Null pooled effect*.	RCTs, non- randomised with comparison (inclusion criteria)	High (10/11)
	<ul> <li>Amount of support: 6 – 1581 hours.</li> <li>Practices: Early Start Denver Model (ESDM); Early Social Interaction Project (ESI); intervention emphasizing joint attention and imitation skill- building (JA/Imitation); Joint Attention, Symbolic Play, Engagement, and Regulation (JASPER); Learning Experiences Alternative Program (LEAP); Pivotal Response Treatment (PRT); Reciprocal Imitation Training (RIT); Focus parent</li> </ul>	<ul> <li>Amount of support: Greater amount of support (total hours) related to greater effect of support on social-communication (joint attention). Amount of support (total hours) not related to effect of support on adaptive behaviour, expressive or receptive language, Cognitive development, overall autism characteristics, social-communication (social engagement), or play.</li> <li>Adverse effects: Not reported.</li> </ul>		

	training program; parent			
	training.			
Sandbank et	Label: Naturalistic	Overall autism characteristics (diagnostic characteristics):	RCTs, non-	High
al. (2020)	developmental behavioural	Null pooled effect.	randomised	(10/11)
	interventions.	Social-communication: Positive pooled effect.	with	
	Setting: Not specified.	Restricted and repetitive interests and behaviours: Null	comparison	
	Format: Not specified.	pooled effect*.		
	Agent: Not specified.	Communication (language): Positive pooled effect.		
	Mode: Not specified.	Cognitive development: Positive pooled effect.		
	Amount of support: Not	Social-emotional development: Null pooled effect*.		
	specified.	Play: Positive pooled effect.		
	Practices: Advancing Social-	Adaptive behaviour: Null pooled effect.		
	Communication and Play (ASAP);			
	Caregiver-based intervention	Adverse effects: Not reported.		
	program in community day-care			
	centers; Denver Model; Early			
	Social Interaction Project			
	(SCERTS); Early Start Denver			
	Model (ESDM); Home-based			
	Building Blocks Program; home-			
	based intervention program;			
	ImPACT Online; Interpersonal			
	Synchrony; Joint Attention			
	Intervention; Joint Attention			
	Symbolic Play Engagement			
	Regulation (JASPER); Joint			
	Engagement Intervention; Joint			
	Engagement Intervention with			
	Creative Movement Therapy;			
	Parent-Early Start Denver Model			
	(P-ESDM); Parent-training			
	intervention; Pivotal Response			
	Treatment (PRT); Reciprocal			
	Imitation Training; Social ABCs			

Crank et al.	Setting: Not specified	Child age: The child's age (chronological age) was not related	RCTs, non-	Low (8/11)
(2021)	Format: Not specified	to the effect of support on general outcomes.	randomised	
	Agent: Parents/caregivers, early	<b>Communication:</b> The child's communication (language age)	with	
	childhood staff,	was not related to the effect of support on general outcomes.	comparison	
	clinicians/researchers, other	Amount of support: The amount of support (cumulative		
	agents	intensity) was not related to the effect of support on general		
	Mode: Not specified	outcomes.		
	Amount of support: M = 556	Agent: The agent (clinicians, educators, caregivers,		
	hours (8 – 3276 hours)	combination) was not related to the effect of support on		
	Practices: Naturalistic	general outcomes.		
	developmental behavioural			
	interventions: Advancing Social	Adverse effects: Not reported.		
	Communication and Play (ASAP);			
	Caregiver-based intervention			
	program in community day-care			
	centers; Denver Model; Early			
	Social Interaction Project			
	(SCERTS); Early Start Denver			
	Model (ESDM); Home-based			
	Building Blocks Program; home-			
	based intervention program;			
	ImPACT Online; Interpersonal			
	Synchrony; Joint Attention			
	Intervention; Joint Attention			
	Symbolic Play Engagement			
	Regulation (JASPER); Joint			
	Engagement Intervention; Joint			
	Engagement Intervention with			
	Creative Movement Therapy;			
	Parent-Early Start Denver Model			
	(P-ESDM); Parent-training			
	intervention; Pivotal Response			
	Treatment (PRT); Reciprocal			
	Imitation Training; Social ABCs;			

	Cognitive behaviour therapy (CBT).			
Systematic r	eviews at the practice level			
	enver Model			
Fuller et al. (2020)	Setting: Not specified. Format: Individual, group. Agent: Parents/caregivers, clinicians/researchers. Mode: Face-to-face. Amount of support: Not specified.	Overall autism characteristics (autism symptoms): Null pooled effect. Social-communication: Null pooled effect. Restricted and repetitive interests and behaviours (repetitive behaviours): Null pooled effect*. Communication (language): Positive pooled effect. Cognitive development: Positive pooled effect. Adaptive behaviour (adaptive functioning): Null pooled effect*. Amount of support: Amount of support (total hours) not related to the effect of support on general outcomes (child outcomes).	RCTs, non- randomised with comparison	High (10/11)
Wang et al. (2021a)	Setting: Not specified. Format: Individuals, groups. Agent: Parents/caregivers, other. Mode: Not specified. Amount of support: Not specified.	Adverse effects: Not reported.         Overall autism characteristics (autism symptoms): Positive pooled effect*.         Social-communication: Null pooled effect*.         Communication (language): Positive pooled effect*.         Cognitive development: Positive pooled effect*.         Agent: The agent (parents, professionals) was not related to the effect of support on overall autism characteristics or communication.         Format: The format (individual, group) was not related to the effect of support on overall autism characteristics or communication.         Adverse effects: Not reported.	RCTs	Low (8/11)

Pivotal Resp	onse Treatment			•
Verschuur et al. (2014)	Setting: Clinic, home, educational. Format: Individual, group. Agent: Parents/caregivers, peers/siblings, educators, clinicians/researchers. Mode: Face-to-face, self- directed learning. Amount of support: Not specified.	General outcomes (child behaviours): Inconsistent summarised effect*. Caregiver social emotional wellbeing (caregiver behaviours): Inconsistent summarised effect*. Adverse effects: Not reported.	RCTs, non- randomised with comparison, non- randomised without comparison, single-case experimental designs, other	Low (6/10)
Ona et al. (2020)	Setting: Clinic, home. Format: Individual, group. Agent: Parents/caregivers, clinicians/researchers. Mode: Face-to-face. Amount of support: Not specified.	Communication: Null pooled effect*. Expressive language: Positive pooled effect*. Adverse effects: Not reported.	RCTs only	Low (8/11)
Pivotal respo	nse treatment (parent-mediated o	nly)		
Deb et al. (2020) <sup>1</sup>	Setting: Home, educational settings, other. Format: Individuals, groups. Agent: Parents/caregivers, early childhood staff, clinicians/researchers, other. Mode: Face-to-face, telehealth, other. Amount of support: Not specified.	General Outcomes (treatment effect): Positive pooled effect. Adverse effects: Not reported.	RCTs	High (9/11)

JASPER								
Waddington et al. (2021)	Setting: Clinics, homes, educational settings, other. Format: Individuals, groups. Agent: Parents/caregivers, early childhood staff, clinicians/researchers. Mode: Face-to-face. Amount of support: Not specified.	Overall autism characteristics (core characteristics of ASD): Null summarised effect*. Social-communication (joint attention and engagement): Positive summarised effect*. Communication (child communication skills): Positive summarised effect*. Expressive language (overall expressive language): Inconsistent summarised effect*. Receptive language: Inconsistent summarised effect. Play: Positive summarised effect*.	RCTs	High (9/10)				
		Adverse effects: Not reported.						

\* This effect is presented in the summary table in Appendix 6.13 (Effect of type of support on child and family outcomes).

<sup>1</sup> This summary of findings is also presented in the 'Delivery Characteristics table' (Appendix 6.11) under 'Agent (parent mediated, pivotal response treatment)'

### Sensory-based Supports

	Characteristics of supports included in the systematic review	Findings form the systematic review	Study designs	Quality (systematic review)
Systematic re	views at the category level			
Sandbank et al. (2020)	Label: Sensory-based supports. Setting: Not specified.	Communication (language): Null pooled effect*.	RCTs, non- randomised with	High (10/11)
	Format: Not specified. Agent: Not specified. Mode: Not specified. Amount of support: not specified Practices: Developmental Speech and Language Training through	Adverse effects: Not reported.	comparison	
	Music; Family-Centered Music			

	Therapy; Improvisational Music			
	Therapy; Music Therapy; Qigong			
	(QST) Massage Treatment; Qigong			
	Massage Treatment; Rhythm			
	Intervention Sensorimotor			
	Enrichment; Sensory Enrichment;			
	Thai Traditional Massage; Tomatis			
	Sound Therapy; Vestibular			
	Stimulation via a Platform Swing			
Systematic re	eviews at the practice level			
Music therap	у			
Geretsegger	Setting: Clinic, home, educational,	Social-communication (social adaptation – overall):	RCTs, non-	High
at al. (2014)	hospital.	Positive pooled effect*.	randomised with	(11/11)
	Format: Individual, group with	Communication (non-verbal, overall): Positive	comparison	
	family.	pooled effect*.	(inclusion criteria)	
	Agent: Clinicians/researchers.	Communication (verbal, overall): Positive pooled		
	Mode: Face-to-face.	effect*.		
	Amount of support: Not specified.	Caregiver social emotional wellbeing (quality of		
		family relationships): Positive pooled effect*.		
		Adverse effects: Considered, and none identified.		
Mayer-	Setting: Home.	Social-communication (joint attention): Null	RCTs, non-	High (8/10)
Benarous et	Format: Individuals, groups.	summarised effect.	randomised with	
al. (2021)	Agent: Not specified.		comparison, non-	
	Mode: Face-to-face.	Adverse effects: Not reported.	randomised	
	Amount of support: Not specified.		without	
			comparison, other	
			study designs	

Treatment and Education of Autistic and related Communications Handicapped Children (TEACCH)

	Characteristics of supports included in the systematic review	Findings form the systematic review	Study designs	Quality (systematic review)
Systematic	reviews at the category level			
Sandbank et al. (2020)	Label: TEACCH Setting: Not specified. Format: Not specified. Agent: Not specified. Mode: Not specified. Amount of support: Not specified. Practices: TEACCH.	Social communication: Null pooled effect*. Adverse effects: Not reported.	RCTs, non-randomised with comparison	High (10/11)

### Technology-based supports

	Characteristics of supports included in the systematic review	Findings form the systematic review	Study designs	Quality (systematic review)
Systematic revie	ews at the category level	1		
Mazon et al. (2019)	Label: Technology-based support.Setting: Clinic, home,educational, therapeutic centre,overtime clinicFormat: Individual.Agent: Not specified.Mode: Face-to-face, computerassisted, robot.Amount of support: Notspecified.Practices: Technology basedsupports including (but not	General outcomes (statistical significance): Inconsistent summarised effect. Adverse effects: Considered and identified: "6 participants were excluded due to refusal or distress" (p. 243-244 of the original article).	RCTs, non- randomised with comparison	Low (6/10)

	limited to) computer and robot-			
	based supports.			
Khan et al.	Label: Web-Based Supports.	General outcomes (condition-specific outcomes	RCTs only	High (9/11)
(2019)	Setting: Clinic, home,	or reducing comorbid psychological symptoms):		
	educational, hospital.	Inconsistent summarised effect*.		
	Format: Individual.			
	Agent: Parents/caregivers,	Adverse effects: Considered, and none identified.		
	clinicians/researchers.			
	Mode: Face-to-face, apps, serious			
	games, online.			
	Amount of support: Not			
	specified.			
	Practices: Apps; serious games;			
	videoconferencing; virtual			
	environment with playable			
	games; Web-based cognitive			
	behavioural therapy (CBT).			
Sandbank et al.	Label: Technology-based	Social-communication: Null pooled effect*.	RCTs, non-	High
(2020)	supports.	Social-emotional development: Null pooled	randomised with	(10/11)
	Setting: Not specified.	effect*.	comparison	
	Format: Not specified.			
	Agent: Not specified.	Adverse effects: Not reported.		
	Mode: Not specified.			
	Amount of support: Not			
	specified.			
	Practices: ABRACADABRA;			
	Emotiplay Serious Game;			
	FaceSay; FindMe iPad App;			
	Gaming Open Library for			
	Intervention in Autism at Home			
	(GOLIAH); Gaze-contingent			
	attention training; Social Skills			
	Training using a robotic			
	behavioral intervention system;			

Sandgreen et al. (2021)	The Transporters animated series; Therapy Outcomes By You (TOBY) App; Transporters DVD; Transporters Program for Children with Autism Setting: Not specified. Format: Individuals. Agent: Early childhood staff, clinician/researcher. Mode: Online contact with a therapist, computer, tablet app, DVD, robot. Amount of support: Not specified. Practices: Computer programs,	Child age: The child's age (age group <5 years, 5- 10 years, >10-15 years) was not related to the effect of support on general outcomes. Adverse effects: Not reported.	RCTs, non- randomised with comparison	Low (8/11)
	tablet apps, robots, interactive DVD.			
Systematic review	vs at the practice level	1		
Apps				
Moon et al. (2019)	Setting: Clinic, home, educational. Format: Individual. Agent: Not specified. Mode: Face-to-face. Amount of support: Not specified.	Social-communication: Null pooled effect*. Communication (gestures): Null pooled effect*. Communication (symbolic): Null pooled effect*. Expressive language: Null pooled effect*. Expressive language (words produced): Null pooled effect*. Receptive language: Null pooled effect*. Cognitive development (visual reception): Positive pooled effect*. Motor (fine motor): Positive pooled effect*.	RCTs only	High (10/11)

Griffith et al.	Setting: Home, educational.	Social-communication: Null summarised effect.	RCTs, non-	High (8/10)
(2020)	Format: Individual.		randomised with	
	Agent: Not specified.	Adverse effects: Not reported.	comparison	
	Mode: Face-to-face, apps.			
	Amount of support: not specified			
Valentine et al.	Setting: Home.	General outcomes (clinical effectiveness):	RCTs, non-	High (9/10)
(2020)	Format: Not specified.	Inconsistent summarised effect*.	randomised with	
	Agent: Not specified.		comparison,	
	Mode: Tablet/mobile apps.	Adverse effects: Not reported.	single case	
	Amount of support: Not		experimental	
	specified.		designs, other	
			designs	
Computer progra	ammes and robots (social skills trainir		1	1
Soares et al.	Setting: Educational settings	Social-communication (social functioning):	RCTs.	High (9/11)
(2021) <sup>1</sup>	Format: Not specified.	Positive pooled effect*.		
	Agent: Early childhood staff,			
	clinicians/researchers.	Adverse effects: Not reported.		
	Mode: Computers and robots.			
	Amount of support: Not			
	specified.			
Gaming				
Valentine et al.	Setting: Home.	General outcomes (clinical effectiveness):	RCTs, non-	High (9/10)
(2020)	Format: Not specified.	Positive summarised effect*.	randomised with	
	Agent: Not specified.		comparison,	
	Mode: Gaming	Adverse effects: Not reported.	single case	
	Amount of support: Not		experimental	
	specified.		designs, other	
			designs	
Mobile technolog	gy			
Leung et al.	Setting: Not specified.	General outcomes (effectiveness): Inconsistent	RCTs	Low (7/10)
(2021)	Format: Not specified.	summarised effect*.		

	Agent: Peers/siblings, early childhood staff. Mode: Mobile/tablet Amount of support: Not specified.	Adverse effects: Not reported.		
Video games (soc	cial training)			
Jiménez-Muñoz et al. (2022) <sup>2</sup>	Setting: Homes, early childhood settings, other. Format: Individuals. Agent: Not specified. Mode: Video games. Amount of support: Not specified.	General outcomes (main findings): Positive summarised effect*.	RCTs, non- randomised with comparison non- randomised without comparison, other study designs.	Low (7/10)
Video/DVD/Video	o modelling			
Valentine et al. (2020)	Setting: Home. Format: Not specified. Agent: Not specified. Mode: Video/DVD/Video modelling. Amount of support: Not specified.	General outcomes (clinical effectiveness): Positive summarised effect*. Adverse effects: Not reported.	RCTs, non- randomised with comparison, single case experimental designs, other designs	High (9/10)

<sup>1</sup>This summary of findings is also presented under 'Other supports (social skills training, delivered by computer programmes and robots)' <sup>2</sup>This summary of findings is also presented under 'Other supports (social skills, video games)'

#### Animal-assisted supports

	Characteristics of supports included in the systematic review	Findings form the systematic review	Study designs	Quality (systematic review)
Systematic re	eviews at the practice level			

Equine assist	ted therapy			
Dimolareva & Dunn (2021)	Setting: Not specified. Format: Not specified. Agent: Not specified. Mode: Animal-assisted. Amount of support: Not specified. Practices: Hippotherapy, Equine assisted therapy, therapeutic horse-riding, equine assisted activity.	Overall autism characteristics (global measures of ASD): Null pooled effect*. Social-communication (social interaction): Positive pooled effect*. Language (communication): Positive pooled effect*. Amount of support: The amount of support (minutes engaged in therapy) was not related to the effect of support on overall autism characteristics, social- communication, or communication (language). Adverse effects: Not reported.	Non-randomised without comparison, other designs not specified	Low (8/11)
Trzmiel et al. (2019)	Setting: Not specified. Format: Individual. Agent: Not specified. Mode: Face-to-face, equine. Amount of support: Not specified.	Social-communication (social): Null pooled effect. Communication: Null pooled effect. Adaptive behaviour: Null pooled effect*. Adverse effects: Not reported.	Not specified	Low (7/11)
Canine assis	ted therapy			
Hardy & Weston (2020)	Setting: Not specified. Format: Individual. Agent: Not specified. Mode: Face-to-face, canine. Amount of support: Not specified.	Social communication (social behaviour): Positive summarised effect*. Adverse effects: Not reported.	Not specified	Low (6/10)

#### Cognitive behavioural therapy

Characteristics of supports	Findings form the systematic review	Study designs	Quality
included in the systematic			(systematic
review			review)

Ho et al. (2014)	Label: Cognitive behavioural approaches. Setting: Clinic. Format: Individual, group. Agent: Parents/caregivers, peers/siblings, clinicians/researchers. Mode: Face-to-face. Amount of support: M = 10.8 hours (7 – 18 hours)	Social-communication (social skills): Positive pooled effect*. Adverse effects: Not reported.	RCT only	Low (7/11)
Wang et al. (2021b)	Setting: Other. Format: Individuals, groups. Agent: Parents/caregivers, early childhood staff, other. Mode: Face-to-face. Amount of support: Not specified.	Overall autism characteristics (Symptoms related to         ASD- self-reported outcomes): Null pooled effect*.         Overall autism characteristics (Symptoms related to         ASD – informant reported outcomes): Positive pooled         effect*.         Overall autism characteristics (Symptoms related to         ASD – clinician reported outcomes): Negative pooled         effect*.         Overall autism characteristics (Symptoms related to         ASD – clinician reported outcomes): Negative pooled         effect*.         Overall autism characteristics (Symptoms related to         ASD – task-based outcomes): Positive pooled effect*.         Social emotional/challenging behaviour (Symptoms of social-emotional problems – self reported outcomes):         Null pooled effect*.         Social emotional/challenging behaviour (Symptoms of social-emotional problems – informant reported outcomes):         Null pooled effect*.         Child age: The relationship between the child's age (mean age: <10, ≥10) and both overall autism characteristics and social emotional/challenging behaviour was inconsistent. The child's age was not related to the effect of support on self-report, clinician	RCTs	High (9/11)

<ul> <li>ratings, and task-based ratings of overall autism</li> <li>characteristics. The child's age was positively associated</li> <li>with the effect of support on informant-reported overall</li> <li>autism characteristics. Children aged ≥10 showed</li> <li>greater reductions than those aged &lt;10. The child's age</li> <li>was not related to the effect of support on self-report</li> <li>and informant report ratings of social</li> <li>emotional/challenging behaviour. The child's age was</li> <li>negatively associated with the effect of support on</li> <li>clinician rated social emotional/challenging behaviour.</li> <li>Children aged &lt;10 showed greater reductions than</li> <li>those aged ≥ 10.</li> </ul> Format: The format (group based, individual based)	
was not related to the effect of support on self- reported, informant reported, or clinician ratings of overall autism characteristics or social-emotional development or task-based ratings of overall autism characteristics.	
Adverse effects: Not reported.	

### Other Supports

	Characteristics of supports included in the systematic review	Findings form the systematic review	Study designs	Quality (systematic review)
Social skills	training (Delivered by computer progi	rammes and robots)		
Soares et al. (2021) <sup>1</sup>	Setting: Educational settings Format: Not specified. Agent: Early childhood staff,	Social-communication (social functioning): Positive pooled effect*.	RCTs.	High (9/11)
	clinicians/researchers.	Adverse effects: Not reported.		

	Mode: Computers and robots.			
	Amount of support: Not specified.			
Social skills	(video games)			
Jiménez- Muñoz et	<b>Setting:</b> Homes, early childhood settings, other.	General outcomes (main findings): Positive summarised effect*.	RCTs, non- randomised with	Low (7/10
al. (2022) <sup>2</sup>	Format: Individuals. Agent: Not specified.	Adverse effects: Not reported.	comparison non- randomised	
	Mode: Video games.		without	
	Amount of support: Not specified.		comparison, other study designs.	
UCLA Progra	m for the Education and Enrichment		1	
Zheng et al. (2021)	<b>Setting:</b> Clinics, educational settings, other.	Social-communication (Self-reported social knowledge – TASSK): Positive pooled effect*.	RCTs, non- randomised	Low (8/11)
	Format: Groups. Agent: Parents/caregivers, early	Social-communication (Parent-reported social knowledge – SSiS): Positive pooled effect.	without comparison.	
	childhood staff, clinican/researcher.	Social-communication (SRS - parent-reported social knowledge): Positive pooled effect*.		
	Mode: Face-to-face. Amount of support: Not specified.	Community participation (Get togethers - self-report QSQ): Positive pooled effect*.		
	Anount of support. Not specifica.	Community participation (Get togethers - parent- report QSQ): Positive pooled effect*.		
		Adverse effects: Not reported.		

<sup>1</sup>This summary of findings is also presented under 'Technology-based supports (computer programmes and robots, social skills training)' <sup>2</sup>This summary of findings is also presented under 'Technology-based supports (social skills, video games)'

Footnote: "Label" refers to the term used by the authors of the systematic review to describe the category of supports being examined; "Practices" refers to the practices described verbatim by the authors as being included in the systematic review; participants in the support group of a systematic review generally only received one practice, though this was not always specified; "pre-support" refers to child characteristics measured prior to the delivery of support; Only outcomes for which evidence was available are included; "Outcomes ()" the first term refers to the outcome categories defined for this umbrella review, the term in parenthesis refers to the author's term(s) for the outcome, where there is no term in brackets, the systematic review author's outcome classification matched that of the current umbrella review; "risk of bias (included studies)" refers to the risk of bias, as assessed by the authors of the systematic review and appraised by current authors during data extraction, the rating indicates the lower bound of quality/risk of bias for studies included in the review.

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Appendix 5.10	Umbrella review - Summary of findings from outcome-
Appendix 5.10	focussed systematic reviews

	Characteristics of supports included in the systematic review	Findings form the systematic review	Study designs	Quality (systematic review)
Social communication				
Murza et al. (2016)	Setting: Clinic, home, educational. Format: Individual, group. Agent: Parents/caregivers, educators, clinicians/researchers. Mode: Face-to-face.	Social-Communication (joint attention): Positive pooled effect. Adverse effects: Not reported.	RCT only	High (9/11)
	Amount of support: 12 – 1196 hours Practices: Joint attention interventions - Assessment, Evaluation and Programming System (AEPS) for Infants and Children; Caregiver Education Model (CEM); Caregiver Mediated Model (CMM); Hanen More Then Words (UMTW): Laint Attention			
	Than Words (HMTW); Joint Attention Mediated Learning (JAML); Joint Attention Symbolic Play Engagement and Regulation (JASPER); Milton and Ethel Harris Research Initiative (MEHRI); Preschool Autism Communication Trial (PACT); parent			
	training modules; and workshop training.			
Parsons, Cordier, Munro et al. (2017)	Setting: Clinic, home, educational. Format: Individual, group. Agent: Parents/caregivers, peers/siblings, educators,	<b>Social-communication</b> (pragmatic language): Positive pooled effect.	RCT only	Low (7/10)

# Appendix 5.10 - Umbrella review - Summary of findings from outcome-focussed systematic reviews

	clinicians/researchers, certified therapeutic riding instructor. <b>Mode:</b> Face-to-face, computer assisted. <b>Amount of support:</b> 4 – 1092 hours. <b>Practices:</b> Pragmatic language interventions - The Junior detective Program; Milton and Ethel Harris Research Initiative Treatment (MEHRIT); Building Blocks Program; Social Emotional NeuroScience Endocrinology (SENSE) theatre; Social Skills Group Intervention- High Functioning Autism; FindMe App; Therapeutic Horse Riding; FaceSay; Joint Attention, Symbolic Play, Engagement, and Regulation (JASPER); Improvisational music therapy; SummerMAX; Mind Reading; Skillstreaming; Emotion Recognition Training; Seaver- NETT.	Child age: Age not related to the effect of support on social communication. Setting: Setting not related to the effect of support on social communication. Format: Format (individual, group) not related to the effect of support on social communication. Agent: Positive effect of support for supports with active parent involvement, but not for supports with parent education alone. Adverse effects: Not reported.		
Bejarano-Martín et al. (2020)	Setting: Not specified.Format: Individual.Agent: Parents/caregiver, peers/siblings, educators, clinicians/researchers.Mode: Face-to-face.Amount of support: Not specified.Practices: Focused practices - Discrete trial training (DTT); Pivotal Response Training (PRT), Contingent imitation; discrete trial training (DTT) plus social interaction, mediated learning with	Social-communication: Positive pooled effect. Social-communication (imitation): Positive pooled effect. Social-communication (joint attention): Positive pooled effect. Social-communication (play): Positive pooled effect.	RCTs, non- randomised with comparison, single-case experimental designs (inclusion criteria)	High (9/11)

	active engagement; picture exchange communication system (PECS); video modelling; prompting and reinforcement; physical and verbal cues; token economy and prompting; photographic schedules.	Child age: Age negatively associated with the effect of support on social- communication. Communication: Child communication skills prior to support not related to the effect of support on social- communication. Cognitive development: Child cognitive development prior to support not related to the effect of support on social- communication. Amount of support: Amount of support (total hours) not related to the effect of support on social-communication. Agent: Agent (caregivers, teachers, clinicians) not related to effect of support on social- communication. Adverse effects: Not reported.		
Expressive language	Cotting of Notice of Cont	<b>F</b>	D 1	II. 1.
Hampton & Kaiser	Setting: Not specified.	Expressive language (spoken	Randomised	High
(2016)	Format: Individual.	language): Positive pooled	controlled	(10/11)
	Agent: Parents/caregivers,	effect.	trials, non-	
	clinicians/researchers.		randomised	
	Mode: Face-to-face.	Child age: Age not related to	with .	
	Amount of support: Not specified.	the effect of support on	comparison	

	Practices: Early interventions- Early Intensive Behavioural Intervention (EIBI); Early Intervention Preschool (EIP); Early Start Denver Model (ESDM); Joint Attention Mediated Learning (JAML); Joint Attention; Structured Play Engagement; and Regulation (JAML); Learning Experiences and Alternative Program (LEAP); Milton and Ethel Harris Research Initiative Treatment (MEHRIT); More Than Words (MTW); Pediatric Autism and Communication Therapy (PACT); Play and Language for Autistic Youngsters; PRT, Pivotal Response Training (Play and Language for Autistic Youngsters); Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH); Scottish Early Intervention Preschool; Parent training model (PSwA); Focused playtime (FPI); Speech remediation; Teach Town basics; Early Social Interaction (ESI); Parent training, Behaviour analytic.	expressive language (spoken language). Amount of support: Amount of support (total hours) not related to the effect of support on expressive language (spoken language). Agent: Supports involving clinicians and caregivers related to greater effect of support on expressive language (spoken language) than clinicians or caregivers alone. Adverse effects: Not reported.		
Play Kant at al. (2020)	Sotting Clinic have alwayting 1	Dery Desitive needed affect	DCT anla	ILinh
Kent et al. (2020)	Setting: Clinic, home, educational, community (theatre group). Format: Individual, group. Agent: Parents/caregivers, peers/siblings, educators, clinicians/researchers, unfamiliar adults. Mode: Face-to-face.	<b>Play:</b> Positive pooled effect. <b>Format</b> : Format (individual, group) did not relate to the effect of support on play.	RCT only	High (10/11)

Amount of supp	port: Not specified.	Setting: Setting (clinic, home)	
Practices: Play-	based interventions-	not related to the effect of	
[Generic] play ir	ntervention; Joint	support on play skills.	
Attention, Symb	olic Play, Engagement,		
and Regulation (	(JASPER); Lego	Adverse effects: Not reported.	
therapy; Social s	tories; behavioural	-	
approaches; peer	r training; teacher		
training; Social	2		
Emotional Neuro	oScience Endocrinology		
(SENSE) Theate	r principles; video		
modelling.			

Footnote: "Outcomes ()" the first term refers to the outcome categories defined for this umbrella review, the term in parenthesis refers to the author's term(s) for the outcome, where there is no term in brackets, the systematic review author's outcome classification matched that of the current umbrella review.

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Appendix 5.11	Umbrella review - Summary of findings from delivery-
Appendix 5.11	focussed systematic reviews

## Appendix 5.11 - Umbrella review - Summary of findings from deliveryfocussed systematic reviews Setting

	Characteristics of supports included in the systematic review	Findings form the systematic review	Study designs	Quality (systematic review)
Inclusiv	e school setting			
Tupou et al. (2019)	Setting: Educational.Format: Individual, group.Agent: Educators.Mode: Face-to-face.Amount of support:Not specified.Practices:Comprehensivetreatmentprogrammes -DevelopmentallyAppropriateTreatment for Autism(DATA); Treatmentand Education ofAutistic and RelatedCommunicationHandicappedChildren (TEACCH);Early IntensiveBehaviouralIntervention (EIBI);Learning Experiencesand AlternativeProgram forPreschoolers (LEAP);ComprehensiveAutism Program(CAP); EIBIintervention describedas being based onLovaas' UCLAmodel; Skills focusedinterventionstargeting -	Overall autism characteristics (autism severity and/or symptoms): Positive summarised effect. Social communication (social skills): Positive summarised effect. Communication (communication and/or language): Positive summarised effect. Social-emotional development (adaptive/maladaptive behaviour): Positive summarised effect. Adaptive behaviour (functional skills): Positive summarised effect. Adverse effects: Not reported.	Randomised controlled trials, non- randomised with comparison, non- randomised without comparison, single-case experimental designs	High (9/10)

communication, play		
skills, peer		
interaction, and		
reading skills.		

### Format

	Characteristics of supports included in the systematic	Findings form the systematic review	Study designs	Quality (systemati
	review	systematic review	ucorgno	c review)
Individual,	group			
Tachibana	Setting: Clinic, home,	Overall autism	RCT only	High
et al.	educational.	characteristics		(11/11)
(2018)	Format: Individual, group.	(autism general		
	Agent: Parents/caregivers,	symptoms –		
	educators, clinicians/researchers.	individual		
	Mode: Face-to-face.	intervention): Null		
	Amount of support: Not	pooled effect.		
	specified.	Social		
	Practices: Social communication	communication		
	intervention - Hanen's More Than	(qualitative		
	Words; Early Start Denver Model	impairment in social		
	(ESDM); Parent training; Joint	interaction –		
	Attention Symbolic Play	individual		
	Engagement and Regulation	intervention): Null		
	(JASPER); Preschool Autism	pooled effect. Social		
	Communication Trial (PACT);	communication		
	Treatment and Education of	(reciprocity of social		
	Autistic and related	interaction towards		
	Communications Handicapped	others – individual		
	Children (TEACCH)-based group	intervention):		
	social skills; Reciprocal Imitation	Positive pooled effect.		
	Training; Caregiver-based	Social		
	intervention program in	communication		
	community day-care centers;	(reciprocity of social		
	Preschool-based joint attention	interaction towards		
	intervention; Caregiver Mediated	others – group		
	Joint Engagement Intervention;	intervention):		
	Improvisational music therapy;	Positive pooled effect.		
	intervention targeting development	Social		
	of socially synchronous	communication		
	engagement; Developmental,	(initiating joint		
	Individual-Difference,	attention-individual		
	Relationship-	intervention): Null		
	Based(DIR)/Floortime interventio	pooled effect.		

n. Eventional Datavian Chills	Social
n; Functional Behavior Skills	Social
Training (FBST); Building Blocks	
Parent delivery of the Early Start	(initiating joint
Denver Model (P-ESDM); Joint	attention – group
Attention Mediated Learning	intervention): Null
(JAML) intervention; Focused	pooled effect.
Playtime Intervention (FPI);	Social
Education and Skills Training	communication
Program for Parents; Parent	(imitation): Null
education and behaviour	pooled effect.
management (PEBM) Skills	Social
training intervention or	communication
comparison for the on specific	(responding to joint
aspects of the PEBM parent	attention – individual
education and counselling	intervention): Null
intervention; Home TEACCHing	pooled effect.
Program.	Restricted and
	repetitive interests
	and behaviours
	(restricted repetitive
	and stereotyped
	patterns behaviours,
	interests and
	activities- individual
	intervention): Null
	pooled effect.
	Communication
	(qualitative
	impairment in
	communication –
	individual
	intervention): Null
	pooled effect.
	Expressive language
	(individual
	intervention): Null
	pooled effect.
	Expressive language
	(group intervention):
	Null pooled effect.
	Receptive language
	(individual
	intervention): Null
	pooled effect.

Receptive language
(group intervention):
Null pooled effect.
Cognitive
development
(developmental
quotient – individual
intervention):
Positive pooled effect.
Adaptive behaviour
(individual
intervention): Null
pooled effect.
Adaptive behaviour
(group intervention):
Null pooled effect.
Caregiver
communication and
interaction (parental
synchrony-
individual
intervention):
Positive pooled effect.
Caregiver social
emotional wellbeing
(parenting stress –
individual
intervention): Null
pooled effect.
Caregiver social
emotional wellbeing
(parenting stress –
group intervention):
Null pooled effect.
Format: Format
(individual, group) did
not relate to the effect
of support on overall
autism characteristics,
social-communication,
expressive language,
receptive language,
Cognitive
development, or
adaptive behaviour.

Groun-base	ed (parent training)	Adverse effects: Not reported.		
O'Donova	Setting: Homes.	Social	Randomise	Low (6/10)
n et al.	Format: Individuals, groups.	emotional/challengin	d controlled	
$(2019)^1$	Agent: Parents/caregivers, early	g behaviour	trial, non-	
	childhood staff.	(problematic	randomised	
	Mode: Not specified.	behaviours): Positive	with	
	Amount of support: Not	summarised effect.	comparison	
	specified.	Caregiver	, non-	
	Practices: Group-based parent	communication and	randomised	
	training interventions: The	interaction (parental	without	
	National Autistic Society (NAS)	skills): Positive	comparison	
	EarlyBird and EarlyBird Plus	summarised effect.	, other	
	Programme (EBPP);		study	
	'Understanding autism and	Adverse effects: Not	designs	
	understanding my child with	reported		
	autism' (UA); TEACCH-based;			
	Incredible Years; Generic support			
	group; Parent management			
	training (PMT); Sleep education			
	workshops; 'Riding the Rapids:			
	Living with Autism or Disability';			
	Psychoeducation groups; 'Riding			
	the Rapids: Living with Autism or			
	Disability'; Parent Education and			
	Behaviour Management (PEBM).			

<sup>1</sup> This summary of findings is also presented under 'Agent (parent training, group based)'

## Agent

Non-special	Characteristics of supports included in the systematic review ist implemented/mediated	Findings form the systematic review	Study designs	Quality (systematic review)
Naveed et al. (2019)	Setting: Clinic, home, educational, community. Format: Individual. Agent: Parents/caregivers, siblings/peers, educators. Mode: Face-to-face, telepractice.	Overall autism characteristics (autism symptom severity): Positive pooled effect. Social communication (social skills): Positive pooled effect. Social communication (joint engagement): Positive pooled effect.	RCT only	High (9/11)

Amount of support: Not	Social communication (joint	
specified.	attention): Null pooled effect.	
Practices: Cognitive	Restricted and repetitive	
behavioural strategies	interests and behaviours	
(CBT); Social Emotional	(repetitive behaviours):	
NeuroScience	Positive pooled effect.	
Endocrinology (SENSE)	<b>Communication:</b> Positive	
theatre; Preschool Autism	pooled effect.	
Communication Trial	Expressive language:	
(PACT); Parent mediated	Positive pooled effect.	
intervention for Autism	Receptive language: Null	
Spectrum Disorders in	pooled effect.	
South Asia (PASS);	Cognitive development	
Project Impact; Peer	(visual reception): Positive	
interventions; Qigong	pooled effect.	
Sensory Treatment	Motor (motor skills): Positive	
(QST); Qigong massage;	pooled effect.	
Joint Attention, Symbolic	Social-emotional	
Play, Engagement, and	development (self-	
Regulation programme	regulation): Positive pooled	
(JASPER); Play project;	effect.	
LEAP project i.e.	Adaptive behaviour: Null	
Learning Experiences and	pooled effect.	
Alternative Program for	Caregiver social emotional	
Preschoolers and Their	wellbeing (parental distress):	
Parents; Hanen's more	Positive pooled effect.	
than words (HMTW)	Caregiver social emotional	
intervention program;	wellbeing (parental self-	
Peer network intervention	efficacy): Positive pooled	
procedure; family	effect.	
centered music therapy;	Caregiver social emotional	
The Managing Repetitive	wellbeing (parent-child	
Behaviours Programme;	relationship): Positive pooled	
psychoeducation	effect.	
program; autism	Child satisfaction (child	
preschool program; Video-feedback	distress): Positive pooled	
	effect.	
Intervention to promote	Child ago: Ago not related to	
Positive Parenting	<b>Child age:</b> Age not related to	
adapted for Autism; Social ABCs; Parent-	the effect of support.	
mediated intervention for	Amount of support: Number	
Autism Spectrum	of support sessions not related	
Disorders in South Asia	to the effect of support.	
(PASS) plus; enhancing	Advarsa officits. Not reported	
interactions tutorial;	Adverse effects: Not reported.	
moractions tutorial,		

	a 117 1 1 1 1 1 1			
	Social Tools And Rules			
	for Teens socialization			
	(START); COMPASS for			
	Hope; Program for the			
	Education and			
	Enrichment of Relational			
	Skills (PEERS)			
	curriculum; Therapeutic			
	Outcome By You			
	(TOBY) application.			
Parent-impl	emented/mediated		•	·
Oono et al.	Setting: Clinic, home,	Overall autism	RCT only	High
(2013)	out of home locations.	characteristics (severity of	5	(11/11)
()	Format: Individual,	autism characteristics):		()
	group.	Positive pooled effect.		
	Agent:	Social communication		
	Parents/caregivers.	(shared or joint attention):		
	Mode: Face-to-face, self-	Positive pooled effect.		
	training with a manual	Social communication (child		
	and videotapes.	initiations): Null pooled		
	Amount of support: Not	effect.		
	specified.	<b>Communication:</b> Null pooled		
	Practices:	effect.		
	Developmental	Communication (joint		
	Individual-Difference	language): Null pooled effect.		
	Relationship-Based (DIR)	Expressive language		
	techniques; massage	(expression - direct or		
	intervention; management	independent assessment):		
	of challenging behaviour;	Null pooled effect.		
	early intensive	Receptive language		
	behavioural intervention;	(comprehension - direct or		
	Pivotal Response	· •		
	Treatment (PRT).	independent assessment): Null pooled effect.		
	Treatment (FKT).	Cognitive development		
		(developmental/intellectual		
		· -		
		<b>gains):</b> Positive summarised effect.		
		Social-emotional		
		development (maladaptive		
		<b>behaviour):</b> Null summarised effect.		
		Adaptive behaviour: Null		
		pooled effect.		
		Caregiver communication		
		and interaction (parental		

		<ul> <li>synchrony): Positive pooled effect.</li> <li>Caregiver social emotional wellbeing (parents' level of stress): Null pooled effect.</li> <li>Adverse effects: Not reported.</li> </ul>		
Nevill et al. (2018)	Setting: Clinic, home, community. Format: Individual, group. Agent: Parents/caregivers. Mode: Face-to-face. Amount of support: Not specified. Practices: Child's Talk Project; Hanen's More than Words (HMTW); DIR/Floortime; Parent Focus Training; Joint Attention Symbolic Play Engagement and Regulation (JASPER); Pivotal Response Training (PRT); Video Intervention to promote Positive Parenting for children with Autism (VIPP-AUTI); Home- based program; Building Blocks; Focused Playtime Intervention; Play and Language for Autistic Youngsters (PLAY) Project; Preschoolers with Autism; Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH); Social Communication, Emotion Regulation, and Transactional Supports	Overall autism characteristics (autism symptom severity): Positive pooled effect. Social communication (socialisation): Positive pooled effect. Communication (language): Positive pooled effect. Cognitive development: Positive pooled effect. Amount of support: Amount of support (total hours) not related to the effect of support on overall autism characteristics (symptom severity), social- communication (socialisation), communication (language), or cognitive development. Adverse effects: Not reported.	RCT only	Low (7/11)

	(SCERTS); Parent-			
	mediated			
	Communication-focused			
	Treatment (PACT).			
Tarver et	Setting: Not specified.	Social-emotional	RCT only	Low (8/11)
al. (2019)	Format: Individual,	development (parent-		
	group, workshops.	reported disruptive		
	Agent:	behaviour): Positive pooled		
	Parents/caregivers.	effect.		
	Mode: Face-to-face.	Social-emotional		
	Amount of support: Not	development (parent-		
	specified.	reported hyperactivity):		
	<b>Practices:</b> Behavioural	Positive pooled effect.		
	parent interventions –	Caregiver social emotional		
	Research Units in	wellbeing (parenting stress):		
	Behavioural Intervention	Positive pooled effect.		
	(RUBI) Parent Training	Caregiver social emotional		
	Manual; Child directed	wellbeing (parenting		
	interaction therapy	efficacy): Null pooled effect.		
	(CDIT); Compass for	cincacy). Nun pooled eneet.		
	help (C-HOPE); Parent	Adverse effects: Not reported.		
	management training;	Auverse enects. Not reported.		
	0			
	parent-child interaction			
	therapy (PCIT); Primary			
	care stepping stones Tripe			
	P (PCSSTP); Stepping			
	stones triple P (SSTP).			
Parent train	0			
Postorino	Setting: Clinic.	Social-emotional	Randomised	Low (7/11)
et al.	Format: Individual,	development (disruptive	controlled	
(2017)	group.	behaviour): Positive pooled	trials, non-	
	Agent:	effect.	randomised	
	Parents/caregivers.		with	
	Mode: Face-to-face,	Adverse effects: Not reported.	comparison	
	telepractice.		_	
	<b>Amount of support:</b> Not			
	specified.			
	<b>Practices:</b> Parent training			
	for disruptive behaviour			
Parent focu	ssed training	1	1	1
Deb et al.,	Setting: Home,	General Outcomes	Randomised	High (9/11)
2020	educational settings,	(treatment effect): Positive	controlled	111gii (7/11)
2020	other.		trials	
		pooled effect.	ulais	
	Format: Individuals,	A decourse offer the NT (		
	groups.	Adverse effects: Not reported.		

	Agent: Parents/caregivers, early childhood staff, clinicians/researchers, other. Mode: Face-to-face, telehealth, other. Amount of support: Not specified. Practices: Parent			
	focussed training.			
Parent train	ing (group based)	I	I	I
O'Donovan et al. (2019) <sup>1</sup>	Setting: Homes. Format: Individuals, groups. Agent: Parents/caregivers, early childhood staff. Mode: Not specified. Amount of support: Not specified. Practices: Group-based parent training interventions: The National Autistic Society (NAS) EarlyBird and EarlyBird Plus Programme (EBPP); 'Understanding autism and understanding my child with autism' (UA); TEACCH-based; Incredible Years; Generic support group; Parent management training (PMT); Sleep education workshops; 'Riding the Rapids: Living with Autism or Disability'; Psychoeducation groups; 'Riding the Rapids: Living with Autism or Disability'; Parent Education and Behaviour Management (PEBM).	Social emotional/challenging behaviour: Positive summarised effect. Caregiver communication and interaction (parental skills): Positive summarised effect. Adverse effects: Not reported	Randomised controlled trial, non- randomised with comparison, non- randomised without comparison, other study designs	Low (6/10)

Parent train	ning (delivered by apps or DV	/ <b>D</b> s)	I	I
Pi et al. (2021) <sup>2</sup>	Setting: Not specified. Format: Groups. Agent: Parents/caregivers. Mode: Telehealth, apps, DVDs Amount of support: Not specified. Practices: Technology assisted parent-mediated intervention: App-based interventions, online/web based, computer based, DVD-based.	Social-communication: Null summarised effect. Social-communication (socialisation): Null summarised effect. Communication (language total score): Null summarised effect. Communication (gestures): Null summarised effect. Expressive language (expressive speech): Null summarised effect. Receptive language: Null summarised effect. Adverse effects: Not reported	Randomised controlled trials	Low (8/11)
Parent train	ing (delivered by website or	online platform)		
Tan- MacNeill et al. (2021) <sup>3</sup>	Setting: Not specified. Format: Not specified. Agent: Not specified. Mode: Website or online platform. Amount of support: Not specified. Practices: Online parent implemented intervention: ImPACT online, POWR Online Communication Training; Pivotal response treament (PRT); enhancing interactions; reciprocal imitation training (RIT); ABA Web-Based Training; Enhancing Interactions; FASD Education and Training; Triple P online (TPOL); Project CHASE (children with autism supported to exercise); parent sleep education intervention;	Social-communication (communication behaviours and language targets): Positive summarised effect. Adverse effects: Not reported	Randomised controlled trial, non- randomised with comparison, non- randomised without comparison	High (8/10)

	· · · · · · · · · · · · · · · · · · ·			
	promoting engagement			
	for ADHD pre-			
	Kindergarteners (PEAK),			
	blended behavioural			
	parent training (BPT).			
Parent med	iated (DIR/Floortime)			
Deb et al.	Setting: Home,	General outcomes	RCTs	High (9/11)
$(2020)^4$	educational settings,	(treatment effect): Positive		
	other.	pooled effect.		
	Format: Individuals,	r · · · · · · · · · · · · · · · · · · ·		
	groups.	Adverse effects: Not reported.		
	Agent:			
	Parents/caregivers, early			
	childhood staff,			
	clinicians/researchers,			
	other.			
	Mode: Face-to-face,			
	telehealth, other.			
	Amount of support: Not			
	specified.			
	specificu.			
	iated (pivotal response trea	tment)	1	I
Deb et al.	Setting: Home,	General outcomes	RCTs	High (9/11)
$(2020)^5$	educational settings,	(treatment effect): Positive		
	other.	pooled effect.		
	Format: Individuals,			
	groups.	Adverse effects: Not reported.		
	Agent:			
	Parents/caregivers, early			
	childhood staff,			
	clinicians/researchers,			
	other.			
	Mode: Face-to-face,			
	telehealth, other.			
	Amount of support: Not			
	specified.			
	1 1		1	1

<sup>1</sup> This summary of findings is also presented under 'Format (group-based, parent training)'

<sup>2</sup> This summary of findings is also presented under 'Mode (apps or DVDs, parent training)'

<sup>3</sup> This summary of findings is also presented under 'Mode (website or online platform, parent training)'

<sup>4</sup> This summary of findings is also presented within the 'Categories and Practices table' (Appendix 6.9) under 'Developmental Supports'

<sup>5</sup> This summary of findings is also presented within the 'Categories and Practices table' (Appendix 6.9) under 'Naturalistic Developmental Behavioural Interventions'

### Mode

	Characteristics of supports included in the	Findings form the systematic review	Study designs	Quality (systematic
	systematic review		ucsigns	review)
Telepraction				
Parsons,	Setting: Home.	Caregiver communication	Randomised	High (9/11)
Cordier,	Format: Individual.	and interaction (parental	controlled	
Vaz et al.	Agent:	knowledge acquisition):	trials, non-	
(2017)	Parents/caregivers.	Positive summarised effect.	randomised	
	Mode: Telepractice,		with	
	videoconferencing, DVD,	Adverse effects: Not reported.	comparison,	
	online modules.		non-	
	Amount of support: Not		randomised	
	specified.		without	
	Practices: Web-based		comparison,	
	training in		single-case	
	behavioural interventions;		experimental	
	Online and Applied		designs.	
	System for Intervention			
	Skills (OASIS) training			
	intervention Research-to-			
	practice; Improving			
	Parents as			
	Communication Teachers			
	(ImPACT) on the Web;			
	Implementation discrete-			
	trial instructions using			
	video training materials;			
	Parent Early Start Denver			
	Model (P-EDSM)			
	training; Functional			
	communication training.			
Ferguson	Setting: Clinic, home.	General outcomes (efficacy	Randomised	High (9/10)
et al.	Format: Individual,	outcomes): Positive	controlled	
(2019)	group.	summarised effect.	trials, non-	
	Agent:		randomised	
	Parents/caregivers,	Adverse effects: Not reported.	with	
	peers/siblings, educators,		comparison,	
	clinicians/researchers,		non-	
	other associated		randomised	
	professionals working in		without	
	the field.		comparison,	
	Mode: Telehealth,		single-case	
	written instructions,		experimental	

[]	· 1 0 ·		1 '	
	videoconferencing,		designs,	
	websites, DVDs.		other.	
	Amount of support: Not			
	specified.			
	Practices: Telehealth			
	interventions with			
	behavioural principles-			
	functional analysis (FA);			
	functional			
	communication training			
	(FCT); naturalistic and			
	incidental teaching;			
	behaviour support			
	strategies (e.g., positive			
	behaviour support);			
	preference assessments;			
	Early Start Denver Model			
	(ESDM); Improving			
	Parents as			
	Communication Teachers			
	(imPACT).			
Sutherland		Canaginar satisfaction	Randomised	$I_{avv}(7/10)$
	Setting: Clinic.	Caregiver satisfaction		Low (7/10)
et al.	Format: Individual.	(satisfaction and	controlled	
(2018)	Agent:	acceptability): Positive	trials,	
	Parents/caregivers,	summarised effect.	single-case	
	educators.	Caregiver communication	experimental	
	Mode: Telepractice,	and interaction (fidelity):	designs,	
	online training.	Positive summarised effect.	other.	
	Amount of support: Not			
	specified.	Adverse effects: Not reported.		
	Practices: Program			
	Improving Parents as			
	Communication Teachers			
	(imPACT); internet-based			
	Parent Implemented			
	Communication			
	Strategies (iPICS);			
	general communication			
	intervention; imitation			
	training; Telehealth			
	diagnostic services;			
	'Telehealth Facing Your			
	Fears' Intervention';			
	functional behaviour			
	assessment and functional			
	communication training;			
L			I	

				1
	school age intervention			
	using web-based			
	education; language			
	intervention.			
	VDs (parent training)			
Pi et al.	Setting: Not specified.	Social-communication: Null	Randomised	Low (8/11)
$(2021)^1$	Format: Groups.	summarised effect.	controlled	
	Agent:	Social-communication	trials	
	Parents/caregivers.	(socialisation): Null		
	Mode: Telehealth, apps,	summarised effect.		
	DVDs	Communication (language		
	Amount of support: Not	total score): Null summarised		
	specified.	effect.		
	Practices: Technology	Communication (gestures):		
	assisted parent-mediated	Null summarised effect.		
	intervention: App-based	Expressive language		
	interventions, online/web	(expressive speech): Null summarised effect.		
	based, computer based, DVD-based.			
	DVD-based.	<b>Receptive language:</b> Null summarised effect.		
		summarised effect.		
		Advance offects. Not reported		
		Adverse effects: Not reported		
Website or	online platform (parent tra	aining)		
Tan-	Setting: Not specified.	Social-communication	Randomised	High (8/10)
MacNeill	Format: Not specified.	(communication behaviours	controlled	
et al.	Agent: Not specified.	and language targets):	trial, non-	
$(2021)^2$	Mode: Website or online	Positive summarised effect.	randomised	
	platform.		with	
	Amount of support: Not	Adverse effects: Not reported	comparison,	
	specified.		non-	
	Practices: Online parent		randomised	
	implemented		without	
	intervention: ImPACT		comparison	
	online, POWR Online			
	Communication Training;			
	Pivotal response treament			
	(PRT); enhancing			
	interactions; reciprocal			
	imitation training (RIT);			
	ABA Web-Based			
	Training; Enhancing			
	Interactions; FASD			
	Education and Training;			
1	$T_{min} = D_{min} = (TDOI)$	1		1
	Triple P online (TPOL); Project CHASE (children			

with autism support	ed to		
exercise); parent sle	ep		
education intervention	on;		
promoting engagem	lent		
for ADHD pre-			
Kindergarteners (PI	EAK),		
blended behavioura	1		
parent training (BP)	Г).		
	,		

<sup>1</sup> This summary of findings is also presented under 'Agent (parent training, delivered by apps or DVDs)' <sup>2</sup> This summary of findings is also presented under 'Agent (parent training, delivered by website or online platform)'

Footnote: "Outcomes ()" the first term refers to the outcome categories defined for this umbrella review, the term in parenthesis refers to the author's term(s) for the outcome, where there is no term in brackets, the systematic review author's outcome classification matched that of the current umbrella review

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Appendix 5.12Umbrella review - Quality appraisal ratings

# Appendix 5.12 - Umbrella review - Quality appraisal ratings

Item-level and total quality appraisal ratings for each included systematic review

	1. Review question stated	2. Inclusion criteria appropriate	3. Search strategy appropriate	4. Sources and resources adequate	5. Quality appraisal appropriate	6. Independent critical appraisal	7. Minimised errors in data extraction	8. Methods to combine studies appropriate	9. Publication bias assessed (meta-analyses)	10. Policy and/or practice recommendations	11. Directives for new research appropriate	Total	<b>Overall Quality</b>
Bejarano-Martìn et al., 2020	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Yes	Yes	Yes	9/11	Η
Binns & Oram Cardy, 2019	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	-	Yes	Yes	9/10	Н
Crank et al., 2021	Yes	No	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	8/11	L
Deb et al., 2020	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	No	Yes	Yes	9/11	Н
Dimolareva & Dunn, 2020	Yes	No	Yes	No	Yes	Yes	No	Yes	Yes	Yes	Yes	8/11	L
Ferguson et al., 2019	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	-	Yes	Yes	9/10	Н
Fuller et al., 2020	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	10/11	Н
Geretsegger et al., 2014	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	11/11	Н
Griffith et al., 2020	Yes	Yes	Yes	No	Yes	Yes	No	Yes	-	Yes	Yes	8/10	Н
Hampton & Kaiser, 2016	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	10/11	Н
Hardy & Weston, 2020	Yes	No	Yes	No	Yes	Yes	No	No	-	Yes	Yes	6/10	L
Ho et al. 2014	Yes	No	Yes	No	Yes	No	Yes	No	Yes	Yes	Yes	7/11	L
Jiménez-Muñoz et al., 2021	Yes	Yes	Yes	Yes	No	Yes	No	Yes	-	No	Yes	7/10	L
Kent et al., 2020	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	10/11	Η
Khan et al., 2019	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Yes	9/11	Η
Leung et al., 2021	Yes	No	Yes	No	Yes	No	Yes	Yes	-	Yes	Yes	7/10	L
Mayer-Benarous, 2021	Yes	Yes	Yes	No	Yes	No	Yes	Yes	-	Yes	Yes	8/10	Н
Mazon et al., 2019	Yes	Yes	Yes	No	Yes	No	No	No	-	Yes	Yes	6/10	L
Moon et al., 2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	10/11	Η
Murza et al., 2016	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	9/11	Η
Naveed et al., 2019	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Yes	Yes	Yes	9/11	Η
Nevill et al., 2018	Yes	Yes	Yes	No	Yes	No	No	Yes	No	Yes	Yes	7/11	L
O'Donovan et al., 2019	Yes	Yes	No	No	Yes	Yes	No	No	-	Yes	Yes	6/10	L

	1	1	1	1	1								
Ona et al., 2020	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	Yes	Yes	8/11	L
Oono et al., 2013	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	11/11	Н
Parsons, Cordier, Munro et al., 2017	Yes	Yes	Yes	No	Yes	Yes	No	No	-	Yes	Yes	7/10	L
Parsons, Cordier, Vaz et al., 2017	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Yes	9/11	Н
Pi et al., 2021	Yes	Yes	Yes	No	Yes	Yes	No	Yes	No	Yes	Yes	8/11	L
Postorino et al., 2017	Yes	Yes	Yes	No	Yes	No	Yes	No	Yes	Yes	No	7/11	L
Reichow et al., 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	11/11	Н
Rodgers et al., 2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	10/11	Н
Sandbank et al., 2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	10/11	Н
Sandgreen et al., 2020	Yes	Yes	Yes	No	Yes	No	No	Yes	Yes	Yes	Yes	8/11	L
Shi et al., 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	11/11	Н
Soares et al., 2020	Yes	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes	Yes	9/11	Н
Sutherland et al., 2018	Yes	Yes	Yes	No	Yes	No	No	Yes	-	Yes	Yes	7/10	L
Tachibana et al., 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	11/11	Н
Tan-MacNeill et al., 2021	Yes	Yes	Yes	Yes	Yes	No	No	Yes	-	Yes	Yes	8/10	Н
Tarver et al., 2019	Yes	Yes	Yes	No	Yes	Yes	No	Yes	No	Yes	Yes	8/11	L
Tiede & Walton, 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	10/11	Η
Trzmiel et al., 2019	Yes	Yes	No	Yes	Yes	Yes	No	No	Yes	No	Yes	7/11	L
Tupou et al., 2020	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	-	Yes	Yes	9/10	Н
Valentine et al., 2020	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	-	Yes	Yes	9/10	Н
Vershuur et al., 2014	Yes	No	Yes	No	Yes	No	No	Yes	-	Yes	Yes	6/10	L
Waddington et al., 2021	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	-	Yes	Yes	9/10	Н
Wang et al., 2021a	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	No	Yes	8/11	L
Wang et al., 2021b	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Yes	Yes	Yes	9/11	Н
Zheng et al., 2021	No	No	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	8/11	L
$\mathbf{N}_{1}$	000/	<b>TT</b> 1	TT' 1 /	11.		/							

Note: L = Low Quality < 80%;  $H = High Quality \ge 80\%$ 

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Appendix 5.13	Umbrella review - Effect of type of support on child and family
Appendix 5.15	outcomes

# Appendix 5.13 - Umbrella review - Effect of type of support on child and family outcomes

Summary of the effect of types of support on child and family outcomes.

		Co	ommu	nicatio	on								aviours			y activ and ticipat				ily wel satisfa			
Type of support	Number of Systematic reviews	Overall communication	Expressive language	Receptive language	Social-communication	Sensory development	Cognitive development	Social-emotional wellbeing	Motor	Academic skills	School/ learning readiness	Overall autism characteristics	Restricted and repetitive interests and behaviours	General child outcomes	Adaptive behaviour	Play	Participation	Child quality of life	Child satisfaction with support	Parent knowledge and skills	Parent social emotional wellbeing	Parent financial wellbeing	Parent satisfaction with support
Behavioural supports (variety of practices)	1	+ H <sup>1</sup>			+ H <sup>1</sup>		+ H <sup>1</sup>	+ H <sup>1</sup>	+ H <sup>1</sup>			+ H <sup>1</sup>			+ H <sup>1</sup>								
Early intensive behavioural intervention	3	+ H <sup>2</sup>	O H²	+ H <sup>2</sup>	+ H <sup>2</sup>		+ H <sup>2</sup>	o H³				0 H <sup>3,4</sup>			? H²								
Developmental supports (variety of practices)	2	o H <sup>1</sup>			+ H <sup>1</sup>																		
Naturalistic developmental behavioural interventions (variety of practices)	2	+ H <sup>1</sup>	+ H⁵	+ H⁵	? H⁵		+ H⁵	o H <sup>1</sup>				+ H⁵	о Н <sup>1</sup>		o H⁵	+ H⁵							

Early Start Denver Model	2	+ L <sup>6</sup>			0 L <sup>6</sup>	+ L <sup>6</sup>				+ L <sup>6</sup>	0 H <sup>7</sup>		0 H <sup>7</sup>					
Pivotal Response Treatment	2	0 L <sup>8</sup>	+ L <sup>8</sup>		-	-						? L <sup>9</sup>				? L <sup>9</sup>		
JASPER	1	+ H <sup>10</sup>	? H <sup>10</sup>	? H <sup>10</sup>	+ H <sup>10</sup>					0 H <sup>10</sup>				+ H <sup>10</sup>				
Sensory-based supports (variety of practices)	1	0 H <sup>1</sup>																
Music therapy	2	+ H <sup>11</sup>			+ H <sup>11</sup>											+ H <sup>11</sup>		
TEACCH (variety of practices)	1				O H <sup>1</sup>													
Technology based supports (variety of practices)	3				0 H <sup>1</sup>		0 H <sup>1</sup>					? H <sup>12</sup>						
Apps	3	0 H <sup>13</sup>	0 H <sup>13</sup>	0 H <sup>13</sup>	0 H <sup>13</sup>	+ H <sup>13</sup>		+ H <sup>13</sup>				? H <sup>14</sup>						
Gaming	1											+ H <sup>14</sup>						
Mobile technology	1											? H <sup>15</sup>						
Videos/DVDs/Video modelling	1											+ H <sup>14</sup>						
Animal-assisted supports (variety of practices)																		
Equine assisted therapy	2	+ L <sup>16</sup>			+ L <sup>16</sup>					0 L <sup>16</sup>			0 L <sup>17</sup>					
Canine assisted therapy	1				+ L <sup>18</sup>													
Cognitive behavioural therapy (variety of practices)	2				+ L <sup>19</sup>		? H <sup>20</sup>			? H <sup>20</sup>								
Other supports																		

Social skills training (computers + robots)	1		+ H <sup>21</sup>										
Social training (video games)	1							+ H <sup>15</sup>					
UCLA PEERS	1		+ L <sup>22</sup>							+ L <sup>22</sup>			

+ = positive therapeutic effect

? = inconsistent therapeutic effect

o = null effect

L = Low quality systematic review

H = High quality systematic review

Blank cells = no therapeutic evidence

Effects in **bold** font are drawn from meta-analyses

Effects in *italicised* font are drawn from narrative syntheses

<sup>1</sup> Sandbank et al. (2020)

<sup>2</sup> Shi et al. (2021)

<sup>3</sup>Reichow et al. (2018)

<sup>4</sup> Rodgers et al. (2020)

<sup>5</sup>Tiede & Walton (2019)

<sup>6</sup> Wang et al. (2021a)

<sup>7</sup> Fuller et al. (2020)

<sup>8</sup> Ona et al. (2020)

<sup>9</sup> Vershuur et al. (2014)

<sup>10</sup> Waddington et al. (2020)

<sup>11</sup> Geretsegger et al. (2014)

<sup>12</sup> Khan et al. (2019)

<sup>13</sup> Moon et al. (2020)

<sup>14</sup> Valentine et al. (2020)

<sup>15</sup> Jiménez-Muñoz et al. (2022)

<sup>16</sup> Dimolareva & Dunn (2021)

<sup>17</sup> Trzmiel et al. (2019)

<sup>18</sup> Hardy & Weston (2020)

<sup>19</sup> Ho et al. (2014)

<sup>20</sup> Wang et al. (2021b)

<sup>21</sup> Soares et al. (2021)

<sup>22</sup> Zheng et al. (2021)

National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia

Appendix 5.14Umbrella review - Raw data and summary statements

# Appendix 5.14 - Umbrella review - Raw data and summary statements

Raw data and summary statements from each included systematic review for all categorised outcomes in the current umbrella review.

Outcome	Context		Stud ies inclu ded	Effect size	Heterog eneity	Categorise d outcome
Social-communication	Overall (gro	oup studies)	18	g = 0.51, 95CI [0.37, 0.65]	$I^2 = 23.01$	Positive pooled effect
Social-communication (Imitation)	Group studi		4	g = 0.43, 95CI [0.10, 0.75]	$I^2 = 6.62$	Positive pooled effect
Social-communication (Joint attention)	Group studi	es	14 6/7 <sup>1</sup>	g = 0.55, 95CI [0.39, 0.70]	$I^2 =$ 19.83	Positive pooled effect
Social-communication (Play)	Group studi	oup studies		g = 0.47, 95CI [0.25, 0.70]	$I^2 = 73.56$	Positive pooled effect
Moderators	Context	Outcome	Stud ies Inclu ded	Verbatim summar systematic review		Categorise d outcome
Child age	Group	Social- communicati on	24 grou p	Group: "did prove t significant, Q (1) = 0.008. Effect sizes when participants' preintervention age lower (see Appendi more information)."	6.95, p = were greater s were x H for	Age negatively associated with the effect of support on social- communica tion.
Child characteristics	Group	Social- communicati on	14 grou p	"nonsignificant for "All the descriptive (overall cognitive a verbal ability) we nonsignificant."	Child communica tion skills and cognitive ability prior to support not related to the effect of support on social- communica tion.	
Amount of support	Group	Social- communicati on	16 grou p	1		Amount of support (total hours) not

Bejarano-Martín et al. (2020)- Meta-analysis

				was not significant ( $r = 0.271$ , p = 0.076). In addition, when we eliminated the two studies where treatment amount was much higher than the rest of the studies, the relationship between the amount and the effect was significantly positive (see Fig. 6 in Appendix I)."	related to the effect of support on social- communica tion.
Agent	Overall	Social-	9	Group: "The effect sizes	Agent
		communicati	grou	ranged from $g = 0.11$ to $g =$	(caregivers,
		on	р	1.02. Fig. 4 shows the	teachers,
				individual effect size for this	clinician)
				analysis ( $g = 0.50, K = 9, 95\%$	not related
				[CI 0.32, 0.68], Z = 5.39, p <	to the effect
				0.001). This was a medium	of support
				effect. The sample of studies	on social-
				was not sufficiently large and	communica
				the $I^2$ statistic (0.00) did not	tion.
				meet the criteria to proceed	
				with moderator or publication	
				bias analyses."	

<sup>1</sup>Both numbers reported.

Outcome	Studies	Verbatim summary from systematic review	Categorised
	included		outcome
Social-	4	"Each of the four studies evaluating social interaction capacities or	Positive
communication		overall social-communication reported positive results, with	summarised
(social		moderate (Solomon et al., 2014; Wetherby et al., 2014) to large	effect
interaction and		effects (Aldred et al., 2004; Green et al., 2010; Pajareya &	
social-		Nopmaneejumruslers, 2011). Aldred et al. (2004) included both	
communication)		social interaction and communication outcome measures, and	
		reported positive results in the social interaction domain of the	
		ADOS, but no significant change on the communication domain."	
Communication	6	"Six studies used standardized language tests as outcome measures	Inconsistent
(language		(e.g. Preschool Language Scale; Zimmerman, Steiner, & Pond,	summarised
capacities)		2006). Of these, three reported mixed results across different	effect
		language tests (Green et al., 2010; Schertz et al., 2013; Wetherby et	
		al., 2014) and three reported no effects (Aldred et al., 2004;	
		Casenhiser et al., 2013; Solomon et al., 2014). Two of the studies	
		that reported mixed results found small to moderate positive effects	
		in children's receptive language, but not in expressive language	
		(Schertz et al., 2013; Wetherby et al., 2014). Green et al. (2010)	
		found no effects using assessor rated measures of language."	

# Binns & Oram Cardy (2019) – Narrative synthesis

# Crank et al. (2021)- Meta-analysis

Outcome	Context	Studi	Effect size	Heterog	Categorised
		es		eneity	outcome
		inclu			
		ded			
Overall autism	-	8	RVE = 0.05, 95%CI	-	Null pooled effect
characteristics (ASD			(-0.38, 0.48)		
symptomology)*					

Social-communication*	-		>10	RVE = 0.35, 95%CI (0.18, 0.53)	-	Positive pooled effect
Restricted and repetitive interests and behaviours*	-		8		-	Null pooled effect
Language*	-		>10	RVE = 0.20, 95%CI (0.03, 0.38)	-	Positive pooled effect
Cognitive development*	-		>10	RVE = 0.26, 95%CI (0.01, 0.51)	-	Positive pooled effect
Social emotional/ challenging behaviour*	-		6	(-0.28, 0.61)	-	Null pooled effect
Play skills*	-		7	(0.13, 0.54)	-	Positive pooled effect
Adaptive behaviour*	-		7	(-0.24, 0.56)	-	Null pooled effect
Moderators	Context	Outcom e	Studi es Inclu ded	Verbatim summary fr systematic review	·om	Categorised outcome
Child age	-	General outcome s	27	"The results of meta-reg models indicated that no mean chronological age -0.06, P = 0.256), nor t language age of sample	either the e (B = the mean	The child's age (chronological age) was not related to the effect of support on general outcomes.
Communication	-	General outcome s	10	study entry (B = $-0.02$ , 0.758)moderated NDI intervention effects."	P =	The child's communication (language age) was not related to the effect of support on general outcomes.
Amount of support	-	General outcome s	12	"Effect sizes did not significantly vary as a f of cumulative intensity support in hours ( $B = 0$ . 0.563)."	of	The amount of support (cumulative intensity) was not related to the effect of support on general outcomes.
Agent	Clinicia n, caregive r, educator , combina tion	General outcome s	27	"Effect sizes did not significantly vary as a f ofthe type of interven that implemented the intervention (clinician H P = 0.539; combination -0.26, $P = 0.215$ ; educa 0.01, $P = 0.931$ ; referen category = caregiver)."	tionist B = 0.12, B = ator $B =$ acc	The agent (clinicians, educators, caregivers, combination) was not related to the effect of support on general outcomes.

\* These effects are identical to those originally reported in Sandbank et al. (2020). Thus, they are reported under Sandbank et al. (2020) only in the summary tables.

Deb et al. (2020)- Meta-analysis

Outcome	Context	Studi es inclu ded	Effect size	Heterog eneity	Categorised outcome
General outcomes (treatment effect)	DIR/Floortime	2	SMD = 0.98, 95%CI (0.41, 1.55)	Tau2 = 0Chi2 =0.55I2 = 0%	Positive pooled effect
General outcomes (treatment effect)	Parent-focussed training	2	SMD = 0.38, 95%CI (0.08, 1.67)	$Tau^2 = 0$ $Chi^2 =$ 0.94 $I^2 = 0\%$	Positive pooled effect
General outcomes (treatment effect)	Pivotal response treatment	2	SMD = 0.73, 95%CI (0.24, 1.21)	Tau2 = 0Chi2 =0.27I2 = 0%	Positive pooled effect

### Dimolareva & Dunn (2021)- Meta-analysis

Outcome Overall autism	Context		Stud ies inclu ded 7	Effect size SMC = -0.19, 95%CI	Heterog eneity I <sup>2</sup> = 0%	Categorised outcome
characteristics (global measures of ASD)	-		/	SMC = -0.19, 95%C1 (-0.39, 0.02)	Q= 13.48	Null pooled effect
Social-communication (social interaction)	-		9	SMC = 0.21, 95%CI (0.07, 0.35)	$I^2 = 0\%$ Q= 6.73	Positive pooled effect
Communication (language)	-		9	SMC = 0.26, 95%CI (0.08, 0.44)	$ \begin{array}{c} I^{2} = \\ 30.1\% \\ Q = \\ 11.02 \end{array} $	Positive pooled effect
Moderators	Context	Outcome	Stud ies Inclu ded	Verbatim summary fi systematic review	rom	Categorised outcome
Amount of support	Minutes engaged in therapy	Overall autism characteri stics Social-	- 9	"The meta-regression r showed no significant relationship between do (approximate mins eng therapy) and improvem social interaction ( $\beta = 0$ 0.00, z = 0.68, Q = 0.4 $0.49$ ), communication ( $\beta = 0.00, z = 0.11, Q$ = 0.91), or Global ASE symptoms ( $\beta =0.00$ 0.00, z = -0.42, Q = 0 0.67)."	$p_{aged}$ in ent in 0.00, SE = 7, p = (β = 0.00, = 0.01, p ) , SE =	The amount of support (minutes engaged in therapy) was not related to the effect of support on overall autism characteristic s. The amount
		communi cation	2	0.07).		of support (minutes engaged in therapy) was not related to the effect of

Communi cation (language )	-	support on social- communicati on. The amount of support (minutes engaged in therapy) was not related to the effect of support on communicati on
		(language).

### Ferguson et al. (2019) – Narrative synthesis

rerguson et	erguson et al. (2019) – Narrahve synthesis					
Outcome	Studies	Verbatim summary from systematic review	Categorised			
	included		outcome			
General	28	"Results of efficacy (Fig. 3) show that 61% (n=17) of studies were rated as	Positive			
outcomes		'positive' in which improvements were achieved by all participants across	summarised			
(efficacy		all dependent variablesOverall, 32% (n=9) of studies received a 'mixed'	effect			
outcomes)		efficacy rating (Barkaia et al. 2017; Bearss et al. 2017; Machalicek et al.				
		2016; Meadan et al. 2016; Suess et al. 2014; Vismara et al. 2013, 2016;				
		Wainer and Ingersoll 2015; Wilczynski et al. 2017). For example, 44%				
		(n=4) of these studies found improvements in interventionist treatment				
		fidelity across all participants but failed to increase scores of social-				
		communication or imitation behaviours consistently across participants				
		(Meadan et al. 2016; Wainer and Ingersoll 2015; Vismara et al. 2013).				
		None of the 28 studies included in this review received a 'negative'				
		rating."				

# Fuller et al. (2020) – Meta-analysis

Outcome	Context	Stud	Effect size	Heterog	Categorise
		ies		eneity	d outcome
		inclu			
Overall autism		ded 9	$\alpha = 0.070$ ( )	I <sup>2</sup> =	Nullmaalad
characteristics (autism	-	9	g = 0.070 (-)	1 – 48.90%	Null pooled effect
symptoms)				$\tau^2 =$	eneci
symptoms)				0.073	
Social-communication	-	8	g = 0.209 (-)	$I^2 =$	Null pooled
Social communication		0	5 0.209 ()	72.53%	effect
				$\tau^2 =$	enteet
				0.176	
Restricted and repetitive	-	5	g = -0.016(-)	-	Null pooled
interests and behaviours					effect
(repetitive behaviours)					
Communication	-	11	g = 0.408 (-)	$I^2 =$	Positive
(language)				52.70%	pooled
				$\tau^2 =$	effect
				0.088	
Cognitive development	-	9	g = 0.412 (-)	$I^2 =$	Positive
(cognition)				66.30%	pooled
					effect

Adaptative behaviour (adaptive functioning) Moderators	- Context	Outcome	6 Stud	g = 0.121 (-)	$\tau^2 =$ 0.145 $I^2 =$ 49.03% $\tau^2 =$ 0.062	Null pooled effect
Moderators	Context	Outcome	ies Inclu ded	Verbatim summary systematic review	Trom	Categorise d outcome
Amount of support	-	General outcomes (Child outcomes)	Not speci fied	"The studies used a v of amount of support intensity and in lengt in intensity from one week to 20 hours per ranging in length from weeks to 156 weeks. resulted in total hour intervention ranging hours to 2080 hours. a meta-regression she child outcomes were significantly related to length of intervention -0.01, p = 0.46), to to per week of intervent -0.02, p = 0.73), or to number of hours (B = = 0.66)."	is both in th, ranging hour per week, and m six This s of from 12 However, owed that not to the n (B = he hours tion (B = o the total	Amount of support (total hours) not related to the effect of support on general outcomes (child outcomes).

# Geretsegger et al. (2014) – Meta-analysis

Outcome	Context	Stud ies inclu ded	Effect size	Heterog eneity	Categorise d outcome
Social-communication (social adaptation)	Overall	4	SMD = 0.41, 95CI [0.21, 0.60]	$Chi^2 =$ 15.34 $I^2 = 80\%$	Positive pooled effect
Communication (non-verbal)	Overall	Not speci fied	SMD = 0.47, 95CI [0.21, 0.73]	Chi2 = 1.32 $I^2 = 0\%$	Positive pooled effect
Communication (verbal)	Overall	6	SMD = 0.33, 95CI [0.16, 0.49]	$Chi^2 = 0.72$ $I^2 = 0\%$	Positive pooled effect
Caregiver social emotional wellbeing (quality of family relationships)	-	2	SMD = 0.82, 95CI [0.13, 1.52]	$Chi^2 = 0.03$ $I^2 = 0\%$	Positive pooled effect

Griffith et al. (2020) – Narrative synthesis

Outcome	Studies	Verbatim summary from systematic review	Categorised
	included		outcome

Social-	3	"None of the 3 studies reported significant improvement in the	Null
communication		primary social-communication skills outcome measures for the app	summarised
		treatment group compared with the comparison group. Effect sizes	effect
		for gains in the app groups on social-communication outcomes	
		ranged from 0 to 0.40."	

Outcome	Context		Stud ies inclu ded	Effect size Heterog eneity		Categorise d outcome
Expressive language (spoken language)	-		26	g = 0.26, 95CI [0.11, 0.42]	$\tau^2 =$ 0.083 Q = 59.08 $I^2 =$ 57.7%	Positive pooled effect
Moderators	Context	Outcome	Stud ies Inclu ded	Verbatim summary systematic review		Categorise d outcome
Child age	-	Expressive language (spoken language)	26	"The second meta-re moderator analysis e the impact of age of participants and inclu- same 26 studies and comparison variables hypothesis could not rejected: the effect of interventions on spol- language for younger participants did not d significantly ( $\beta$ = 0.092,SE=0.096). Th accounted for none of heterogeneity (R2=0 indicating that interv delivered at different resulted in similar ou	xamined ided the s. The null be f cen- r and older liffer is analysis f the .00%), entions ages	Age not related to the effect of support on expressive (spoken) language.
Amount of support	-	Expressive language (spoken language)	26	resulted in similar outcomes." "The first meta-regression included all 26 studies. The results indicated the total intervention dose ( $\beta$ =0.008,SE =0.010; total hours of intervention computed as length of treatment x hours per week), and number of indicators of bias ( $\beta$ =0.027,SE=0.027) did not significantly predict the magnitude of spoken-language outcomes."		Amount of support (total hours) not related to the effect of support on expressive (spoken) language.
Agent	-	Expressive language	26	"The random effects model for the sub-gre analysis of implement	oup	Supports involving clinicians

# Hampton & Kaiser (2016) – Meta-analysis

(spoken language)	(clinician only, parent only or parent plus clinician) summarises the outcomes within types of implementers (Fig.2). There was a significant difference among the sub- groups [Q=59.08(25),P<0.001]. None of the heterogeneity was explained within the parent-	and parents related to greater effect of support on expressive (spoken) language than clinicians
	groups [Q=59.08(25),P<0.001]. None of the heterogeneity was	(spoken) language than

### Hardy & Weston (2020) – Narrative synthesis

Outcome	Studies	Verbatim summary from systematic review	Categorised
	included		outcome
Social-	5	"Results of the five studies indicated positive effects of CAT on the	Positive
communication		frequency and duration of social behavior of children with ASD	summarised
(social		(Becker et al. 2017; Fung and Leung 2014; Grigore and Rusu 2014;	effect
behaviour)		Martin and Farnum 2002; Redefer and Goodman 1989)However,	
		due to the methodological weaknesses of these studies, it would be	
		unfitting to make any assertions about the degree to which CAT	
		impacts social behavior."	

# Ho et al. (2014) – Meta-analysis

Outcome	Context	Stud ies inclu ded	Effect size	Heterog eneity	Categorise d outcome
Social-communication (social skills)	-	3	g = 0.98, 95CI [0.47, 1.49]	-	Positive pooled effect

### Jiménez-Muñoz et al. (2022)- Narrative analysis

Outcome	Stud ies	Verbatim summary from systematic review	Categorise d outcome
	Inclu		
	ded		
General outcomes (main findings)	5	"[Four] of the five studies that focused on social training found significant improvement in the outcomes explored (Beaumont et al. 2021; Ben-Sasson et al. 2013; Chung et al. 2016; Wang et al. 2018), while one failed to find statistically significant changes after the intervention (Bernardini et al. 2014)."	Positive summarise d effect

Kent et al. (2020) – Meta-analysis

Kent et al. (2020) – N Outcome	Context		Stud ies inclu ded 11	Effect size	Heterog eneity	Categorise d outcome
Play		Pre/post within group analysis of intervention groups		g = 0.439, 95CI [0.209, 0.669]	Q = 17.210 $I^2 =$ 41.9%	Positive pooled effect
	Between-gro	oup analysis	8	g = 0.335, 95CI [0.083, 0.586]	-	Positive pooled effect
Moderators	Context	Outcome	Stud ies Inclu ded	Verbatim summary systematic review	from	Categorise d outcome
Format	Individual, group	Play	8	"Following the subgr analysis of interventi characteristics, a met regression analysis w performed on eight s further explain varial the results (Chang et b; Goods et al. 2013, et al. 2006, b, 2012, 1 2015, b; Poslawsky e b; Quirmbach et al. 2 The analysis of inter- characteristics indica setting and group vs [Table 5: $Q = 1.06$ , d 0.5897] were not sig mediators of interven effects (see Table 5). focus of the interven child, parent, peer or was found to be a sig mediator of play out ( $Q(3) = 8.52$ , $p = 0.0$	on a- vas tudies to bility of al. 2016, b; Kasari b, 2014, b, et al. 2015, 2009, b). vention ted that individual f=2, p = nificant tion However, tion (i.e., teacher) pificant comes	The format (individual, group) did not relate to the effect of support on play.
Setting	Clinic, home, school	Play	Not speci fied	"No effect size for the home, or school setti significant (clinic $z(2)$ 1.221,p=0.222, Hed g=0.887,95%CI[-0.5 2.311]; home: $z(2) =0.161$ , Hedges' $g=0$ . CI [-0.114, 0.685]; s z(4) = 1.469,p=0.14. g=0.259, 95% CI [-(0 0.605]) The analysi intervention character indicated that setting vs individual were no significant mediators	e clinic, ng was 2) = ges' 537, 1.402,p= 286, 95% chool: 2, Hedges' 0.087, sis of ristics and group ot	Setting not related to the effect of support on play skills.

		intervention effects (see	
		Table5)."	

#### Khan et al. (2019) – Meta-analysis (relevant outcomes based on narrative synthesis only)

Outcome	Studies	Verbatim summary from systematic review	Categorised
	included		outcome
General	10	"Primary outcomes: Of 10 interventions, 4 interventions in the	Inconsistent
outcomes		included studies were aimed at a youth population with ASD;	summarised
(condition-		however, just one [25] of these trials found that Web-based	effect
specific		interventions were effective. In the study by Fridenson-Hayo et al	
outcomes or		[25], children with ASD who received an internet-based serious game	
reducing		improved in ER tasks compared with the WLC group who received	
comorbid		TAU. A total of 3 studies [23,24,26] comparing iPad or tablet apps	
psychological		with WLC/TAU groups for children with ASD found no difference in	
symptoms)		outcome between the groups."	

### Leung et al. (2021)- Narrative synthesis

Outcome	Stud ies Inclu ded	Verbatim summary from systematic review	Categorise d outcome
General outcomes (effectiveness)	6	"the effectiveness was less robust among younger children, as shown in Table 2 (2 effective, 2 partially effective, and 2 ineffective)."	Inconsisten t summarise d effect

### Mayer-Benarous et al. (2021)- Narrative synthesis

Outcome	Stud ies Inclu ded	Verbatim summary from systematic review	Categorise d outcome
Social-communication (joint attention)	4	"Four studies evaluated the benefit of educational music therapy on joint attention (23, 25, 26, 32)None of these studies reported a statistically significant effect of these interventions on the joint attention of children with ASD."	Null summarise d effect

### Mazon et al. (2019) – Narrative synthesis

Outcome	Included	Verbatim summary from systematic review	Categorised
	studies		outcome
General	23	"Overall, TE studies reported inconsistent results concerning the TBI	Inconsistent
outcomes		effect, i.e., 7 with highly-positive, 8 with slightly-positive, and 8 with	summarised
(statistical		limited evidence. Fewer of the TBI effects reported in RCT studies	effect
significance)		were highly-positive (N = $3/14$ ) than in controlled studies (N = $4/8$ ,	
		Table 5). Although there were fewer TU studies, all controlled trials,	
		the TBI effects reported were mostly slightly-positive ( $N = 4/6$ ).	
		Hence, the highly-positive evidence for TBI was dependent on the	
		study design, irrespective of its aim (TE vs. TU): the more robust the	
		study design, the less consistent the results."	

### Moon et al. (2020) – Meta-analysis

Outcome	Context	Stud	Effect size	Heterog	Categorise
		ies		eneity	d outcome
		inclu			
		ded			

Social-communication	3-month follow-up	2	SMD = 0.18, 95CI	$I^2 = 0\%$	Null pooled
	1		[-0.20, 0.56]		effect
	6-month follow-up	2	SMD = 0.00, 95CI	$I^2 = 0\%$	Null pooled
	_		[-0.55, 0.55]		effect
Communication	3-month follow-up	2	SMD = 0.32, 95CI	$I^2 = 0\%$	Null pooled
(gestures)	_		[-0.05, 0.69]		effect
Communication	3-month follow-up	2	SMD = 0.05, 95CI	$I^2 = 0\%$	Null pooled
(symbolic)			[-0.33, 0.43]		effect
Expressive language	-	2	SMD = 0.25, 95CI	$I^2 =$	Null pooled
			[-0.36, 0.86]	60.99%	effect
Expressive language	-	2	SMD = -0.23, 95CI	$I^2 =$	Null pooled
(words produced)			[-0.68, 0.22]	32.56%	effect
Receptive language	-	2	SMD = 0.24, 95CI	$I^2 = 0\%$	Null pooled
			[-0.13, 0.61]		effect
Cognitive development	-	2	SMD = 0.41, 95CI	$I^2 = 0\%$	Positive
(visual reception)			[0.03, 0.80]		pooled
					effect
Motor (fine motor)	-	2	SMD = 0.44, 95CI	$I^2 =$	Positive
			[0.06, 0.81]	5.2%	pooled
			_		effect

# Murza et al. (2016) – Meta-analysis

Outcome	Context	Stud ies inclu ded	Effect size	Heterog eneity	Categorise d outcome
Social-communication (joint attention)	Joint attention versus control group	9	g = 0.660 (0.395, 0.925)	Not specified	Positive pooled effect
	Joint attention versus symbolic play	2	g = 0.527 (0.077, 0.978)	Not specified	Positive pooled effect
	Joint attention versus control group: treatment administered by parent	5	g = 0.678 (0.313, 1.043)	Not specified	Positive pooled effect
	Joint attention versus control group: discrete trial training plus social interactive approach	5	g = 0.762 (0.337, 1.187)	Not specified	Positive pooled effect
	Joint attention versus control group: social interactive approach only	4	g = 0.589 (0.194, 0.983)	Not specified	Positive pooled effect

# Naveed et al. (2019) – Meta-analysis

Outcome	Context	Studies include d	Effect size	Heterog eneity	Categorise d outcome
Overall autism characteristics (autism symptom severity)	-	7 trials, 10 studies <sup>1</sup>	SMD = 0.44, 95CI [0.27, 0.60]	$I^2 = 0\%$ Chi <sup>2</sup> = 5.42	Positive pooled effect
Social-communication (social skills)	-	10 trials, 18 studies <sup>1</sup>	SMD = 0.53, 95CI [0.34, 0.73]	$I^2 =$ 48.59% Chi <sup>2</sup> = 31.12	Positive pooled effect

Caregiver social emotional wellbeing (parent-child relationship) Child satisfaction (child distress) Moderators	- - Context	Outcome	4 6 2 Studies	SMD = 0.42, 95CI [0.23, 0.62] SMD = 0.67, 95CI [0.23, 1.10] SMD= 0.55, 95CI [0.25, 0.85] Verbatim summary	$I^{2} = 0\%$ Chi <sup>2</sup> = 4.64 $I^{2} = 76.0\%$ Chi <sup>2</sup> = 20.83 $I^{2} = 0\%$ Chi <sup>2</sup> = 1.76 7 from	Positive pooled effect Positive pooled effect Positive pooled effect <b>Categorise</b>
emotional wellbeing (parent-child relationship) Child satisfaction (child	-		6	[0.23, 0.62] SMD = 0.67, 95CI [0.23, 1.10] SMD= 0.55, 95CI	$\begin{array}{c} {\rm Chi}^2 = \\ 4.64 \\ {\rm I}^2 = \\ 76.0\% \\ {\rm Chi}^2 = \\ 20.83 \\ {\rm I}^2 = 0\% \\ {\rm Chi}^2 = \end{array}$	pooled effect Positive pooled effect Positive pooled
emotional wellbeing (parent-child relationship)	-		6	[0.23, 0.62] SMD = 0.67, 95CI [0.23, 1.10]	Chi2 = 4.64I2 = 76.0%Chi2 = 20.83	pooled effect Positive pooled effect
emotional wellbeing (parent-child				[0.23, 0.62] SMD = 0.67, 95CI	$Chi^{2} = 4.64 I^{2} = 76.0% Chi^{2} = $	pooled effect Positive pooled
emotional wellbeing				[0.23, 0.62] SMD = 0.67, 95CI	Chi <sup>2</sup> = $4.64$ I <sup>2</sup> = 76.0%	pooled effect Positive pooled
				[0.23, 0.62] SMD = 0.67, 95CI	$Chi^2 = 4.64$ $I^2 =$	pooled effect Positive
				[0.23, 0.62]	Chi <sup>2</sup> = 4.64	pooled effect
(parental self-efficacy)	-		4	-	Chi <sup>2</sup> =	pooled
emotional wellbeing	-		4	SMD = 0.42, 95CI		Positive
Caregiver social						
<b>`</b>					18.75	
(parental distress)				[,	$Chi^2 =$	effect
emotional wellbeing			,	[0.09, 0.57]	52.01%	pooled
Caregiver social	_		7	SMD = 0.33, 95CI	$I_{10.2.5}^{10.2.5}$	Positive
			studies		10.25	
			7 studies <sup>1</sup>	[-0.001, 0.52]	41.44% Chi <sup>2</sup> =	effect
Adaptive behaviour	-		6 trials,	SMD = 0.26, 95CI	$I^2 =$	Null pooled effect
regulation)			6		4.36	
behaviour (self-					Chi <sup>2</sup> =	effect
emotional/challenging				[0.06, 1.03]	55.91%	pooled
Social	-		3	SMD = 0.54, 95CI	$I^2 =$	Positive
			studies <sup>1</sup>	[	4.18	effect
motor (motor skills)			6 5 triais,	[0.02, 0.48]	$Chi^2 =$	pooled
Motor (motor skills)	-		5 trials,	SMD = 0.25, 95CI	I.22 $I^2 = 0\%$	Positive
(visual reception)				[0.01, 0.37]	$Cn1^2 = 1.22$	effect
Cognitive development (visual reception)	-		3	SMD = 0.29, 95CI [0.01, 0.57]	$I^2 = 0\%$ Chi <sup>2</sup> =	Positive pooled
			studies <sup>1</sup>		7.38	D ''
			4/5		$Chi^2 =$	
			trials,	[-0.24, 0.55]	53.34%	effect
Receptive language	-		15	SMD = 0.16, 95CI	$I^2 =$	Null pooled
					8.62	
			studies1		Chi <sup>2</sup> =	effect
1			trials, 6	[0.22, 0.72]	53.59%	pooled
Expressive language	-		15	SMD = 0.47, 95CI	$I^{2} =$	Positive
			studies <sup>1</sup>		17.73	
			trials, 13	[0.03, 0.42]	37.96% Chi <sup>2</sup> =	pooled effect
Communication	-		15 triala	SMD = 0.23, 95CI	$I^2 = 37.96\%$	Positive
(repetitive behaviours)			studies <sup>1</sup>		0.17	effect
interests and behaviours			3	[0.05, 0.62]	$Chi^2 =$	pooled
Restricted and repetitive	-		2 trials,	SMD = 0.33, 95CI	$I^2 = 0\%$	Positive
					29.32	
~			studies1	_	Chi <sup>2</sup> =	
(joint attention)			8	[-0.22, 0.54]	76.13%	effect
Social-communication	-		7 trials,	SMD = 0.16, 95CI	$I^2 =$	Null pooled
			studies		24.87	encer
(joint engagement)			/ studies <sup>1</sup>	[0.21, 1.06]	75.88% Chi <sup>2</sup> =	pooled effect
Social-communication	-		4 trials, 7	SMD = 0.63, 95CI	$I^2 = 75.88\%$	Positive

Child age	-	General	-	"Initially, meta-regression	Age not
-		outcomes		analysis was run inclusive for	related to
				all outcomes. It did not reveal	the effect
				any significant effects of age,	of support.
Amount of support	-	General	-	year of publication or duration	Number of
		outcomes		of program and session or	support
				number of sessions or quality	sessions not
				of trials on the significance of	related to
				these interventions."	the effect
					of support.

<sup>1</sup>Both numbers reported

Nevill et al. (2018) – Meta-analysis
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Outcome	Context		Studies included	Effect size	Heterog eneity	Categorise d outcome
Overall autism characteristics (autism symptom severity)	-		6	g = 0.22, 95CI [0.03, 0.41]	Q = 3.79 $I^2 = 0\%$	Positive pooled effect
Social-communication (socialisation)	-		13	g = 0.23, 95CI [0.09, 0.36]	Q = 35.90 $I^2 =$ 66.57%	Positive pooled effect
Communication (language)	-		13	g = 0.16, 95CI [0.02, 0.31]	Q = 11.50 $I^2 = 0\%$	Positive pooled effect
Cognitive development (cognition)	-		6	g = 0.24, 95CI [0.03, 0.46]	Q = 1.86 $I^2 = 0\%$	Positive pooled effect
Moderators	Context	Outcome	Studies Included	Verbatim summary from systematic review		Categorise d outcome
Amount of support	<20h parent training vs 20 hours or higher of parent training	Overall autism characteri stics (symptom severity), social- communi cation (socialisat ion), communi cation (language ), cognitive developm ent (cognition )	Overall autism characteri stics (symptom severity): <20h n=2 $\ge 20h n=4$ Social- communi cation (socialisat ion): <20h n=5 $\ge 20h n=8$ Communi cation (language ): <20h n=6 $\ge 20h n=7$	"Effect of intervention of parent training. Du active intervention ra 2.3 to 104 h. Studies coded as providing la 20h (k=9) or 20h or ra (k=10) of parent train in the active treatment Results of subgroup analyses based on do shown in Table 8. For with less than 20 h o training, socialization weighted $g = 0.25, 9$ (-0.004, 0.51] and communication lang [Table 8: weighted g 95%CI (0.01 to 0.49] associated with small effects. Analyses we performed for cognitt ASD symptom sever because there was or study assessing chan cognitive developmed	ose of anged from were ess than more ning while nt group. meta- ose are or studies f parent n [Table 8: 5%CI uage = 0.25, )] was l treatment re not ion or ity uly one ge in	Amount of support (total hours) not related to the effect of support on overall autism characterist ics (symptom severity), social- communica tion (socialisati on), communica tion (language), or cognitive developme nt.

Cognitive ASD syr	nptom severity. Across
	1
1	vith doses at or above
ent: 20h, sma	all effects were
<20h n=1 observed	l for socialization
$\geq$ 20h n=5 [Table 8	
	0.06 to 0.38)] and
cognition	n [Table 8: weighted g
	25%CI (0.02, 0.46)],
and trivi	al non-significant
effects w	vere observed for ASD
sympton	n severity [Table 8:
weighted	f g = 0.14, 95%CI (-
0.07, 0.3	5)] and
commun	ication-language
[Table 8	: weighted $g = 0.14$ ,
	-0.04, 0.31)].
Outcome	es were not
significa	ntly different based on
dose of t	reatment. Hedges' Q
homoger	neity tests were non-
	nt across outcomes."

### O'Donovan et al. (2019)- Narrative synthesis

Outcome	Stud ies Inclu ded	Verbatim summary from systematic review	Categorise d outcome
Social emotional/ challenging behaviour (problematic behaviours)	4	"Problematic behaviours were measured in three studies (Roberts and Pickering 2010; Sofronoff and Farbotko 2002; Stuttard et al. 2014) by the Eyberg Child Behaviour Inventory (ECBI) and by Todd et al. (2010) using an alternative service- specific measure. All four studies found a reduction in the frequency of children's problematic behaviours post- intervention"	Positive summarise d effect
Caregiver communication and interaction (parental skills)	2	"Clubb (2012) and Probst and Glen (2011) report improvements in parental skills following interventions."	Positive summarise d effect

# Ona et al. (2020) – Meta-analysis

			Effect size	Heterog	
				eneity	
Communication	-	2	SMD = 1.12, 95CI	$I^2 = 89\%$	Null pooled
			[-0.49, 2.73]	$\tau^2 = 1.2$	effect
Expressive language	-	2	SMD = 0.48, 95CI	$I^2 = 0\%$	Positive
			[0.04, 0.93]	$\tau^2 = 0.0$	pooled
					effect

# Oono et al. (2013) – Meta-analysis

Outcome	Context	Stud	Effect size	Heterog	Categorise
		ies		eneity	d outcome
		inclu			
		ded			

		(		T2 00/	D :::
Overall autism	-	6	SMD = -0.30, 95CI	$I^2 = 0\%$	Positive
characteristics (severity			[-0.52,		pooled
of autism characteristics)			-0.08]		effect
Social-communication	-	3	SMD = 0.41, 95CI	$I^2 = 0\%$	Positive
(shared or joint			[0.14, 0.68]		pooled
attention)					effect
Social-communication	-	4	SMD = 0.38, 95CI	$I^2 = 60\%$	Null pooled
(child initiations)			[-0.07, 0.82]		effect
Communication	Parent or teacher report	3	SMD = 5.31, 95CI	$I^2 = 75\%$	Null pooled
		•	[-6.77, 17.39]		effect
Communication (joint	Direct or independent	2	SMD = 0.45, 95CI	$I^2 = 0\%$	Null pooled
language)	assessment	-	[-0.05, 0.95]	1 0/0	effect
Expressive language	Direct or independent	3	SMD = 0.14, 95CI	$I^2 = 29\%$	Null pooled
(expression)	assessment	5	[-0.16, 0.45]	1 - 2970	effect
		2	SMD = 0.29, 95CI	$I^2 = 57\%$	Null pooled
Receptive language	Direct or independent	2		$I^{-} = 5 / \%_{0}$	
(comprehension)	assessment		[-0.20, 0.78]	C C	effect
			Verbatim summary	from	
			systematic review		
Cognitive	-	-	"five studies (Smith	· · ·	Positive
(developmental/intellect			Drew 2002; Rickards	· · ·	summarise
ual gains)			Dawson 2010; Tonge		d effect
			with varying theoreti		
			and methods for asse		
			developmental/intell		
			gains reported on thi		
			Dawson 2010 and Ri	ckards	
			2007 suggest that sm	all gains	
			were made in this do	main	
			following intervention	on.	
			However, Drew 2002	2 and	
			Tonge 2012 (individ	ual and	
			group intervention,		
			respectively) did not	report any	
			difference in this dor		
			between intervention		
			control groups follow		
			intervention. Smith 2		
			greater gains for the		
			therapist-delivered in		
			condition. Evidence		
			from parent-mediate		
			intervention therefor		
			suggested. However,		
			formal assessment m		
			reflect child co-opera		
Social-emotional					Null
	-	-	"Four studies (Smith		
development			Tonge 2006/Tonge 2		summarise
(maladaptive behaviour)			Rickards 2007; Robe		d effect
			reported on this outc		
			to significant and im		
			differences between		
			studies in theoretical		
	1		outcome measures us	sed a	
			meta-analysis could conducted. None fou	not be	

			significant difference in maladaptive behaviour in favour of the intervention group, even where that was the focus of intervention (Tonge 2012)."		
			Effect size	Heterog eneity	
Adaptive behaviour	-	2	SMD = 1.06, 95CI [-2.95, 5.06]	$I^2 = 86\%$	Null pooled effect
Caregiver communication and interaction (parental synchrony)	-	3	SMD = 0.90, 95CI [0.56, 1.23]	$I^2 = 27\%$	Positive pooled effect
Caregiver social emotional wellbeing (parents' level of stress)	-	2	SMD = -0.17, 95CI [-0.70, 0.36]	$I^2 = 0\%$	Null pooled effect

D	<b>C</b> 11				
Parsons,	Cordier,	Munro	et al. (	(2017	) – Meta-analysis

Outcome	Context		Studies included	Effect size	Heterog eneity	Categorise d outcome
Social-communication (pragmatic language)	Compared	to controls	17 interventi on groups from 15 studies	g = 0.274, 95CI [0.088, 0.460]	Q = 19.413 $I^2 =$ 17.570%	Positive pooled effect
	Intervention within inter group, pre- compariso	/post	17 interventi on groups from 15 studies	g = 0.500, 95CI [0.352, 0.647]		Positive pooled effect
Moderators	Context	Outcome	Studies Included	Verbatim summary from systematic review		Categorise d outcome
Child age	-	Social- communic ation (pragmatic language)	17 interventi on groups from 15 studies	"No differences were in outcomes as a resu- participant age or me pragmatic language measurement (i.e., pa report, observation, of task)Lastly, as ther concordance between age and receiving int in a group, participan examined in relation This did not produce significant result, ind age did not mediate t of mode of delivery ( individual, group, or	lt of ethod of arent or lab e was a n increased ervention at age was to mode. a licating he effect (i.e.,	Age not related to the effect of support on social- communica tion.
Setting	Home, school, clinic	Social- communic ation (pragmatic language)	17 interventi on groups from 15 studies	"Interventions set in demonstrated a signi moderate effect size 5.758, p < 0.001, He 0.535, 95%CI = 0.35 which was the larges	the clinic ficant, (z(12) = dge's g = 3-0.718),	Setting not related to the effect of support on social-

	T		1		. 1
				size calculated as a function of	communica
				setting. Interventions set in the	tion.
				school were approaching	
				significance, with a small	
				effect ( $z(3) = 1.925$ , $p = 0.054$ ,	
				Hedge's $g = 0.408, 95\%$ CI = -	
				0.007–0.824), Interventions set	
				in the clinic demonstrated a	
				significant, moderate effect	
				significant, inductate critect size $(z (12) = 5.758, p < 0.001,$	
				Hedge's $g = 0.535, 95\%$ CI =	
				0.353-0.718), which was the	
				largest effect and interventions	
				set in the home did not have a	
				significant effect on improving	
				pragmatic language skills when	
				compared to the other settings	
				(z(2) = 1.846, p = 0.065).	
				However, these results should	
				be interpreted with caution as	
				only two studies were set in the	
				home and just one at school	
				compared to 12 in the clinic	
				setting group."	
Format	Individu	Social-	17	"Whether interventions were	Format
Tormat	al, group	communic	interventi	administered to a group, the	(individual,
	ai, group	ation		individual or both, effects were	(individual, group) not
			on groups from 15		related to
		(pragmatic		significant and moderate in	
		language)	studies	size. Group interventions	the effect
				produced the largest effect of	of support
				the three modalities $(z(5) =$	on social-
				3.811, p < 0.001, Hedge's g =	communica
				0.553, 95%CI = $0.269-0.838$ ).	tion.
				The analysis of intervention	
				characteristics indicated that	
				setting and mode were not	
				significant mediators of	
				intervention effect."	
Agent	Child,	Social-	17	"Approaches that integrated a	Positive
	parent,	communic	interventi	caregiver into the program via	effect of
	children	ation	on groups	education and/or coaching in	support for
	and	(pragmatic	from 15	intervention techniques	supports
		language)	studies	demonstrated a significant,	with active
	parent	language)	suures		
				moderate-large effect ( $z(4) =$	parent involvemen
				5.265, p < 0.001, Hedge's g =	
				0.760, 95%CI = $0.477-1.043$ ),	t, but not
				while the intervention that	for supports
				focused on parent education	with parent
				only had no significant impact	education
				on the pragmatic language	alone.
				skills of children with ASD	
				(z(1) = 0.341, p = 0.733). The	
				majority of studies focused on	
				administering the intervention	
				directly to the children with	
				ASD, and these interventions	
	1	1	1	and mose must venuolis	

demonstrated a significant, moderate effect $(z(12) =$ 5.842,p < 0.001, Hedge's g = 0.482, 95%CI = $0.320-0.644$ ). Again, caution is required in interpreting these results as there is only one study in the parent focused group, and 12 and 4 in the child focused and combined child and parent focused groups respectivelyintervention
focus (e.g. child, parent or child and parent) was found to be a significant mediator of pragmatic language outcomes
(F(2) = 4.17, p = 0.0381), accounting for all of the between study variance in the model (R2 = 100%)."

### Parsons, Cordier, Vaz et al. (2017) – Narrative synthesis

Outcome	Studies	Verbatim summary from systematic review	Categorised
	included		outcome
Caregiver	5	"Parents' skills in implementing the acquired therapy techniques	Positive
communication		were investigated by Heitzman-Powell et al [50], St. Peter et al [46],	summarised
and interaction		Vismara et al [12,48], Wacker et al [47], and in the study by	effect
(parental		Ingersoll and Berger [43], Ingersoll et al [44], and Pickard et al [45].	
knowledge		All of the studies reported statistically significant improvements in	
acquisition)		parents' skills in administering skills learnt through the	
		interventions. These findings present evidence that parents who	
		received the appropriate training could gain skills in the delivery of	
		interventions, thus improving the skills in social-communication	
		and behavior of their children with ASD."	

# Pi et al. (2021)- Meta-analysis

Outcome	Cont	Stud ies	Effect size	Heterog	Categorise d outcome
	ext	inclu ded		eneity	a outcome
Social-communication	-	6	MD = 0.75, 95%CI (-0.16, 1.68)	$I^2 = 39\%$	Null summarise d effect
Social-communication (socialisation)	VAB S	2	MD = 1.83, 95%CI (-2.01, 5.68)	$I^2 = 0\%$	Null summarise d effect
Communication (language total score)	-	3	MD = -0.06, 95%CI (-2.76, 2.64)	$I^2 = 43\%$	Null summarise d effect
Communication (gestures)	-	2	MD = 1.71, 95%CI (-1.24, 4.66)	$I^2 = 0\%$	Null summarise d effect
Expressive language (expressive speech)	-	2	MD = 0.03, 95%CI (-0.36, 0.42)	$I^2 = 0\%$	Null summarise d effect

Receptive language	-	3	MD = 10.49, 95%CI (-13.11, 34.09)	$I^2 = 59\%$	Null
					summarise
					d effect

### Postorino et al. (2017) – Meta-analysis

Outcome	Context	Stud ies inclu ded	Effect size	Heterog eneity	Categorise d outcome
Social	-	8	SMD = -0.59, 95CI	Q =	Positive
emotional/challenging			[-0.88,	16.77	pooled
behaviour (disruptive			-0.30]	$I^2 =$	effect
behaviour)				57.8%	

### Reichow et al. (2018) – Meta-analysis

Reichow et al. (2018) – Me Outcome	Context	Stud ies inclu ded	Effect size	Heterog eneity	Categorise d outcome
Overall autism characteristics (autism symptoms)	EIBI vs treatment as usual	2	SMD = -0.34, 95CI [-0.79, 0.11]	Q = 0.23 $I^2 = 0\%$ $Tau^2 =$ 0.00	Null pooled effect
Social-communication (social competence)		5	MD = 6.56, 95CI [1.52, 11.61]	Q = 5.25 $I^2 =$ 23.87% Tau <sup>2</sup> = 7.94	Positive pooled effect
Communication		5	MD = 11.22, 95CI [5.39, 17.04]	Q = 1.86 $I^2 = 0\%$ $Tau^2 =$ 0.00	Positive pooled effect
Expressive language		4	SMD = 0.51, 95CI [0.12, 0.90]	Q = 4.46 $I^2 =$ 32.77% $Tau^2 =$ 0.05	Positive pooled effect
Receptive language		4	SMD = 0.55, 95CI [0.23, 0.87]	Q = 1.52 $I^2 = 0\%$ $Tau^2 =$ 0.00	Positive pooled effect
Cognitive development (intelligence quotient)		5	MD = 15.44, 95CI [9.29, 21.59]	Q = 1.16 $I^2 = 0\%$ $Tau^2 =$ 0.00	Positive pooled effect
Social emotional/challenging behaviour (problem behaviour)		2	SMD = -0.58, 95CI [-1.24, 0.07]	Q = 1.71 I2 =41.37% Tau2 =0.09	Null pooled effect
Adaptive behaviour		5	MD = 9.58, 95CI [5.57, 13.60]	Q = 2.43 $I^2 = 0\%$ $Tau^2 =$ 0.00	Positive pooled effect

Adaptive behaviour	5	MD = 7.77, 95CI	Q = 1.73	Positive
(daily living skills)		[3.75, 11.79]	$I^2 = 0\%$	pooled
			$Tau^2 =$	effect
			0.00	

Rodgers et al. (2020)- Met			G( 1		TT (	
Outcome	Context		Stud ies inclu ded	Effect size	Heterog eneity	Categorised outcome
Overall autism characteristics (autism symptom severity)	1 year		2	MD = 0.27, 95%CI (-0.19, 0.73)	I <sup>2</sup> = 0%	Null pooled effect
Cognitive development (cognitive ability)	1 year		5	MD = 10.12, 95%CI (5.81, 14.44)	$I^2 = 0\%$	Positive pooled effect
Cognitive development (cognitive ability)	2 years		6	MD = 11.97, 95%CI (6.74, 17.20)	$I^2 = 15\%$	Positive pooled effect
Adaptive behaviour	1 year		8	MD = 1.82, 95%CI (-2.79, 6.43)	$I^2 = 80\%$	Null pooled effect
Adaptive behaviour	2 years		7	MD = 7.74, 95%CI (1.87, 13.61)	$I^2 = 72\%$	Positive pooled effect
Moderators	Context	Outco me	Stud ies Inclu ded	Verbatim summary from systematic review		Categorised outcome
Child age		Cogniti ve develop ment	-	"There is no clear evid any interaction between factors [age at recruitr age at baseline, IQ at I and either IQ or VABS (e.g. no evidence that children gain greater be from early intensive A interventions than with alternative intervention younger children)." From table 5: Age at recruitment, MD = 0. (-0.26, 0.42).	The child's age (age at recruitment) was not related to the effect of support on cognitive development.	
Cognitive development		Cogniti ve develop ment	-	"There is no clear evidence of any interaction between these factors [age at recruitment, sex, age at baseline, IQ at baseline] and either IQ or VABS score (e.g. no evidence that older children gain greater benefit from early intensive ABA-based interventions than with alternative interventions than younger children)." From table 5: IQ at baseline, MD = 0.09 95%CI (-0.13, 0.31).		The child's cognitive development (IQ at baseline) was not related to the effect of support on cognitive development.
Adaptive behaviour		Cogniti ve	-	"There is no clear evid any interaction betwee factors [age at recruit	lence of en these	The child's adaptive behaviour

### Rodgers et al. (2020)- Meta-analysis

	develop		age at baseline, IQ at baseline]	(VABS at
	ment		and either IQ or VABS score	baseline) was not
			(e.g. no evidence that older	related to the
			children gain greater benefit	effect of support
			from early intensive ABA-based	on cognitive
			interventions than with	development.
			alternative interventions than	
			younger children)." From table 5: VABS at baseline,	
			MD = -0.1195%  CI(-0.58,	
			0.35).	
Child age	Adapti	_	"There is no clear evidence of	The child's age
	ve		any interaction between these	(age at
	behavio		factors [age at recruitment, sex,	recruitment) was
	ur		age at baseline, IQ at baseline]	not related to the
			and either IQ or VABS score	effect of support
			(e.g. no evidence that older	on adaptive
			children gain greater benefit	behaviour.
			from early intensive ABA-based	
			interventions than with	
			alternative interventions than	
			younger children)."	
			From table 5: Age at	
			recruitment, $MD = -0.0595\%$	
			CI (-0.29, 0.18).	
Cognitive development	Adapti	-	"There is no clear evidence of	The child's
	ve behavio		any interaction between these	cognitive
	ur		factors [age at recruitment, sex, age at baseline, IQ at baseline]	development (IQ at baseline) was
	ui		and either IQ or VABS score	not related to the
			(e.g. no evidence that older	effect of support
			children gain greater benefit	on adaptive
			from early intensive ABA-based	behaviour.
			interventions than with	
			alternative interventions than	
			younger children)."	
			From table 5: IQ at baseline,	
			MD = 0.09 95%CI (-0.06, 0.23).	
Adaptive behaviour	Adapti	-	"There is no clear evidence of	The child's
	ve		any interaction between these	adaptive
	behavio		factors [age at recruitment, sex,	behaviour
	ur		age at baseline, IQ at baseline]	(VABS at
			and either IQ or VABS score	baseline) was not related to the
			(e.g. no evidence that older children gain greater benefit	effect of support
			from early intensive ABA-based	on adaptive
			interventions than with	behaviour.
			alternative interventions than	
			younger children)."	
			From table 5: VABS at baseline,	
			MD = -0.05 95%CI (-0.28,	
			0.18).	
Setting	Cogniti	-	"Table 6 presents a summary of	The setting
	ve		these subgroup analyses for	(delivery setting-
	develop		outcomes at 2 years. For IQ, all	home, school,
	ment		p-values are $> 0.05$ and there are	specialist centre)

				no clear patterns of variation in treatment effect across analyses. For VABS composite score, all p-values are < 0.1, but these are a consequence of extreme results in a single subgroup, driven by extreme results in a single trial,85,95 and are unlikely to represent genuine differences between subgroups." Table 6; p-value of interaction = 0.62.	was not related to the effect of support on cognitive development.
Agent		Cogniti ve develop ment (cogniti on)		"Table 6 presents a summary of these subgroup analyses for outcomes at 2 years. For IQ, all p-values are > 0.05 and there are no clear patterns of variation in treatment effect across analyses. For VABS composite score, all p-values are < 0.1, but these are a consequence of extreme results in a single subgroup, driven by extreme results in a single trial,85,95 and are unlikely to represent genuine differences between subgroups." Table 6: P-value of interaction = 0.52, 95% CI for all effect sizes positive.	The agent (4 hours/week, encouraged, some) was not related to the effect of support on cognitive development.
Setting	Home, school, specialist centre	Adapti ve behavio ur	-	"Table 6 presents a summary of these subgroup analyses for outcomes at 2 years. For IQ, all p-values are > 0.05 and there are no clear patterns of variation in treatment effect across analyses. For VABS composite score, all p-values are < 0.1, but these are a consequence of extreme results in a single subgroup, driven by extreme results in a single trial,85,95 and are unlikely to represent genuine differences between subgroups." Table 6: P <0.01, mean for school is highest, mean for specialist centre is lowest, no post-hoc testing.	The setting (delivery setting- home, school, specialist centre) was not associated with the effect of support on adaptive behaviour.
Agent		Adapti ve behavio ur	-	"Table 6 presents a summary of these subgroup analyses for outcomes at 2 years. For IQ, all p-values are > 0.05 and there are no clear patterns of variation in treatment effect across analyses. For VABS composite score, all p-values are < 0.1, but these are a consequence of extreme	The agent (parental involvement 10 hours/week, 4 hours/week, encouraged, some) was not related to the effect of support

Amount of support	Home.	Cogniti	3	results in a single subgroup, driven by extreme results in a single trial,85,95 and are unlikely to represent genuine differences between subgroups." Table 6: $p = 0.1$ . "Three studies compared high-	on adaptive behaviour. The amount of
Amount of support	Home, school, specialist centre	cogniti ve develop ment (cogniti on)	5	intensity EIBI (> 15 hours/week) with lower- intensity EIBI.26,90,91,98,103 IQ was the only outcome recorded consistently in all three studies. A repeated measures meta-analysis of IQ comparing high- with low-intensity early ABA-based intervention is shown in Figure 14. This suggests that high-intensity ABA-based interventions produced much larger improvements in IQ than low- intensity ABA-based interventions, with differences of between 10 and 20 points from 1 to 4 years after recruitment, although results are not statistically significant at 1 and 3 years."	The amount of support (high intensity versus low intensity) was positively associated with the effect of support on cognitive development. Children in high intensity ABA conditions had larger improvements in cognitive development at 4 and 7 years after recruitment but there were no differences at 1 and 3 years.

### Sandbank et al. (2020) - Meta-analysis

Outcome	Context	Stud ies inclu ded	Effect size	Heterog eneity	Categorise d outcome
Behavioural Supports Overall autism characteristics (diagnostic characteristics)	All studies	8	g = 0.45, 95CI [0.26, 0.63]	Not specified	Positive pooled effect
Social-communication	All studies	20	g = 0.40, 95CI [0.18, 0.61]	Not specified	Positive pooled effect
Communication (language)	All studies	14	g = 0.24, 95CI [0.01, 0.47]	Not specified	Positive pooled effect
Cognitive development	All studies	21	g = 0.29, 95CI [0.05, 0.54]	Not specified	Positive pooled effect
Motor	All studies	8	g = 0.42, 95CI [0.13, 0.72]	Not specified	Positive pooled effect
Social emotional/challenging behaviour	All studies	13	g = 0.46, 95CI [0.27, 0.66]	Not specified	Positive pooled effect

Adaptive behaviour Developmental Supports	All studies	21	g = 0.38, 95CI [0.19, 0.56]	Not specified	Positive pooled effect
Social-communication	All studies	14	g = 0.30, 95CI [0.11, 0.50]	Not specified	Positive pooled effect
Communication (language)	All studies 1 behavioural interventions (1)	8 NDBIs)	g = 0.06, 95CI [- 0.08, 0.21]	Not specified	Null pooled effect
Overall autism characteristics (diagnostic characteristics)	All studies	6	g = 0.05, 95CI [- 0.38, 0.48]	Not specified	Null pooled effect
Social-communication	All studies	24	g = 0.35, 95CI [0.18, 0.53]	Not specified	Positive pooled effect
Restricted and repetitive interests and behaviours	All studies	7	g = -0.01, 95CI [- 0.34, 0.32]	Not specified	Null pooled effect
Communication (language)	All studies	19	g = 0.20, 95CI [0.03, 0.38]	Not specified	Positive pooled effect
Cognitive development	All studies	9	g = 0.26, 95CI [0.01, 0.51]	Not specified	Positive pooled effect
Social emotional/challenging behaviour	All studies	6	g = 0.17, 95CI [- 0.28, 0.61]	Not specified	Null pooled effect
Play	All studies	6	g = 0.33, 95CI [0.13, 0.54]	Not specified	Positive pooled effect
Adaptive behaviour	All studies	6	g = 0.16, 95CI [- 0.24, 0.56]	Not specified	Null pooled effect
Sensory-based Supports Communication (language)	All studies	7	g = 0.28, 95CI [- 0.19, 0.76]	Not specified	Null pooled effect
Treatment and Education Social-communication	of Autistic and related Comm All studies	6	s Handicapped Childre g = -0.11, 95CI [-0.93, 0.71]	n (TEACCH Not specified	Null pooled effect
Technology-based Suppor	ts				
Social-communication	All studies	9	g = 0.05, 95CI [- 0.18, 0.27]	Not specified	Null pooled effect
Social emotional/challenging behaviour	All studies	7	g = 0.42, 95CI [- 0.19, 1.03]	Not specified	Null pooled effect

# Sandgreen et al. (2021)- Meta-analysis

Moderators	Context	Outcome	Stud ies Inclu ded	Verbatim summary from systematic review	Categorise d outcome
Child age	<5 years, 5-10 years, >10-15 years	General outcomes	-	"The meta regression analysis revealed no significant associations between Cohen's d and any of the variables	The child's age (age group <5 years, 5-10

	between subg $\beta = -0.35$ , p	baseline); $> 10-$ - 0.25, p = related to the effect of support on general
		outcomes.

### Shi et al. (2021)- Meta-analysis

Outcome	Conte	Studie	Effect size	Heterogen	Categorised
	xt	S		eity	outcome
		includ			
		ed			
Social-communication (VABS	-	5	SMD = 0.38, 95%CI	$I^2 = 20.8\%$	Positive pooled
Social)			(0.03, 0.73)		effect
Communication (VABS	-	5	SMD = 0.38, 95%CI	$I^2 = 21\%$	Positive pooled
communication)			(0.03, 0.73)		effect
Expressive language	-	4	SMD = 0.46, 95%CI (-	$I^2 = 56.1\%$	Null pooled effect
			0.08, 1.00)		
Receptive language	-	4	SMD = 0.42, 95%CI (-	$I^2 = 45.5\%$	Null pooled effect
			0.06, 0.91)		
Cognitive development (IQ)	-	6	SMD = 0.53, 95%CI	$I^2 = 41.3\%$	Positive pooled
			(0.16, 0.90)		effect
Adaptive behaviour (VABS	-	5	SMD = 0.47, 95%CI	$I^2 = 24.2\%$	Positive pooled
composite)			(0.11, 0.83)		effect
Adaptive behaviour (daily	-	4	SMD = 0.18, 95%CI (-	$I^2 = 0\%$	Null pooled effect
living skills)			0.16, 0.53)		

### Soares et al. (2021)- Meta-analysis

Outcome	Context	Stud ies inclu ded	Effect size	Heterog eneity	Categorise d outcome
Social-communication (social functioning)	-	4	g = 0.93, 95%CI (0.57, 1.29)	$\chi^2 = 4.32$ $I^2 = 7.31$	Positive pooled effect

### Sutherland et al. (2018) – Narrative synthesis

Outcome	Studies	Verbatim summary from systematic review	Categorised
	included		outcome
Caregiver	9	"Satisfaction and acceptability. Parent satisfaction was a reported	Positive
satisfaction		outcome for nine of the 14 studies (Baharav & Reiser, 2010;	summarised
(satisfaction		Hepburn et al., 2016; Ingersoll & Berger, 2015; Meadan et al.,	effect
and		2016; Pickard et al., 2016; Reese, Braun, et al., 2015; Schutte et al.,	
acceptability)		2015; Suess et al., 2016; Wainer & Ingersoll, 2015). All studies	
		reported high levels of programme acceptability and parent	
		satisfaction with the telehealth component of the intervention or	
		assessment. In addition, two studies that involved direct telehealth	
		involvement with individuals on the spectrum (Hepburn et al., 2016;	
		Schutte et al., 2015) reported high participant satisfaction with the	
		methods used."	
Caregiver	7	"Measurement of fidelity of parent implementation of tasks was a	Positive
communication		focus of seven of the 14 studies (Hepburn, et al., 2016; Ingersoll &	summarised
		Berger, 2015; Ingersoll et al., 2016; Meadan et al., 2016; Reese,	effect

and interaction	Jamison, et al., 2013; Suess et al., 2016; Wainer & Ingersoll, 2015).
(fidelity)	The fidelity of parent administration of assessment tasks in the
	diagnosis study (Reese, Jamison, et al., 2013) was described as
	'adequate'', while parent fidelity in the behaviour study of Suess et
	al. (2016) varied across the coached and independent trials "The
	remaining studies reported high levels of parent fidelity for
	interventions provided via telehealth (Hepburn et al., 2016;
	Ingersoll et al., 2016), with a number reporting that the fidelity of
	programmes taught to parents online was improved when telehealth
	coaching was provided (Ingersoll & Berger, 2015; Meadan et al.,
	2016; Wainer & Ingersoll, 2015)."

Outcome	Context	Stud ies inclu ded	Effect size	Heterog eneity	Categorise d outcome
Overall autism characteristics (autism general symptoms)	Individual intervention (Analysis I)	3	SMD = -0.31, 95CI [-0.63, 0.01]	$I^2 = 0\%$	Null pooled effect
Social-communication (qualitative impairment in social interaction)	Individual intervention (Analysis I)	2	SMD = -0.15, 95CI [-0.40, 0.10]	$I^2 = 0\%$	Null pooled effect
Social-communication (reciprocity of social interaction towards	Individual intervention (Analysis I)	5	SMD = 0.59, 95CI [0.25, 0.93]	I <sup>2</sup> = 18%	Positive pooled effect
others)	Group intervention (Analysis I)	3	SMD = 0.45, 95CI [0.02, 0.88]	$I^2 = 0\%$	Positive pooled effect
Social-communication (initiating joint attention)	Individual intervention (Analysis I)	4	SMD = 0.48, 95CI [-0.14, 1.10]	$I^2 = 78\%$	Null pooled effect
	Group intervention (Analysis I)	2	SMD = 0.15, 95CI [-0.38, 0.68]	$I^2 = 15\%$	Null pooled effect
Social-communication (imitation)	Individual intervention (Analysis I)	Not speci fied	SMD = 0.54, 95CI [-0.25,1.33]	$I^2 = 62\%$	Null pooled effect
Social-communication (responding to joint attention)	Individual intervention (Analysis I)	3	SMD = 0.63, 95CI [-0.14,1.39]	$I^2 = 97\%$	Null pooled effect
Restricted and repetitive interests and behaviours (restricted repetitive and stereotyped patterns behaviours, interests and activities)	Individual intervention (Analysis I)	3	SMD = -0.21, 95CI [-0.52, 0.09]	I <sup>2</sup> = 39%	Null pooled effect
Communication (qualitative impairment in communication)	Individual intervention (Analysis I)	1	SMD = -0.03, 95CI [-0.35, 0.29]	N/A	Null pooled effect
Expressive language	Individual intervention (Analysis I)	7	SMD = 0.13, 95CI [-0.06, 0.33]	$I^2 = 0\%$	Null pooled effect
	Group intervention (Analysis I)	1	SMD = -0.03, 95CI [-0.54, 0.48]	N/A	Null pooled effect
Receptive language	Individual intervention (Analysis I)	7	SMD = 0.17, 95CI [-0.09, 0.42]	$I^2 = 28\%$	Null pooled effect

### Tachibana et al. (2018) – Meta-analysis

	Group interv	ention	1	SMD = 0.14, 95CI	N/A	Null pooled
	(Analysis I)	cittion	1	[-0.65, 0.37]	IN/A	effect
Cognitive development	Individual in	tomion	4/51	SMD = 0.36, 95CI	$I^2 = 20\%$	Positive
(developmental quotient)	(Analysis I)		4/3	[0.05, 0.66]	1 = 2070	pooled
(developmental quotient)	(Analysis I)			[0.05, 0.00]		effect
Adaptive behaviour	Individual intervention		7	SMD = -0.05,	$I^2 = 39\%$	Null pooled
Adaptive benaviour	(Analysis I)		/	95CI [-0.25, 0.14]	1 3770	effect
	Group interv	ention	1	SMD = 0.44, 95CI	N/A	Null pooled
	(Analysis I)	cittion	1	[-0.07, 1.65]	1 <b>N/A</b>	effect
Caregiver	Individual In	tervention	3	SMD = 0.99 [0.70,	Not	Positive
communication and	(Analysis I)		5	1.29]	specified	pooled
interaction (parental	(7 mary 515 1)			1.29]	specifica	effect
synchrony)						enteet
Caregiver social	Individual in	tervention	2	SMD = -0.30, 95CI	$I^2 = 0\%$	Null pooled
emotional wellbeing	(Analysis I)		2	[-0.93, 0.32]	1 0/0	effect
(parenting stress)	Group interv	ention	2	SMD = -0.29, 95CI	$I^2 = 0\%$	Null pooled
(parenning stress)	(Analysis I)		-	[-0.81, 0.22]	1 0/0	effect
Moderators	Context	Outcome	Stud	Verbatim summary	from	Categorise
			ies	systematic review		d outcome
			Inclu	~,~~~~		
			ded			
Format	Individual,	Overall	Not	"There were no signi	ficant	Format
	group	autism	speci	differences between		(individual,
		characteristic	fied	individual and group		group) did
		s (autism		intervention studies	on the	not relate to
		general		outcomes reviewed.'	,	the effect
		symptoms),				of support
		social-				on overall
		communicati				autistm
		on				characterist
		(reciprocity				ics, social-
		of social				communica
		interaction				tion,
		towards				expressive
		others),				language,
		expressive				receptive
		language,				language,
		receptive				cognitive
		language,				developme
		cognitive				nt, or
		development				adaptive
		(development				behaviour.
		al quotient),				Sonuviour.
		adaptive				
		behaviour				
Doth mumbers non-orted		Jenavioui		1		

<sup>1</sup>Both numbers reported **Tan-MacNeill et al. (2021)-** <u>Narrative synthesis</u>.

Outcome	Stud ies inclu ded	Verbatim Summary from Systematic Review	Categorised outcome
Social-communication (communication behaviours and language targets)	3	"All three of the social-communication interventions improved children's communication behaviors and language targets (Douglas et al., 2018; Ingersoll et al., 2016; McGarry et al., 2019)."	Positive summarised effect

### Tarver et al. (2019) – Meta-analysis

Outcome	Context	Stud ies inclu ded	Effect size	Heterog eneity	Categorise d outcome
Social emotional/challenging behaviour	Parent-reported disruptive behaviour	9	SMD = 0.67, 95CI [0.49, 0.85]	$I^2 = 0\%$	Positive pooled effect
	Parent-reported hyperactivity	3	SMD = 0.31, 95CI [0.07, 0.56]	$I^2 = 0\%$	Positive pooled effect
Caregiver social emotional wellbeing (parenting stress)	-	7	SMD = 0.37, 95CI [0.17, 0.57]	$I^2 = 0\%$	Positive pooled effect
Caregiver social emotional wellbeing (parenting efficacy)	-	5	SMD = 0.39, 95CI [-0.17, 0.95]	$I^2 = 81\%$	Null pooled effect

### Tiede & Walton (2019) – Meta-analysis

Outcome	Context		Stud ies inclu ded	Effect size	Heterog eneity	Categorise d outcome
Overall autism characteristics (symptoms of ASD)	-		9	g = -0.38, 95CI [-0.71, -0.04]	Q = 26.1 $I^2 = 67\%$	Positive pooled effect
Social-communication (joint attention)	Initiating join	nt attention	15	g = 0.14, 95CI [-0.01, 0.28]	Q = 16.0 $I^2 = 7\%$	Null pooled effect
Social-communication (social engagement)	-		12	g = 0.65, 95CI [0.37, 0.93]	Q = 34.2 $I^2 = 64\%$	Positive pooled effect
Expressive language	-		12	g = 0.32, 95CI [0.07, 0.56]	Q = 22.9 $I^2 = 54\%$	Positive pooled effect
Receptive language	-		10	g = 0.28, 95CI [-0.02, 0.58]	Q = 24.9 $I^2 = 64\%$	Positive pooled effect
Cognitive development	Composite IO	2	5	g = 0.48, 95CI [0.22, 0.74]	Q = 5.3 $I^2 = 30\%$	Positive pooled effect
Cognitive development (nonverbal IQ)	-	-		g = 0.21, 95Cl [0.01, 0.41]	Q = 6.1   <sup>2</sup> = <1%	Positive pooled effect
Play	-		8	g = 0.23, 95CI [0.04, 0.41]	Q = 7.7 $I^2 = 11\%$	Positive pooled effect
Adaptive behaviour	-		5	g = 0.09, 95CI [-0.24, 0.42]	Q = 9.1 $I^2 = 56\%$	Null pooled effect
Moderators	Context	Outcome	Stud ies Inclu ded	Verbatim summary systematic review	r from	Categorise d outcome

Amount of support	-	Social-	Not	[Social-communication - joint	Greater
<sup>2</sup> mount of support		communicati	speci	attention]: "Dosage	amount of
		on (joint	fied	significantly moderated the	support
		attention,		results such that increased	(total
		social		hours of professional contact	hours)
		engagement),		resulted in more positive joint	related to
		expressive		attention outcomes ( $\beta = 0.17 \text{ p}$	greater
		language,		= 0.02, 95% CI $= 0.02$ to	effect of
		receptive		0.32)."	support on
		language,			social-
		cognitive		[Expressive Language]:	communica
		development		"Dosage did not moderate	tion (joint
		(cognition),		effects ( $\beta = 0.09$ , p = 0.35,	attention).
		adaptive		95%	Amount of
		behaviour,		CI = -0.10 to 0.29)."	support
		overall			(total
		autism characteristic		[Receptive Language]: "When study quality and dosage were	hours) not related to
		s, play		added as moderators, neither	effect of
		s, piuy		dosage ( $\beta = 0.15$ , $p = 0.35$ ,	support on
				95% CI = $-0.16$ to $0.46$ ) nor	adaptive
				study quality ( $\beta = -0.28$ , p =	behaviour,
				0.36, 95% CI = $-0.87$ to $0.32$ )	expressive
				significantly moderated	or receptive
				the effects."	language,
					cognition,
				[Cognitive development]: "for	overall
				composite IQ/cognitive	autism
				development Dosage ( $\beta =$	characterist
				0.06, p = 0.79, 95% CI = -0.36 to 0.47) and study quality ( $\beta$ =	ics, social- communica
				-0.09, p = 0.80, 95% CI =	tion (social
				-0.82 to 0.63) did not	engagemen
				significantly moderate the	t), or play.
				effects. For nonverbal IQ	), I J
				Neither study quality ( $\beta = 0.24$ ,	
				p = 0.25, 95% CI = -0.17 to	
				0.65) nor dosage significantly	
				moderated the effects ( $\beta =$	
				0.18, p = 0.14, 95% CI = -0.06	
				to 0.42)."	
				[Adaptive behaviour]: "A	
				marginally significant effect was found for dosage; more	
				professional	
				contact hours were associated	
				with more positive findings ( $\beta$	
				= 0.30, p = 0.06, 95% CI =	
				-0.02 to $0.62$ )."	
				, , , , , , , , , , , , , , , , , , ,	
				[Overall autism	
				characteristics]: "Neither	
				dosage ( $\beta = 0.13$ , p = 0.54,	
				95% CI = $-0.28$ to $0.54$ ) nor	
				study quality ( $\beta = -0.07$ , p =	

0.86, 95% CI = $-0.89$ to 0.74) moderated the results."
[Social-communication – social engagement]: "Neither dosage ( $\beta = 0.17$ , p = 0.20, 95% CI = -0.09 to 0.44) nor study quality ( $\beta = 0.25$ , p = 0.42, 95% CI = -0.36 to 0.85) moderated the results."
[Play]: "Dosage did not significantly moderate the results ( $\beta = -0.11$ , p = 0.21, 95% CI = -0.27 to 0.06; see Figure 2(h))."

# Trzmiel et al. (2019) – Meta-analysis

Outcome	Context	Stud ies inclu ded	Effect size	Heterog eneity	Categorised outcome
Social-communication (social)	-	3	SMD = .220, 95CI [130, .580]	$Chi^2 = 0.55$ $I^2 = 0.0\%$	Null pooled effect
Communication	-	3	SMD = .191, 95CI [165, .547]	$Chi^{2} = 0.48$ $I^{2} = 0.0\%$	Null pooled effect
Adaptive behaviour	-	3	SMD = .742, 95CI [010, 1.494]	Chi <sup>2</sup> = 5.87 $I^2$ = 66.0%	Null pooled effect

### Tupou et al. (2019) – Narrative synthesis

Outcome	Studies included	Verbatim summary from systematic review	Categorised outcome
Overall autism characteristics (autism severity and/or symptoms)	4	[group design studies only] "Four (57%) of the seven group studies reported on measures of autism severity and/or symptoms (D'Elia et al. 2014; Eikeseth et al. 2012; Strain and Bovey 2011; Young et al. 2016) using the Autism Diagnostic Observation Schedule (ADOS; Lord et al.2008), or the Childhood Autism Rating Scale (CARS; Schopleretal. 2002). D'Elia et al. (2014) reported decreases in autism diagnoses across both EGs and CGs, as measured by the ADOS, with a larger decrease observed in the EG. Similarly, in the study by Strain and Bovey (2011), the EG demonstrated a greater decrease in CARS scores than the CG. The Eikeseth study (2012) reported a significant decrease in CARS scores for the EG, but did not report comparison data for the CG. The authors of the final study (Young et al.2016) did not report any significant change in CARS scores."	Positive summarised effect

Social- communication (social skills)	2	[group design studies only] "Two (29%) of the group studies (Strain and Bovey 2011; Young et al. 2016) reported on social skills, which were measured via the Social Skills Rating System (SSRS; Gresham and Elliott 1990) and the Autism Screening Instrument for Educational Planning (ASIEP; Krug et al.2008). Both studies reported positive results, with the EG making greater improvements than the CG in both cases."	Positive summarised effect
Communication (communication and/or language)	5	[group design studies only] "Child communication and/or language was measured in five (71%) of the group studies (Boulware et al. 2006; D'Elia et al. 2014; Fleury and Schwartz 2017; Strain and Bovey 2011; Young et al. 2016) via a range of different instruments including (a) Communication, Social, and Symbolic Behavior Scales (CSBS; Wetherby and Prizant 2002); (b) MacArthur Communication Developmental Inventories (CDI; Fenson et al. 1993; Fenson et al. 1994); (c) Preschool Language Scale (PLS; Zimmerman et al. 1991); (d) Expressive One Word Picture Vocabulary Test (EOWPVT; Brownell 2000a); (e) Receptive One Word Picture Vocabulary Test (ROWPVT; Brownell2000b); and (f) a researcher-delivered book vocabulary assessment (Fleury and Schwartz 2017). Participants demonstrated improvement on at least one communication/language outcome across all five of these studies."	Positive summarised effect
Social emotional/challenging behaviour (adaptive/maladaptive behaviour)	5	[group design studies only] "Five (71%) of these group design studies that measured adaptive/maladaptive behavior reported positive results (Boulware et al. 2006; D'Elia et al. 2014; Eikeseth et al. 2012; Eldevik et al. 2012; Strain and Bovey 2011), while the remaining study was coded as having no effect because there were no significant changes in participant scores for the EG (Young et al. 2016)."	Positive summarised effect
Adaptive behaviour (functional skills)	2	[group design studies only] "Functional skills were measured as outcomes in two (29%) of the group studies (Boulware et al. 2006; Schwartz et al. 2004) and were assessed using (a) Bayley Scales of Infant Development (Bayley 2006); (b) Assessment, Evaluation, and Programming System for Infants and Children (AEPS; Bricker 1994); (c) a researcher-developed functional outcomes index (Schwartz et al. 2004); and (d) a researcher developed functional outcomes scale (Boulware et al. 2006). Participating children from both studies demonstrated gains across at least one functional outcome, and participants from the Schwartz et al. (2004) study made gains across all six of the functional outcomes measured."	Positive summarised effect

#### Valentine et al. (2020)- Narrative synthesis

Outcome	Studies included	Context	Verbatim summary from systematic review	Categorised outcome
General outcomes (clinical effectiveness)	6	Gaming	"Five papers reported gaming to be clinically effective and one reported a lack of clinical effectiveness."	Positive summarised effect

General	9	Tablet/mobile	"Tablet / Mobile phone applications (apps). Clinical	Inconsistent
outcomes		apps	effectiveness: As seen in Table 7, nine papers	summarised
(clinical			focussed on treatment in an ASD sample. Five of	effect
effectiveness)			these papers reported the tablet/mobile app to be	
			clinically effective/partially effective."	
General	5	Video/DVD/	"Clinical effectiveness: Most papers (5/6) reported	Positive
outcomes		Video	on clinical efficacy, however, sample sizes were	summarised
(clinical		modelling	small with four papers reporting three or fewer	effect
effectiveness)			participants (Kern Koegel, Ashbaugh, Navab, &	
			Koegel, 2016; Kourassanis, Jones, & Fienup, 2014;	
			Radley et al., 2015; Stewart & Umeda, 2014). Three	
			of these papers reported positive clinical	
			effectiveness and video-modelling was found to	
			increase empathic communication (Kern Koegel et	
			al., 2016), improve social game behaviours	
			(Kourassanis et al., 2014) and social skills accuracy	
			(Radley et al., 2015). The findings of Stewart and	
			Umeda (2014) were more mixed, reporting that it	
			was effective in teaching motor imitation only in	
			some children. In a larger study with 38 participants,	
			Dai et al. (2018) used a DVD to deliver an ASD	
			parenting intervention reporting mixed results, with	
			parents' confidence about their parenting abilities	
			significantly increasing, knowledge increasing	
			slightly, but self-efficacy remaining constant."	

#### Verschuur et al. (2014) – Narrative synthesis

Outcome	Studi	Verbatim summary from systematic review	Categorise
	es		d outcome
	includ		
	ed		
General	35	"Of the 35 studies targeting child behaviors, 15 studies (42.9 %) reported	Inconsisten
outcomes		positive outcomes and 20 studies (57.1 %) reported mixed outcomes."	t
(child		[Outcomes include communication and language skills; play skills;	summarise
behaviours)		adaptive functioning; maladaptive behaviours; autism symptoms]	d effect
Caregiver	13	"Of the 13 studies targeting caregiver behaviors, 7 studies (53.8 %)	Inconsisten
social		reported positive outcomes and 5 studies (38.5 %) reported mixed	t
emotional		outcomes."	summarise
wellbeing		[Outcomes include caregiver fidelity of implementation of PRT/NLP;	d effect
(caregiver		parental stress; parental affect; parental self-efficacy; parent	
behaviours)		verbalisations]	

Outcome	Studies	Verbatim summary from systematic review	Categorised
	included		outcome
Overall autism	2	"Autism characteristics: Several studies measured the effect of	Null
characteristics		intervention on core characteristics of ASD. These studies reported	summarised
(core		that there was no significant post-treatment difference in restricted	effect
characteristics		and repetitive behaviours (Harrop et al., 2017), or 'global autism	
of ASD)		symptoms' (Nordahl-Hansen et al., 2016) between the intervention	
		and comparison groups at any timepoint."	
Social-	13	"Table 2 indicates the effects of intervention on children's joint	Positive
communication		attention and engagement skills. All 13 studies reported at least one	summarised
(joint attention		positive effect of intervention on at least one outcome."	effect

#### Waddington et al. (2021)- Narrative synthesis

and engagement)			
Communication (child communication skills)	7	"Table 3 also indicates the effects of intervention on child communication skills, for the seven studies that assessed this outcome. Five of these studies reported positive effects for at least one outcome."	Positive summarised effect
Expressive language (overall expressive language)	6	"Two of six studies reported positive effects for overall expressive language."	Inconsistent summarised effect
Receptive language	4	"Only one of four studies reported a positive intervention effect for receptive language."	Inconsistent summarised effect
Play	9	"Table 3 indicates the effects of intervention on child play skills, for the nine studies which assessed this outcome. All but one study (Wong, 2013) reported positive effects for at least one outcome."	Positive summarised effect

#### Wang et al. (2021a)- Meta-analysis

Outcome	Context		Stud ies inclu ded	Effect size	Heterogeneity	Categorised outcome
Overall autism characteristi cs (autism symptoms)	-		8	g = 0.272, 95%CI (0.018, 0.526)	I <sup>2</sup> = 53.06%	Positive pooled effect
Social communicat ion	-		7	g = 0.010, 95%CI (- 0.184, 0.204)	$I^2 = 47.48\%$	Null pooled effect
Communica tion (language)	-		7	g = 0.278, 95%CI (0.002, 0.555)	$I^2 = 70.82\%$	Positive pooled effect
Cognitive developmen t (cognition)	-		7	g = 0.278, 95%CI (0.108, 0.449)	$I^2 = 1.38\%$	Positive pooled effect
Moderators	Context	Outcome	Stud ies Inclu ded	Verbatim summary review	Categorised outcome	
Agent	Parent, professiona 1	Overall autism characteristic s	9	"The primary implem format were independ heterogeneity in the e From table 2: Q betwo 0.12	The agent (parents, professionals) was not related to the effect of support on overall autism characteristics	
Format	Group, individual	Overall autism characteristic s	9	"The primary implem format were independ heterogeneity in the e From table 2: Q betwo	The format (individual, group) was not related to	

					the effect of support on overall autism characteristics
Amount of support	Intensity of support	Overall autism characteristic s	_	"Table 3 shows that the results of the regression model were not significant, and the length and intensity of the intervention could not predict the results. In other words, increasing the length and intensity of the intervention does not produce significant effects on autism symptoms." From table 3: Tau squared = 0.10, p = $0.74$ .	The amount of support (intensity) was not related to the effect of support on overall autism characteristics
Agent	Parent, professiona l	Communicati on	13	"The primary implementer and the format were independent of the heterogeneity in the effect sizes." From Table 4: Q between = 6.82, p = 0.12.	The agent (parents, professionals) was not related to the effect of support on communicatio n.
Format	Group, individual	Communicati on	13	"The primary implementer and the format were independent of the heterogeneity in the effect sizes." From table 4: Q between = 0.22, p = 0.64.	The format (individual, group) was not related to the effect of support on communicatio n.

#### Wang et al. (2021b)- Meta-analysis

Outcome	Context	Stud ies inclu ded	Effect size	Heter ogenei ty	Categorised outcome
Overall autism characteristics (symptoms related to ASD)	Self-reported outcomes	10	SMD = -0.09, 95%CI (-0.42, 0.24)	I <sup>2</sup> = 69.3%	Null pooled effect
Overall autism characteristics (symptoms related to ASD)	Informant- reported outcomes	23	SMD = -0.57, 95%CI (-0.90, - 0.24)	I <sup>2</sup> = 87.8%	Positive pooled effect
Overall autism characteristics (symptoms related to ASD)	Clinician reported outcomes	5	SMD = 0.75, 95%CI (0.10, 1.41)	$I^2 = 55.1\%$	Negative pooled effect
Overall autism characteristics (symptoms related to ASD)	Task-based outcomes	11	SMD = -0.41, 95%CI (-0.75, - 0.08)	$I^2 = 70.9\%$	Positive pooled effect
Social emotional/challenging behaviour (symptoms of social- emotional problems)	Self-reported outcomes	9	SMD = -0.42 95%CI (-0.90, 0.07)	I <sup>2</sup> = 78.6%	Null pooled effect
Social emotional/challenging behaviour (symptoms of social- emotional problems)	Informant reported outcomes	19	SMD = -0.71, 95%CI (-1.04, - 0.38)	I <sup>2</sup> = 77.3%	Positive pooled effect

Social emotional/challenging behaviour (symptoms of social- emotional problems)	outcom		9	SMD = 1.02, 95%CI (0.58, 1.46)	I <sup>2</sup> = 68.6%	Negative pooled effect Note: Described as positive by the authors contradictory to the direction of the effect so excluded from summary tables.
Moderators	Cont ext	Outcome	Stud ies Incl uded	Verbatim summary systematic review	r from	Categorised outcome
Child age	≥10, <10 years	Overall autism characteri stics (self- reported)	10	Table 1: Between su p-value = 0.479	bgroups	The child's age (mean age: $<10$ , $\ge 10$ ) was not related to the effect of support on self-reported overall autism characteristic s.
Child age	≥10, <10 years	Overall autism characteri stics (informan t- reported)	23	Table 1: Between su p-value = 0.007; ≥10 (-1.3,-0.22); <10 = -0 0.79, -0.02)	= -0.76	The child's age (mean age: $<10$ , $\ge 10$ ) was positively associated with the effect of support on informant- reported overall autism characteristic s. Children aged $\ge 10$ showed greater reductions than those aged $< 10$ .
Child age	≥10, <10 years	Overall autism characteri stics	5	Table 1. Between su p-value = .136	bgroups	The child's age (mean age: $<10$ , $\ge 10$ ) was not related to the

		(clinician			effect of
		reported)			support on clinician ratings of overall autism characteristic s.
Child age	≥10, <10 years	Overall autism characteri stics (task- based)	11	Table 1: Between subgroups p-value = 0.237	The child's age (mean age: <10, $\geq$ 10) was not related to the effect of support on task-based ratings of overall autism characteristic s.
Format	Grou p, indivi dual	Overall autism characteri stics (self- reported)	10	Table 1: Between subgroups p-value = 0.696	The format (group based, individual based) was not related to the effect of support on self-reported overall autism characteristic s.
Format	Grou p, indivi dual	Overall autism characteri stics (informan t- reported)	23	Table 1: Between subgroups p-value = 0.815	The format (group based, individual based) was not related to the effect of support on informant reported overall autism characteristic s.
Format	Grou p, indivi dual	Overall autism characteri stics (clinician- reported)	5	Table 1: Between groups p- value = 0.610	The format (group based, individual based) was not related to the effect of support on clinician ratings of overall

Format	Grou	Overall	11	Table 1: Between subgroups	autism characteristic s. The format
	p, indivi dual	autism characteri stics (task- based)		p-value = 0.110	(group based, individual based) was not related to the effect of support on task-based ratings of overall autism characteristic s.
Child age	≥10, <10 years	Social- emotional and challengi ng behaviour (self- reported)	9	Table 1: Between groups p- value = 0.255	The child's age (mean age: <10, $\geq$ 10) was not related to the effect of support on self-reported social emotional/ challenging behaviour.
Child age	≥10, <10 years	Social- emotional and challengi ng behaviour (informan t- reported)	19	Table 1: Between groups p- value = 0.391	The child's age (mean age: <10, $\geq$ 10) was not related to the effect of support on informant reported social emotional/ challenging behaviour.
Child age	≥10, <10 years	Social- emotional and challengi ng behaviour (clinician- reported)	9	Table 1: Between groups p- value = $0.018$ ; $\geq 10 = 0.80$ (0.40, 1.19); $<10 = 1.64$ (0.1,3.19)	The child's age was negatively associated with the effect of support on clinician rated social emotional/ challenging behaviour. Children aged <10 showed

					greater reductions than those aged $\geq 10$ .
Format	Grou p, indivi dual	Social- emotional and challengi ng behaviour (self- reported)	9	Table 1: Between groups p- value = 0.069	The format (group based, individual based) was not related to the effect of support on self-reported social emotional/ challenging behaviour.
Format	Grou p, indivi dual	Social- emotional and challengi ng behaviour (informan t- reported)	19	Table 1: Between groups p- value = 0.481	The format (group based, individual based) was not related to the effect of support on informant reported social emotional/ challenging behaviour.
Format	Grou p, indivi dual	Social- emotional and challengi ng behaviour (clinician- reported)	9	Table 1: Between groups p- value = 0.335	The format (group based, individual based) was not related to the effect of support on clinician reported social emotional/ challenging behaviour.

#### Zheng et al. (2021)- Meta-analysis

Outcome	Context	Stud ies inclu ded	Effect size	Heterog eneity	Categorise d outcome
Social-communication	Self-reported social knowledge - TASSK	9	g = 2.15, 95%Cl (1.54, 2.77)	$I^2 = 71\%$	Positive pooled effect
Social-communication	Parent-reported social knowledge - SSiS	5	g = 0.71, 95%Cl (0.26, 1.15)	$I^2 = 4\%$	Positive pooled effect

Social-communication	SRS - parent-reported social knowledge	5	g = 0.72, 95%Cl (0.33, 1.10)	$I^2 = 0\%$	Positive pooled effect
Community participation	Get togethers (self-report QSQ)	9	g = 0.60, 95Cl (0.27,0.93)	$I^2 = 49\%$	Positive pooled effect
Community participation	Get togethers (parent-report QSQ)	6	g = 0.55, 95%Cl (0.16,0.93)	$I^2 = 12\%$	Positive pooled effect

Footnote: ES = Effect size; MD = mean difference; NS = Not stated; SMD = standardised mean difference; SMC = standard mean change; RVE = Robust Variance Estimation

 Appendix 5.15
 Umbrella review - Adverse effects

## Appendix 5.15 - Umbrella review - Adverse effects

Information on the influence of different support delivery characteristics on the effect of support.

Focus of	Frequency of consideration	Evidence for	adverse effects
Systematic Review		Systematic review	Author statement (verbatim quote)
Behavioural supports	Considered in 1/4 systematic reviews (identified in 0)	-	_
Developmental supports	Considered in 0/3 systematic reviews	-	-
Naturalistic developmental behavioural interventions	Considered in 0/8 systematic reviews	-	-
Sensory-based supports	Considered in 1/3 systematic reviews (identified in 0)	-	
ТЕАССН	Considered in 0/1 systematic reviews	-	

Technology- based supports	Considered in 2/10 systematic reviews (identified in 1)	Mazon et al. (2019)	"Sample sizes across studies ranged from 5 to 23 participants per group, with an average around 10 participants per group. According to the Jadad scale, 5 of out the 6 studies scored 0 and the remaining study scored 1, thanks to the inclusion of a statement about dropouts (6 participants were excluded due to refusal or distress; Bekele et al., 2014)." (p.243-244)
Animal- assisted supports	Considered in in 1/3 systematic reviews (identified in 0)		
Cognitive behaviour therapy	Considered in 0/2 systematic reviews	-	-
Other supports	Considered in 0/3 systematic reviews	-	-
Child outcomes	Considered in 0/5 systematic reviews	-	-
Delivery characteristics	Considered in 0/13 systematic reviews	-	-

Appendix 5.16	Umbrella review - Influence of delivery characteristics on
	child and family support outcomes

# Appendix 5.16 - Umbrella review - Influence of delivery characteristics on child and family support outcomes

Characteristic	Systematic review	Summary of evidence
Setting	Parsons, Cordier, Munro et al. (2017)	<b>Social communication outcomes:</b> Setting not related to the effect of support on social-communication.
	Kent et al. (2020)	<b>Play outcomes:</b> Setting (clinic, home) not related to the effect of support on play.
Format	Wang et al. (2021a)	<b>Early Start Denver Model (practice):</b> Format (individual, group) not related to the effect of support on overall autism characteristics or communication.
	Wang et al. (2021b)	<b>Cognitive behavioural therapy (category):</b> Format (individual, group) not related to the effect of support on overall autism characteristics or social-emotional development.
	Parsons, Cordier, Munro et al. (2017)	<b>Social communication outcomes:</b> Format (individual, group) not related to the effect of support on social-communication.
	Kent et al. (2020)	<b>Play outcomes:</b> Format (individual, group) not related to the effect of support on play.
	Tachibana et al., (2018)	<b>Effect of format:</b> Format (individual, group) was not related to the effect of support on overall autism characteristics, social-communication, expressive language, receptive language, cognitive development, or adaptive behaviour.
Agent	Crank et al. (2021).	Naturalistic developmental behavioural intervention (category): Agent (clinicians, educators, caregivers, combination) was not related to the effect of support on general outcomes.
	Wang et al. (2021a)	<b>Early Start Denver Model (practice):</b> Agent (parents, professionals) was not related to the effect of support on overall autism characteristics or communication.

Bejarano-Martín et al. (2020)	<b>Social communication outcomes:</b> Agent (caregivers, teachers, clinicians) not related to effect of support on social-communication.
Parsons, Cordier, Munro et al. (2017)	<b>Social communication outcomes:</b> Positive effect of support for supports with active caregiver involvement, but not for supports with parent education alone.
Hampton & Kaiser (2016)	<b>Expressive language outcomes:</b> Supports involving clinicians and caregivers related to greater effect of support on expressive language (spoken language) than clinicians or caregivers alone.

Appendix 5.17	Umbrella review - Influence of amount of support on child and
	family support outcomes

# Appendix 5.17 - Umbrella review - Influence of amount of support on child and family support outcomes

Systematic review	Focus of systematic review (specific focus)	Summary of evidence
Tiede & Walton (2019)	Practice/category (NDBI category)	Greater effect of support on social-communication (joint attention), but not on outcomes relating to overall autism characteristics, social-communication (social engagement), expressive or receptive language, cognitive development (cognition), play, or adaptive behaviour.
Crank et al. (2021)	Practice/category (NDBI category)	Cumulative intensity not related to the effect of support on general outcomes.
Fuller et al. (2020)	Practice/category (Early Start Denver Model practice)	Total hours of support not related to general outcomes (child outcomes).
Dimolareva & Dunn (2021)	Animal assisted (category)	Minutes engaged in therapy not related to the effect of support on overall autism characteristics, social-communication, or communication (language).
Bejarano-Martín et al. (2020)	Outcomes (Social-communication)	Total hours not related to the effect of support on social- communication.
Hampton & Kaiser (2016)	Outcomes (Expressive language)	Total hours not related to the effect of support on expressive language (spoken language).
Naveed et al. (2019)	Delivery characteristics (Non-specialist mediated)	Number of intervention sessions not related to the effect of support.
Nevill et al. (2018)	Delivery characteristics (Parent-mediated)	Total hours not related to the effect of support on overall autism characteristics, social-communication (socialisation), communication (language), or cognitive development (cognition).

Appendix 5.18	Umbrella review - Influence of child characteristics on child
	and family support outcomes

## Appendix 5.18 - Umbrella review - Influence of child characteristics on child and family support outcomes

Child characteristic	Systematic review	Summary of evidence
Age	Rodgers et al. (2020)	<b>Early intensive behavioural intervention (practice):</b> Age (at recruitment) was not related to the effect of support on cognitive development (cognition) or adaptive behaviour.
	Crank et al. (2021)	Naturalistic developmental behavioural intervention (category): Age not related to the effect of support on general outcomes.
	Sandgreen et al. (2021)	<b>Technology-based supports (category):</b> age (<5 years, 5-10 years, >10-15 years) not related to the effect of support on general outcomes.
	Wang et al. (2021b)	<b>Cognitive behavioural therapy (category):</b> Age inconsistently related to the effect of support on overall autism characteristics and social emotional/challenging behaviour.
	Bejarano-Martín et al. (2020)	<b>Social-communication outcomes:</b> Age negatively related to the effect of support on social-communication.
	Parsons, Cordier, Munro et al. (2017)	Social-communication outcomes: Age not related to the effect of support on social-communication.
	Hampton & Kaiser (2016)	<b>Expressive language:</b> Age not related to the effect of support on expressive language (spoken language).
	Naveed et al. (2019)	<b>Effect of non-specialist mediated support:</b> Age not related to the effect of support.
Communication	Bejarano-Martín et al. (2020)	<b>Social-communication outcomes:</b> Communication skills prior to support not related to the effect of support on social-communication.

	Crank et al. (2021)	Naturalistic developmental behavioural intervention (category): Communication (language age) was not related to the effect of support on general outcomes.
Cognitive development	Bejarano-Martín et al. (2020)	<b>Social-communication outcomes:</b> Cognitive development (cognition) prior to support not related to the effect of support on social-communication.
	Rodgers et al. (2020)	<b>Early intensive behavioural intervention (practice):</b> Cognitive development (IQ at baseline) not related to the effect of support on cognitive development or adaptive behaviour.
Adaptive behaviour	Rodgers et al. (2020)	<b>Early intensive behavioural intervention (practice):</b> Adaptive behaviour (at baseline) was not related to the effect of support on cognitive development or adaptive behaviour.

Appendix 6w.1	Individual and family experiences review - Database search
	strings

#### Individual and family experiences review - Database search strings

#### Searches conducted 14.12.21

#### **CINAHL (via EBSCO)**

(((MH "Asperger Syndrome") OR (MH "Autistic Disorder") OR (MH "Pervasive Developmental Disorder-Not Otherwise Specified")) AND (Autis\* OR ASD\* OR Asperger\* OR "pervasive developmental disorder\*" OR PDD\* OR "pervasive child development disorder\*" OR "pervasive childhood developmental disorder\*" OR PCDD\* OR ("disintegrative disorder"))) AND (intervent\* OR therap\* OR treat\* OR teach\* OR program\* OR package\*) AND (experien\* OR feedback\* OR social validity\* OR view\* OR opinion\* OR accept\* OR satisfaction\* OR criticis\* OR perception\*) AND Australia\*)

= 65 results

#### **EBSCO Education Source**

(((MH "Asperger Syndrome") OR (MH "Autistic Disorder") OR (MH "Pervasive Developmental Disorder-Not Otherwise Specified")) AND (Autis\* OR ASD\* OR Asperger\* OR "pervasive developmental disorder\*" OR PDD\* OR "pervasive child development disorder\*" OR "pervasive childhood developmental disorder\*" OR PCDD\* OR ("disintegrative disorder"))) AND (intervent\* OR therap\* OR treat\* OR teach\* OR program\* OR package\*) AND (experien\* OR feedback\* OR social validity\* OR view\* OR opinion\* OR accept\* OR satisfaction\* OR criticis\* OR perception\*) AND Australia\*)))

= 0 results

#### **Education Resources Information Centre (ERIC, via ProQuest)**

(((Autism\* OR ASD\* OR Asperger\* OR "pervasive developmental disorder\*" OR PDD\* OR "pervasive child development disorder\*" OR "pervasive childhood developmental disorder\*" OR PCDD\* OR ("disintegrative disorder")) AND (intervent\* OR therap\* OR treat\* OR teach\* OR program\* OR package\*) AND (experien\* OR feedback\* OR social validity\* OR view\* OR opinion\* OR accept\* OR satisfaction\* OR criticis\* OR perception\*) AND Australia\*))

= 93 results

#### **EMBASE**

(Autism\* OR ASD\* OR Asperger\* OR "pervasive developmental disorder\*" OR PDD\* OR "pervasive child development disorder\*" OR "pervasive childhood developmental disorder\*" OR PCDD\* OR "disintegrative disorder") AND (intervent\* OR therap\* OR treat\* OR teach\* OR program\* OR package\*) AND (experien\* OR feedback\* OR (social AND validity) OR view\* OR opinion\* OR accept\* OR satisfaction\* OR criticis\* OR perception\*) AND Australia\*

= 950 results

#### Epistemonikos.

(autism\* OR asd\* OR asperger\* OR "pervasive developmental disorder\*" OR pdd\* OR "pervasive child development disorder\*" OR "pervasive childhood developmental disorder\*" OR pcdd\* OR "disintegrative disorder\*") AND ( intervent\* OR therap\* OR treat\* OR teach\* OR program\* OR package\*) AND ( experien\* OR feedback\* OR social AND validity\* OR view\* OR opinion\* OR accept\* OR satisfaction\* OR criticis\* OR perce ption\* ) AND Australia\*

= 13 results

#### Medline (via Ovid)

((Autism\* or ASD or Asperger\* or "pervasive developmental disorder\*" or PDD\* or "pervasive child development disorder\*" or "pervasive childhood developmental disorder\*" or PCDD\* or "disintegrative disorder\*") and (intervent\* or therap\* or treat\* or teach\* or program\* or package\*) and (experien\* or feedback\* or social validity\* or view\* or opinion\* or accept\* or satisfaction\* or criticis\* or perception\*) and Australia\*)

= 72 results

#### PsycINFO

((Autism\* or ASD\* or Asperger\* or "pervasive developmental disorder\*" or PDD\* or "pervasive child development disorder\*" or "pervasive childhood developmental disorder\*" or PCDD\* or "disintegrative disorder\*") and (intervent\* or therap\* or treat\* or teach\* or program\* or package\*) and (experien\* or feedback\* or social validity\* or view\* or opinion\* or accept\* or satisfaction\* or criticis\* or perception\*) AND Australia\*)

= 117 results

#### PubMed

(Child Development Disorders, Pervasive [Mesh]) AND (Autism OR ASD OR Asperger OR Aspergers OR "pervasive developmental disorder" OR PDD OR PCDD OR "disintegrative disorder") AND (intervention OR interventions OR therapy OR therapies OR treatment OR treatments OR teach OR program OR programs OR package OR packages) AND (experience OR feedback OR "social validity" OR view OR opinion OR acceptance OR satisfaction OR perception OR criticism) AND Australia\*

=401 results

#### Scopus

```
(ALL (australia*) AND TITLE-ABS-KEY ((
```

autism\* OR asd\* OR asperger\* OR "pervasive developmental disorder\*" OR pdd\* OR "pervasive child development disorder\*" OR "pervasive childhood developmental disorder\*" OR pcdd\* OR "disintegrative disorder\*") AND ( intervent\* OR therap\* OR treat\* OR teach\* OR program\* OR package\*) AND ( experien\* OR feedback\* OR social AND validity\* OR view\* OR opinion\* OR accept \* OR satisfaction\* OR criticis\* OR perception\*)))

= 658 results

### Individual and family experiences review - Standardised data extraction form

### Data Extraction Template

Field label	Field Description/Response Options
General information	
Author	
Title	
Year	
Country of Publication	[take from method, if country where study conducted not explicitly stated, enter NS {not specified)]
Characteristics of Publication	<u> </u>
Study Abstract	Copied directly from text
Aim of study/viewpoint	[direct quote from abstract or introduction]
Publication type	[free text or from a selection]
	e.g., qualitative study of
Design/Method	e.g., focus groups, survey etc.
Study participants	[who are the participants]
	e.g., parents of children enrolled in an early intervention service
No of participants	
Evidence that study refers to children	[outline age range of children in study/in question if original research or highlight statement from commentary/viewpoint which supports author reflecting on experiences as a young child]
Types/category/name of supports (interventions) experienced	[from a selection or intervention categories? Or free text with intervention names]
Setting/s supports were delivered in	[copied from article]
Format	[copied from article]
Mode	[copied from article]
Agent	[copied from article]
Amount	[copied from article]
Sample questions	[copied from article]

Appendix 6.3	Individual and family experiences review - Study characteristics and exemplar quotes

### Individual and family experiences review - Study characteristics and exemplar quotes

Author and Year of Publication	Study aim (Taken verbatim from abstract, or first place mentioned in article)	Participants	Principles coded (n = no. times coded in each paper)	Examples
		mothers and 3 fathers)	Affirming (1)	The most common priority expressed by participants in this study was to find a SLP who could relate to their children on a personal level. More specifically, Lina sought an SLP who could build rapport with her children, and with whom she and her children felt comfortable
	parents in their efforts to access evidence-based speech-language		Child and family centred (6)	Other participants suggested that the SLP 's role should extend to supplying parents with information, including relevant research literature, and involving them in the therapy process
	pathology (SLP) services for their children with autism spectrum disorders (ASD).		Empirically supported (5)	In support of this principle: Ron, for example, said that he wanted a SLP who knows and understands the research evidence for the treatments she provides.
				Contrary to this principle: Not all participants believed that the research evidence was a crucial factor in determining which treatments to use
			Holistic (1)	Several participants explained that they also sought SLPs who showed empathy and understanding for their individual needs. Marley, for example, spoke positively about the empathy, time, and support she was given by a SLP at the time her child was first diagnosed
			Informed consent (2)	the extent to which the participants had been given clear information regarding their children's therapy programs (e.g., through integrated education plans) and the rationales for treatment decisions (e.g., by being given references and written information) appeared to have direct bearing on their ability to make informed decisions as partners in the therapy process.

			Personalised (1)	As illustrated by the following dialogue, participants initially turned to intuition about their children ' s capacity to concentrate in order to respond to the question "it all has to be based on individual needs and their capacity"
			Supported (3)	Emad, for example, suggested that SLPs should help parents to not only understand the role of the SLP in delivering the therapy, but also their own role as parents in the therapy process.
			Qualified practitioners (6)	There was consensus among the participants that finding a SLP that had knowledge and experience working with children with ASD was, in their opinion, a key factor in achieving successful therapy outcomes.
Donato et al., 2014	To explore the views of key stakeholders on using visual supports for children with developmental	Parents (n = 4), educators (n = 4), and health professionals (n = 5)*	Affirming (2)	Participants also agreed that there was a lack of awareness of the purpose of visual supports broader community, and some reported feeling uncomfortable at being 'stared at' when they used visual supports with their children. They tried to ignore this, particularly when children were exhibiting challenging behaviours
	disabilities in early intervention group settings. Specifically, this study aimed to determine stakeholders' views on the barriers to and facilitators for the use of visual supports in these settings to inform the feasibility of implementing an immersive Visual Language in Autism program.	sabilities in early tervention group ttings. Specifically, this udy aimed to etermine stakeholders' ews on the barriers to ad facilitators for the e of visual supports in ese settings to inform e feasibility of uplementing an umersive Visual nguage in Autism ogram.	Coordinated (4)	Across focus groups, participants viewed consistency in the use of visual supports across settings as being an important facilitator for children learning use of the visual supports to communicate. Parents agreed that 'routine and consistency is the most important thing'.
			Empirically supported (1)	Participants agreed that if they had been provided with positive parental reports and 'evidence' to the use of visual supports they might have invested earlier in the idea of using visual supports for their child.
			Equity (2)	They reported having limited access to allied health professionals such as occupational therapists and speech pathologists. Their need for multi-disciplinary services increased funding demands.
			Holistic (2)	Parents were also enabled by encouragement and support to persist with the difficulties (e.g., increased demands on time) and they also provided this to other parents.
			Personalised (2)	Many expressed a preference for mobile technologies over low technology (e.g., multiple card sets) to use visual supports and discussed their children's interest and interaction with digital media, including children's television programs and video games

Edwards et al., 2016	perspectives on the EI message.	Parents (n = 17 mothers and fathers, n = 3 assisted in interview guide preparation, n = 14 participated in interviews)	Lifespan	Several of the parents reported that they were unwilling to wait for services, given that they believed that intervention needed to be implemented as early as possible in order for it to be effective. To this end, some parents selected intervention programmes based purely on availability. In some cases, parents were surprised to find that therapies implemented once their children were older were more effective than El programmes had been. Contrary to this principle: Other participants reported that their decision-making was influenced by the perceived need to have intensive therapy, as opposed to just accessing therapy to address their child's specific needs.
Edwards et al., 2018	study was to explore how parents of children with ASD make decisions about which intervention	fathers, n = 3 assisted in interview guide preparation, n		As time progressed post-diagnosis, the parents in this study reported feeling that they had a better understanding of ASD as a neuro-developmental disorder. With increased understanding, some of parents in this study started to accept the lifelong nature of ASD. Where parents were previously aiming for a cure, parents then focused on achieving more functional goals. In support of this principle: The parents in this study identified that with time and experience, they trusted
				their own decision-making to the point that they felt that they understood the needs of their child better than any professional. Contrary to this principle: Parents felt unqualified to make the decisions that they were faced with, and that they were parents trying to make decisions that should be made by experts
			Equity (2)	At all stages of the journey, parents had to filter their decision-making through the reality of logistics, for example, the cost and availability of services. This tended to be influenced by external factors (e.g. availability of funding) as well as factors related to the family (i.e. family income).
			Holistic (1)	For the majority of the families in this study during the 'Experience and Evaluate' stage, there was an increasing recognition of the needs of the family, not just the needs of the child. With time, most of the parents in this study

				identified that prioritizing the needs of the family was actually in the child's best interest.
			Personalised (4)	The parents in this study reported that with experience, they started to gain a better understanding of their child's needs and learning style, which informed their subsequent decision-making.
			Supported (1)	During this stage, a number of the parents in this study started to make connections with other parents of children with ASD, and therefore were able to gain information regarding service providers and intervention approaches.
Grant et al., 2015	, ,	Parents (n = 23)	Child and family centred (2)	Parents reported that their confidence was generally low to begin with, but improved as they became more familiar with their child's diagnosis, had opportunities to speak to a number of clinicians
	making processes and information preferences following the diagnosis of ASD for their child.	of	Empirically supported (3)	In contrast to this principle: Typically, parents assumed and trusted that mainstream interventions such as occupational therapy and speech therapy were based on evidence as they are readily available.
				Contrary to this principle: Parents usually did not consider whether an intervention had research to support its effectiveness and no participant accurately explained the term 'evidence-based'.
			Equity (1)	Of greater priority when selecting interventions were logistical issues such as access to funding, and availability and location of services.
			Evidence-based approach (1)	Contrary to this principle: Pragmatically, parents described a journey from the point of diagnosis that involved seeking information on ASD interventions from a number of sources, and a 'trial and error' approach to choosing and evaluating these interventions
			Qualified practitioners (2)	Participants appeared to seek advice from trusted professionals in the absence of other reliable sources or perceived lack of decision-making support from other sources.
Gray, 1993	relationship between		Developmental perspective (1)	Two other factors seemed to reconcile parents to the eventual institutionalisation of their child. One was the illness. The failure of the child to overcome his or her autistic symptoms by adolescenceconvinced many parents that their child could not remain with the family indefinitely.

	treatment centre staff at a state autistic		Equity (1)	Given the high costs involved, the hope for a 'halfway house' placement is unlikely to be fulfilled.
	association.		Holistic	Another related factor was the family's exhaustionin that most parents with older children accepted that their child would eventually be institutionalised.
			Lifespan perspective (1)	However, most parents recognised that their child was likely to outlive them and few wanted their other children to be endlessly burdened by caring for an autistic sibling.
lacono et al., 2016	Our aim was to explore parent and practitioner uses of technology, and views about telehealth, including perceived barriers, for autism early intervention service delivery in a regional town in Australia.	Parents (n = 15 mothers)	Equity (2)	Some mothers provided reasons for responses about their willingness to receive telehealth services (Table 1), including concerns about internet access or quality and the need for practitioners to directly interact with their children.
lacono et al., 2018	We sought to understand the real world translation context for interventions	mothers),	Equity (3)	One respondent commented on the difficulties in obtaining assistance for behavioural problems, noting "It's pathetic trying to get help in [town name] for behaviour issues and psychologists [sic].
	or reflect best practice.	provider managers* (n = 15), frontline practitioners* (n = 19)	Holistic (1)	Most respondents reported that the travel resulted in some form of interruption (Table 2): One mother noted having to leave her employment because of the care requirements for her child, while another missed time from her studies.
Jones et al., 2021	studies that explored community attitudes to autism in Australia; and autistic people and their families' perspectives of community attitudes.	· ·	Equity (2)	<i>Of those currently receiving services, 42.8% (n = 389) reported that the level of support is inadequate and a further 9.4% (n = 85) were unsure.</i>

		49.4% carer of autistic person, 5.8% as autistic person)		
MacKintosh et al., 2012	in the current study, we sought to learn more about parents' experiences seeking and using treatments for their children with ASD by asking the open- ended question "What do you like/dislike about the treatment(s) you are currently using?"	Parents (n=486 parents, 2.4% of sample were Australian)		Note: only 2 responses were linked to Australian participants in this sample and these were not linked to principles.
Valentine, 2010	This paper reports on a qualitative study of parents' experience of diagnosis and treatment, conducted in four states in Australia in 2008.	Parents (n = 32) and early intervention service providers* (n = 2, who also identified as parents)	Child and family centred (4)	In support of this principle: These parents have become experts not only in their child's symptoms, but also in the research literature and practices of treating autism. They describe taking on the responsibility of choice and engagement Contrary to this principle: However, parents are often required to make decisions when they do not feel that they have sufficient information to do so, and to act as clinical experts rather than expert in their knowledge of their children.
			Empirically Supported (1) Equity (5)	A number of parents who had chosen ABA also talked about no other choice being plausible, and they drew on the logic of evidence based medicine to do so. Very active parents construe their choices as necessity, not as choice. By their account, decisions and consequences are left 'up to the parents' and the

				services that exist are unsatisfactory: schools are ill-equipped, doctors ill- informed.
			Supported (1)	Parents also described a range of other responses, including very active engagement in treatment, and investing significant resources in assisting other parents or lobbying for services.
			Qualified practitioners (1)	Parents reported frustration at the reluctance of diagnosing clinicians and peak bodies to make specific recommendations about treatment.
Wilson et al., 2021	The aim of the current study was to explore	Parents (n = 14)	Coordinated (1)	Some parents raised the importance of collaboration between their child's supports (e.g., school and therapists).
	parent-reported influences on decisions.		Developmental perspective (1)	Child age and developmental readiness was also an influence on therapy and intervention decisions
			Empirically supported (1)	Consideration of research evidence was raised by a parent discussing behavioural therapy (i.e., ABA)
			Equity (1)	The logistics of accessing therapies (e.g., costs, funding, wait lists, availability and location) was raised by all participants.
			Holistic (3)	Issues regarding the intensity, frequency and comprehensiveness of therapies were raised by parents. Some parents were reluctant to utilise therapies that were too intensive (i.e., too many hours), other parents indicated that sufficient hours are a necessary aspect of early intervention.
			Lifespan perspective (1)	Some parents expressed that their child had used a strategy (e.g., sensory approach or communication system) that they no longer required since they had outgrown the need.
			Personalised (3)	Child qualities and preferences were often considered. Parents reported pursuing strategies that fit their child's interests and preferences.
			Qualified practitioners (2)	The importance of finding clinicians who were a good fit with regard to experience, expertise and rapport, was raised by most parents.

 Appendix 7.1
 Online survey – Adults





## Supporting Children National Guideline

Page 1



#### Information Statement for the Research Project:

Development of a National Practice Guideline for Supporting Children on the Autism Spectrum and their Families: Community Consultation Online Survey (GU ref no:2021/843)

#### Part 1: Participation Information

#### What is this project about?

Autism CRC is leading the development of a National Practice Guideline for supporting children on the autism spectrum and their families in Australia. The Guideline will be developed based on both research and consultation with the community. The result will be a set of recommendations to guide the delivery of therapy and support services for children on the autism spectrum and their families.

#### Why are you being invited to participate?

We want to hear the voices of all community members with an interest in the Guideline. We are inviting you to participate, by completing an online survey. We anticipate it will take approximately 60 minutes to complete if you answer all questions. However, it could be shorter (as little as 15 minutes) or longer, depending on how much information you would like to provide.

#### Who can participate in the research?

We would like to hear from the following community members;

Adults and young people on the autism spectrum. Parents or caregivers of a child/children on the autism spectrum (this can be an adult child). Family members of children on the autism spectrum. Practitioners who provide supports to children on the autism spectrum. Other members of the autism community (e.g., service providers, researchers). You do not need to have had previous experience or involvement in the development of Practice Guidelines to participate.

#### What would I need to do?

If you agree to complete the survey, it will appear on your screen after you provide informed consent (below). As specified above, the survey may take up to 60 minutes to complete. The survey will ask you to provide your views and perspectives on how therapies and supports should be planned, delivered, and their outcomes assessed. We will invite you to reflect on your experiences.

#### Do I have to participate?

Participation in this research is entirely your choice. Only information collected from those who give consent will be included in this project. If you decide not to participate, this decision will not disadvantage you or impact your relationship with Griffith University or any other institutions affiliated with this research.

#### What happens if I change my mind?

If you begin the survey and decide that you would like to withdraw consent, there is a button at the end of the survey you can select to indicate that you no longer want the information you provided to be used in the project. If you decide to withdraw consent after submitting the survey, your individual responses will not be able to identified, due to the anonymous nature of data collection.

#### What are the benefits of participating?

We hope that it will be a positive experience for you, in helping to inform the Guideline. While you may not receive any direct benefits from participating in this research, the benefits of the research more broadly include an increase in knowledge and understanding regarding the most important factors relevant to the delivery of therapies and supports for young children on the autism spectrum.

#### Are there any potential risks?

We do not believe there are any direct risks associated with participation in this research. However, we understand that for some people thinking and talking about their experiences, can lead to a mixture of emotions, including sadness. If you, or anyone close to you, participates in this research and experiences any distress, we ask that you contact Lifeline on 13 11 14.

#### Who are the researchers?

Professor Andrew Whitehouse, Angela Wright Bennett Professor of Autism & Director, CliniKids, Telethon Kids Institute

A/Professor David Trembath, Menzies Health Institute Queensland, Griffith University Dr Kandice Varcin, Research Fellow, Menzies Health Institute Queensland, Griffith University Dr Rhylee Sulek, Research Fellow, School of Health Sciences and Social Work, Griffith University Dr Hannah Waddington, Lecturer, School of Education, Victoria University of Wellington Ms Sarah Pillar, Integration Project Manager, CliniKids, Telethon Kids Institute

#### Who/sapplicentact for further information?

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You might be unsure if you are able to participate or unsure about how the research process works. We encourage you to contact the research team at supportingchildren@griffith.edu.au to discuss this and anything else you might wish to talk about in relation to the project.

How can I receive information about the research results?

Regular updates regarding the progress of the Guideline including a summary of the outcomes of this survey, will be provided on the Supporting Children National Guideline web pages on the Autism CRC website. Participants will be able to access a copy of the Guideline, once published. If you would like to discuss this further with the research team, you can do so via email.

### How can I trust this research is safe for me?

This research is being conducted by skilled research staff and supported by a Guideline Development Group that includes people with a range of knowledge and experience, including autistic adults and parents raising children on the autism spectrum. The team has carefully selected the questions, considered how they are presented in the survey, and has made available different options for you and other people to share your thoughts. Only anonymous, summarised and combined survey data will be used and reported.

Part 2: Ethical Information we must provide you.

### What will be done with the data?

We will use the information you and others provide to help develop a set of draft recommendations for supporting children and their families, and then share these with the community for feedback.

When we share our findings, we will:

Present a summary of de-identified information about who participated (e.g., the variety of professionals, broad geographical areas represented). Present the themes that emerge from responses, and use direct quotes from participants to help explain what the themes are about. Any quotes will be presented anonymously, not using your real name. It is possible that if you read the findings or see them presented at a workshop or seminar that you might recognise your own quotes, but we will never attach real names to these quotes. How will privacy be protected? The conduct of this research involves the collection, access, storage and/or use of your deidentified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. Your anonymity will at all times be safeguarded. For further information consult the University's Privacy Plan at http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan or telephone (07) 3735 4375.

To further explain how your privacy will be protected, all of the data that is collected through the survey will be completely confidential. All data will be stored securely on an encrypted and password protected storage drive that will be accessible only by the members of the research team. This data will be stored securely for five years.

## The ethical conduct of this research

Griffith University conducts research in accordance with the National Statement on Ethical Conduct in Human Research. Please feel free to contact the researchers if you have any questions (supportingchildren@griffith.edu.au). If you have any additional questions or concerns about ethical issues, please contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee (research-ethics@griffith.edu.au; 07 3735 4375).

THIS SURVEY WILL CLOSE AT 5pm ON THE 29th MARCH, 2022.

[Attachment: "Online survey\_Participant Information statement.docx"]

[Attachment: "Voice-to-text instructions.doc"]

### **Consent to Participate**

Consent Form for the Research Project: Development of a National Practice Guideline for Supporting Children on the Autism Spectrum and their Families: Community Consultation Online Survey (GU ref no:2021/843)

By selecting the check box below, I confirm that I have read and understood the information sheet and I have noted that:

I understand that my participation in this research will include: Completing a survey, which we anticipate may take up to 60 minutes to complete I understand that the responses to the survey will be used to inform the development of National Practice Guideline for supporting children on the autism spectrum and their families in Australia I have read the Information Statement, or someone has read it to me in a language that I understand I understand why this research is being conducted and how I can participate I understand any risks as described above I have had an opportunity to ask questions and I am satisfied with the answers I have received I understand that I am free to withdraw at any time during the project without comment or consequence I understand that I can contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee if I have any concerns about the ethical conduct of this project I agree to participate in the research

I agree to participate in this research	○ No
	⊖ Yes

Thank you again for your interest in this research.

As a reminder, you will have the opportunity to save your responses and return at a later time to complete this survey. To assist us in our data collection, we ask that you please finalise your responses within one week of starting the survey. We will not analyse any additional answers provided after this time.

Which of the following best describes you?	<ul> <li>Autistic individual/Person on the autism spectrum</li> <li>Parent/primary caregiver of someone on the autism spectrum</li> <li>Family member of person on the autism spectrum</li> <li>An individual who provides services to children (0-12 years) on the autism spectrum</li> <li>A member of an organisation or service which provides services to children (0-12 years) on the autism spectrum</li> <li>A member of an organisation or service which provides services to children (0-12 years) on the autism spectrum and their families</li> <li>Other</li> </ul>
Please indicate if you are:	<ul> <li>Completing this yourself</li> <li>Completing this on behalf of an autistic individual/someone on the autism spectrum</li> </ul>
Please specify your relationship to the person on the autism spectrum (e.g., grandparent, sibling)	
Please indicate if you are:	<ul> <li>Completing this survey as an individual member of the organisation</li> <li>Completing this survey as the nominated representative of the organisation (e.g., you are making a submission on behalf of the organisation as a whole)</li> </ul>
Please specify if other	



Please indicate any additional perspectives you bring to this survey (select all that apply)	<ul> <li>Autistic individual/person on the autism spectrum</li> <li>Parent/primary caregiver of someone on the autism spectrum</li> <li>Family member of person on the autism spectrum</li> <li>An individual who provides services to children (0-12 years) on the autism spectrum</li> <li>A member of an organisation or service which provides services to children (0-12 years) on the autism spectrum</li> <li>A member of an organisation or service which provides services to children (0-12 years) on the autism spectrum</li> </ul>
Please specify your relationship to the person on the autism spectrum (e.g., grandparent, sibling)	
Please specify if other	
With which gender do you identify?	<ul> <li>Female</li> <li>Male</li> <li>Non-binary</li> <li>Prefer not to say</li> <li>Other</li> </ul>
Please specify if other	
Which state or territory of Australia do you currently reside in?	<ul> <li>Australian Capital Territory</li> <li>New South Wales</li> <li>Northern Territory</li> <li>Queensland</li> <li>South Australia</li> <li>Tasmania</li> <li>Victoria</li> <li>Western Australia</li> <li>Do not currently reside in Australia</li> </ul>
Which of the following best describes where you live?	<ul> <li>Major city</li> <li>Regional and/or remote area</li> </ul>
Do you self-identify as Aboriginal and/or Torres Strait Islander?	<ul> <li>No</li> <li>Yes, Aboriginal</li> <li>Yes, Torres Strait Islander</li> <li>Yes, both Aboriginal and Torres Strait Islander</li> </ul>
Are you of Aboriginal and/or Torres Strait Islander heritage?	<ul> <li>No</li> <li>Yes, Aboriginal</li> <li>Yes, Torres Strait Islander</li> <li>Yes, both Aboriginal and Torres Strait Islander</li> </ul>
Were you born in Australia?	○ No ○ Yes
In what country were you born?	
Do you speak one or more languages other than English in the home?	○ No ○ Yes



How many languages, including English, do you speak at home?

What is your age?	<ul> <li>0-17 years</li> <li>18-20 years</li> <li>21-30 years</li> <li>31-40 years</li> <li>41-50 years</li> <li>51-60 years</li> <li>61-70 years</li> <li>71-80 years</li> <li>81-90 years</li> <li>91-100 years</li> <li>100+ years</li> </ul>
Are you happy to tell us more about your experience of autism, in terms of diagnosis?	○ Yes ○ No
Which of the following best describes your circumstances?	<ul> <li>I have been given a formal diagnosis of autism (or a related diagnosis e.g., Asperger's, Pervasive Developmental Disorder) by one or more qualified health practitioners (e.g., paediatrician, clinical psychologist, psychiatrist)</li> <li>I am currently being assessed for a possible diagnosis of autism</li> <li>I self-identify as autistic, but have not been given a formal diagnosis by a health professional.</li> </ul>
At what age did you receive a formal diagnosis? Please specify in years	
What was your diagnosis?	
Did you receive or access autism specific therapies and supports between the ages of 0-6 years?	○ No ○ Yes
Did you receive or access autism specific therapies and supports between the ages of 7-12 years?	○ No ○ Yes



The below table outlines the three levels of support required within the autism spectrum as described in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5).

Level

Social communication

Restricted, repetitive behaviors

Level 3 "Requiring very substantial support"

Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches

Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.

Level 2 "Requiring substantial support"

Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.

Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.

### Level 1 "Requiring support"

Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.

Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

If you were diagnosed as a child under the DSM-5, please indicate which support level was associated with your diagnosis.	<ul> <li>Level 1 - Requires support</li> <li>Level 2 - Requires substantial support</li> <li>Level 3 - Required very substantial support</li> <li>I am unsure</li> <li>I would prefer not to say</li> </ul>
If you were not diagnosed as a child under the DSM-5, or you received a diagnosis in adulthood, please indicate which level would have best represented your support needs as a child.	<ul> <li>Level 1 - Requires support</li> <li>Level 2 - Requires substantial support</li> <li>Level 3 - Required very substantial support</li> <li>I am unsure</li> <li>I would prefer not to say</li> </ul>

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Are you happy to tell us more about your child(ren) on the autism spectrum?	<pre>○ Yes ○ No</pre>
This includes your children who are now teenagers or adults. We will ask you to focus on just one child at a time.	
How old is your child (years)	
How old is your child (months)	
Has your child received a formal diagnosis of autism (or a related disorder e.g., Asperger's, Pervasive Developmental Disorder)?	○ No ○ Yes
At what age was your child diagnosed (please round to the nearest year)?	
Did you access therapies and/or supports for your child at some stage between the ages of 0-6 years?	○ No ○ Yes
Did you access therapies and/or supports for your child at some stage between the ages of 7-12 years?	○ No ○ Yes

The below table outlines the three levels of support required within the autism spectrum as described in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5).

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Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.

Level 2 "Requiring substantial support"

Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.

Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.

## Level 1 "Requiring support"

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interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.

Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

If your child was diagnosed under the DSM-5, please indicate which support level is associated with their diagnosis.	<ul> <li>Level 1 - Requires support</li> <li>Level 2 - Requires substantial support</li> <li>Level 3 - Required very substantial support</li> <li>I am unsure</li> <li>I would prefer not to say</li> </ul>
If your child has not yet received a formal diagnosis or was not diagnosed as a child under the DSM-5, please indicate which level you feel would have best represented their support needs as a child.	<ul> <li>Level 1 - Requires support</li> <li>Level 2 - Requires substantial support</li> <li>Level 3 - Required very substantial support</li> <li>I am unsure</li> <li>I would prefer not to say</li> </ul>
Do you wish to provide details for another child on the autism spectrum?	○ No ○ Yes
How old is your child (years)	
How old is your child (months)	
Has your child received a formal diagnosis of autism (or a related disorder e.g., Asperger's, Pervasive Developmental Disorder)?	○ No ○ Yes
At what age was your child diagnosed (please round to the nearest year)?	
Did you access therapies and/or supports for your child at some stage between the ages of 0-6 years?	○ No ○ Yes
Did you access therapies and/or supports for your child at some stage between the ages of 7-12 years?	○ No ○ Yes

The below table outlines the three levels of support required within the autism spectrum as described in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5).

Level

Social communication

Restricted, repetitive behaviors

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Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.

Level 2 "Requiring substantial support"

Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.

Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.

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Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.

Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

If your child was diagnosed under the DSM-5, please indicate which support level is associated with their diagnosis.	<ul> <li>Level 1 - Requires support</li> <li>Level 2 - Requires substantial support</li> <li>Level 3 - Required very substantial support</li> <li>I am unsure</li> <li>I would prefer not to say</li> </ul>
If your child has not yet received a formal diagnosis or was not diagnosed as a child under the DSM-5, please indicate which level you feel would have best represented their support needs as a child.	<ul> <li>Level 1 - Requires support</li> <li>Level 2 - Requires substantial support</li> <li>Level 3 - Required very substantial support</li> <li>I am unsure</li> <li>I would prefer not to say</li> </ul>
Do you wish to provide details for another child on the autism spectrum?	○ No ○ Yes





How old is your child (years)	
How old is your child (months)	
Has your child received a formal diagnosis of autism (or a related disorder e.g., Asperger's, Pervasive Developmental Disorder)?	○ No ○ Yes
At what age was your child diagnosed (please round to the nearest year)?	
Did you access therapies and/or supports for your child at some stage between the ages of 0-6 years?	○ No ○ Yes
Did you access therapies and/or supports for your child at some stage between the ages of 7-12 years?	○ No ○ Yes

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The below table outlines the three levels of support required within the autism spectrum as described in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5).

Level

Social communication

Restricted, repetitive behaviors

Level 3 "Requiring very substantial support"

Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches

Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.

Level 2 "Requiring substantial support"

Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.

Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.

#### Level 1 "Requiring support"

Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.

Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching

If your child was diagnosed under the DSM-5, please indicate which support level is associated with their diagnosis.	<ul> <li>Level 1 - Requires support</li> <li>Level 2 - Requires substantial support</li> <li>Level 3 - Required very substantial support</li> <li>I am unsure</li> <li>I would prefer not to say</li> </ul>
If your child has not yet received a formal diagnosis or was not diagnosed as a child under the DSM-5, please indicate which level you feel would have best represented their support needs as a child.	<ul> <li>Level 1 - Requires support</li> <li>Level 2 - Requires substantial support</li> <li>Level 3 - Required very substantial support</li> <li>I am unsure</li> <li>I would prefer not to say</li> </ul>
Do you wish to provide details for another child on the autism spectrum?	○ No ○ Yes
How old is your child (years)	
How old is your child (months)	
Has your child received a formal diagnosis of autism (or a related disorder e.g., Asperger's, Pervasive Developmental Disorder)?	○ No ○ Yes
At what age was your child diagnosed (please round to the nearest year)?	
Did you access therapies and/or supports for your child at some stage between the ages of 0-6 years?	○ No ○ Yes
Did you access therapies and/or supports for your child at some stage between the ages of 7-12 years?	○ No ○ Yes

The below table outlines the three levels of support required within the autism spectrum as described in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5).

Level

Social communication

Restricted, repetitive behaviors

Level 3 "Requiring very substantial support"

Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches

Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.

Level 2 "Requiring substantial support"

Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special freeses, and markedly odd nonverbal communication.

Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.

## Level 1 "Requiring support"

Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.

Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

If your child was diagnosed under the DSM-5, please indicate which support level is associated with their diagnosis.	<ul> <li>Level 1 - Requires support</li> <li>Level 2 - Requires substantial support</li> <li>Level 3 - Required very substantial support</li> <li>I am unsure</li> <li>I would prefer not to say</li> </ul>
If your child has not yet received a formal diagnosis or was not diagnosed as a child under the DSM-5, please indicate which level you feel would have best represented their support needs as a child.	<ul> <li>Level 1 - Requires support</li> <li>Level 2 - Requires substantial support</li> <li>Level 3 - Required very substantial support</li> <li>I am unsure</li> </ul>

O I would prefer not to say

## The following questions ask about your work in providing therapies and supports to young children on the autism spectrum.

What is your profession (select all that apply)?	<ul> <li>Aboriginal and Torres Strait Islander Health Worker or Health Practitioner</li> <li>Aboriginal and Torres Strait Islander Health Advocate</li> <li>Art therapist</li> <li>Behaviour Therapist (not Board Certified)</li> <li>Board Certified Behaviour Analyst</li> <li>Developmental Educator</li> <li>Drama therapist</li> <li>Educator (early childhood)</li> <li>Educator (primary school)</li> <li>Educator (high school)</li> <li>Exercise Scientist</li> <li>General Practitioner</li> <li>Music therapist</li> <li>Paediatrician</li> <li>Physiotherapist</li> <li>Play therapist</li> <li>Psychiatrist</li> <li>Social Worker</li> <li>Speech Pathologist</li> <li>Support worker</li> <li>Other</li> </ul>
Please specify if other	
How are you currently involved in the delivery of services for children on the autism spectrum? (select all that apply)	<ul> <li>I provide therapy and support to children on the autism spectrum</li> <li>I provide advocacy for children on the autism spectrum and their families</li> <li>I supervise others who deliver therapy and support to children on the autism spectrum</li> <li>I conduct research on therapy and support for children on the autism spectrum</li> <li>I am responsible for staff and/or business processes that result in the provision of therapy and support to children on the autism spectrum</li> </ul>
Please specify if other	
In which of the following service settings do you	Private, including non-government organisations

currently provide therapies and supports for children on the autism spectrum and their families (select all that apply)? Private, including non-government organisations
 Government organisation



In which of the following service settings to do you currently provide therapies and supports for children on the autism spectrum and their families? (select all that apply)	<ul> <li>Child's home</li> <li>Hospital (inpatient/outpatient)</li> <li>Community clinic (including private practice)</li> <li>University clinic (includes providing services as part of student training and research)</li> <li>Early childhood education centre (prior to formal schooling, and commonly referred to as day care/childcare)</li> <li>Early childhood education centre in a specialised setting (prior to formal school and catering only to children with additional learning needs)</li> <li>Mainstream school</li> <li>School specifically for children on the autism spectrum</li> <li>School specifically for children with additional learning needs, that includes children on the autism spectrum</li> <li>Other</li> </ul>
Please specify if other	
How many years of experience do you have working in clinical practice with children on the autism spectrum?	
In 2021, approximately what proportion of your caseload were children on the autism spectrum?	<ul> <li>○ 0-25%</li> <li>○ 26-50%</li> <li>○ 51-75%</li> <li>○ 76-100%</li> </ul>
In 2021, what age groups did you provide therapies and supports for children on the autism spectrum (select all that apply)?	<ul> <li>0-3 years</li> <li>4-6 years</li> <li>7-9 years</li> <li>10-12 years</li> <li>13-15 years</li> <li>16-18 years</li> <li>19 years and older</li> </ul>
As part of your practice, do you see children on the autism spectrum who have any of the following co-occurring conditions (Select all that apply):	<ul> <li>Physical disability (e.g., cerebral palsy)</li> <li>Cognitive impairment (e.g., Intellectual Disability)</li> <li>Health conditions (e.g., asthma, metabolic conditions)</li> <li>Mental health conditions (e.g., anxiety, depression)</li> <li>Genetic conditions (e.g., Fragile X, Down syndrome)</li> <li>Sensory impairment (vision/hearing)</li> <li>Other (please specify)</li> </ul>

Please specify if other



In which state/territory do you currently practice? (select all that apply)	<ul> <li>Australian Capital Territory</li> <li>New South Wales</li> <li>Northern Territory</li> <li>Queensland</li> <li>South Australia</li> <li>Tasmania</li> <li>Victoria</li> <li>Western Australia</li> </ul>
In which areas do you conduct your work with children on the autism spectrum and their families? (Select all that apply)	<ul> <li>Major cities</li> <li>Regional and remote areas</li> </ul>
Please indicate how children and families access your services (select all that apply):	<ul> <li>Face to face delivery</li> <li>Telepactice/videoconferencing delivery</li> </ul>
In 2021, did you provide therapies and supports for children on the autism spectrum and their families who were from non-English speaking countries and speak languages other than English in the home (i.e., families who are culturally and linguistically diverse [CALD])?	○ No ○ Yes
In 2021, did you provide therapies and supports for children on the autism spectrum and their families who identify as being Aboriginal and/or Torres Strait Islander peoples?	○ No ○ Yes



# The following questions ask about your work in providing services to young children on the autism spectrum.

What is the name of your organisation/service?	
If available, please provide a link to your organisation's webpage.	
In 20-30 words, please provide a description of your organisation.	
Please explain how your organisation is relevant to supporting the learning and participation of children on the autism spectrum, aged 0-12, and their families.	
Approximately how many staff work at your organisation in either a paid or voluntary capacity?	
If relevant, approximately how many members are registered with your organisation?	
For example, if you are a peak registration body for a profession, approximately how many people are registered with your organisation?	
In which states/territories does your organisation provide services? (select all that apply)	<ul> <li>Australian Capital Territory</li> <li>New South Wales</li> <li>Northern Territory</li> <li>Queensland</li> <li>South Australia</li> <li>Tasmania</li> <li>Victoria</li> <li>Western Australia</li> </ul>
In which areas does your organisation conduct work with children on the autism spectrum and their families? Select all that apply	<ul> <li>Major cities</li> <li>Regional and remote areas</li> </ul>



Which of the following represents individuals involved with your organisation? (select all that apply)	<ul> <li>Aboriginal and Torres Strait Islander Health Worker or Health Practitioner</li> <li>Aboriginal and Torres Strait Islander Health Advocate</li> <li>Art therapist</li> <li>Behaviour Therapist (not Board Certified)</li> <li>Board Certified Behaviour Analyst</li> <li>Developmental Educator</li> <li>Drama therapist</li> <li>Educator (early childhood)</li> <li>Educator (primary school)</li> <li>Educator (high school)</li> <li>Exercise Scientist</li> <li>General Practitioner</li> <li>Music therapist</li> <li>Paediatrician</li> <li>Physiotherapist</li> <li>Play therapist</li> <li>Psychologist</li> <li>Researcher</li> <li>Social Worker</li> <li>Speech Pathologist</li> <li>Support worker</li> <li>Other</li> </ul>
Please specify if other	
In which of the following settings does your organisation provide services for children on the autism spectrum and their families? (select all that apply)	<ul> <li>Child's home</li> <li>Hospital (inpatient/outpatient)</li> <li>Community clinic (including private practice)</li> <li>University clinic (includes providing services as part of student training and research)</li> <li>Early childhood education centre (prior to formal schooling, and commonly referred to as day care/childcare)</li> <li>Early childhood education centre in a specialised setting (prior to formal school and catering only to children with additional learning needs)</li> <li>Mainstream school</li> <li>Support class/unit within a mainstream school</li> <li>School specifically for children on the autism spectrum</li> <li>School specifically for children with additional learning needs, that includes children on the autism spectrum</li> <li>Other</li> </ul>
Please specify if other	
Would you like to tell us your story about getting support for your child?	<ul> <li>Yes</li> <li>No - skip to next section</li> <li>No - exit survey</li> </ul>
Type your answers to the questions below, or upload a three (3) minute video file answering them here.	



When thinking about getting autism specific support for your child:		
What has been good?		
What has been bad?		
What should have been done better?		
Would you like to tell us your story about getting support?	<ul> <li>Yes</li> <li>No - skip to next section</li> <li>No - exit survey</li> </ul>	
Type your answers to the questions below, or upload a three (3) minute video file answering them here.		
When thinking about getting autism specific support:		
What has been good?		
What has been bad?		
What should have been done better?		
2. Your thoughts about the development of the guideline		
What do you think are the three most important things that should be addressed in the guideline?		
What are the potential benefits of having a guideline?		
What concerns, if any, do you have about the development of a guideline?		
At the moment, where do you get information about therapies and supports for children on the autism spectrum (select all that apply)?	<ul> <li>Online searches</li> <li>Social media</li> <li>Family and friends</li> <li>Autistic people (e.g., personal accounts online)</li> <li>Teachers</li> <li>Medical practitioners</li> <li>Allied health practitioners</li> <li>Word of mouth</li> <li>Research articles</li> <li>Other</li> </ul>	published



Please specify if other.



## 3. Language preferences in relation to autism

The following questions ask about language preferences in relation to autism. Would you like to provide responses to these questions? Yes
 No - skip to next section
 No - exit survey

Autism CRC understands that different people have different views and preferences about terminology used to describe autism and people on the autism spectrum (see here for Autism CRC statement).

For this guideline, we will make decisions about language and terminology based on feedback from you and other members of the community, collected in this survey.

Our goal is to choose terminology that:

Is preferred by the majority of the autistic community. Is acceptable to the majority of parents/caregivers and practitioners, in that the term/s used would not stop them making use of the practice guideline. We are talking here only about the use of terminology in the guideline document itself, and when Autism CRC and the project team are communicating about the guideline. We understand that people may have different preferences about terminology, depending on the situation (for example when referring to themselves versus others), but we are focusing only on the guideline in this survey.

To help us choose terminology, please answer the following questions.

1. Please tell us what term/s you would like to see used in the guideline by giving each a rating.

	Strongly dislike	Dislike	Somewhat dislike	Neutral	Somewhat like	Like	Strongly like
Autistic	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Autistic person (e.g., autistic children)	0	0	0	0	$\bigcirc$	0	$\bigcirc$
Person with autism (e.g., children with autism)	0	0	0	$\bigcirc$	0	0	0
Person on the autism spectrum (e.g., children on the autism spectrum)	0	0	0	$\bigcirc$	0	0	0
Person with autism spectrum disorder (e.g., children with ASD)	0	0	0	0	0	0	0
Person with autism spectrum condition (e.g., children with ASC)	0	0	0	0	0	0	0

2. Please now tell us if you think each of these terms are acceptable for use in the guideline.

When we say acceptable, we mean that the term would not stop you supporting and/or using the guideline, even if it is not your personal preference.

	Unacceptable: I would not support and/or use the guideline if this term is used	Acceptable: I would support and/or use the guideline if this term is used, even if it is not my personal preference
Autistic	0	0
Autistic child	0	0



Child with autism	0	0
Child on the autism spectrum	0	0
Child with autism spectrum	0	0
disorder (child with ASD) Child with autism spectrum condition (child with ASC)	0	0



## 4. Underlying Principles

The following set of questions ask you to provide your thoughts on principles that are important to the delivery of therapies and supports for children on the autism spectrum and their families. Would you like to provide responses to these questions?

○ Yes
 ○ No - skip to next section
 ○ No - exit survey



The following statements describe principles that have been identified by research as having importance for all aspects of providing therapies and supports for children and their families on the autism spectrum. While some principles refer to both children and their families in the same item to acknowledge the family unit, we do so noting that the individual preferences, needs, and rights of each person are always to be considered and maintained.

needs, and rights of each pe	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Holistic: When providing therapy and supports, we should consider an individual's life history, culture, strengths and challenges, goals and preferences, and environmental factors that impact their learning, participation, and quality of life.	O	0	0	0	0
Child and family-centred: The child and their family members should be considered equal partners with practitioners in the therapy process.	0	0	0	0	0
Supported: The child and their family should be supported to include people they feel are relevant in the therapy process, including for advocacy and support.	0	0	0	0	0
Lifespan perspective: When providing therapies and supports, decision making should account for the current stage of life of the child, as well as appropriate planning for both the short and longer term.	0	0	0	0	0
Developmental perspective: Decision-making should account for, and be responsive to, the individual, family and social changes that occur through childhood.	0	0	0	0	0



Empirically-supported: Therapies and supports should be underpinned by published, peer-reviewed scientific evidence demonstrating their effectiveness and safety.	0	0	0	0	0
Evidence-based practice approach: Decision-making should draw on and combine research and clinical evidence alongside the preferences and values of the child and their family.	0	0	0	0	0
Ethical practice: The provision of therapies and supports should be underpinned by an ethical framework that follows the principles of beneficence, non-maleficence, autonomy and fairness.	0	0	0	0	0
Culturally aware and responsive: The values, knowledge, preferences and cultural perspectives of the child and family should be sought, respected, and evident in the provision of therapies and supports.	0	0	0	0	0
Equity: All children and families, regardless of age, gender, cultural background, socioeconomic status or geographical location should be able to access timely, safe, desirable and effective therapies and supports.	0	0	0	0	0
Strengths-focused: Therapies and supports should focus on understanding, embracing and developing the strengths of an individual and their family.	0	0	0	0	0
Coordinated: A coordinated approach across practitioners, organisations, and agencies should be taken.	0	0	0	0	0



Personalised: Therapies and supports should be tailored to the unique strengths, needs, and preferences of each child and family.	0	0	0	0	0
Accessible: The process of planning, delivering, and monitoring therapies and support, including interactions and documentation, should be accessible.	0	0	0	0	0
Informed consent (parents): Informed parental consent should be obtained for therapies and supports provided.	0	0	0	0	0
Assent (children): Children's assent (expression of approval) should be obtained, wherever possible, for therapies and supports provided.	0	0	0	0	0
Qualified practitioners: People involved in the provision of therapies and supports should have relevant qualifications and professional regulation, and only engage in goal setting and the delivery of therapies and supports that are within their scope of practice.	0	0	0	0	0

What other principles not listed above, are important to the delivery of therapies and supports?



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5a. Understanding the child, family, and context	
The following set of questions ask you to provide your thoughts on understanding children, their family, and their context, in the provision of therapies and supports. Would you like to:	<ul> <li>Skip this section</li> <li>Provide your general thoughts on this</li> <li>Answer our specific questions</li> <li>Exit the survey</li> </ul>
In clinical practice, assessment involves collecting information family, and the broader context. Assessment may involve a ra practitioners), include the use of a range of tools (e.g., observe assessments), and draw on both current and historical informa-	nge of people (e.g., the child, family, other ation, interviewing, functional assessment, dynamic
From your perspective, what are the most important considerations for practitioners trying to understand the child, family, and their context?	
How important do you think it is to understand the child, their family, and their context when making decisions about therapies and supports for children on the autism spectrum?	<ul> <li>Not at all important</li> <li>Slightly important</li> <li>Moderately important</li> <li>Very important</li> <li>Extremely important</li> </ul>
What information do you think is most important to collect to understand the child, their family, and their context?	
What would you suggest practitioners (i.e., people working directly with the child on the autism spectrum) do to ensure they understand the child, their family, and their context? Provide up to three	

suggestions.

5b. Goal Setting	
The following questions ask about the process of planning, selecting and prioritising goals for therapy for young children on the autism spectrum. Would you like to :	<ul> <li>Skip this section</li> <li>Provide your general thoughts on this</li> <li>Answer our specific questions</li> <li>Exit the survey</li> </ul>
From your perspective, what are the most important considerations for practitioners when planning, selecting, and prioritising goals for children?	
How important do you think it is to select appropriate goals for therapy when working with children on the autism spectrum and their families?	<ul> <li>Not at all important</li> <li>Slightly important</li> <li>Moderately important</li> <li>Very important</li> <li>Extremely important</li> </ul>
Who is important to involve (e.g., child, parents, practitioners, others) in planning, selecting, and prioritising goals to support the learning and participation of children on the autism spectrum and their families?	
What types of goals are likely to be relevant to supporting the learning and participation of children on the autism spectrum and their families?	
What can practitioners do to ensure appropriate goals are selected? Provide up to three suggestions.	



5c. Selecting Therapies and Supports	
The following questions ask about the process of planning and selecting specific therapies and supports for young children on the autism spectrum. Would you like to:	<ul> <li>Skip this section</li> <li>Provide your general thoughts on this</li> <li>Answer our specific questions</li> <li>Exit the survey</li> </ul>
From your perspective, what are the most important considerations for practitioners when planning and selecting therapies and supports for children?	
How important do you think it is to select appropriate therapies and supports when working with children on the autism spectrum and their families?	<ul> <li>Not at all important</li> <li>Slightly important</li> <li>Moderately important</li> <li>Very important</li> <li>Extremely important</li> </ul>
Who is important to involve (e.g., parents, practitioners, the child) in selecting therapies and supports for children on the autism spectrum and their families?	
If your response is the same as goal setting, please type "See previous section" here.	
What types of therapies and supports are relevant to supporting the learning and participation of children on the autism spectrum and their families?	
What can practitioners do to ensure that appropriate therapies and supports are selected? Provide up to three suggestions.	
If your response is the same as for goal setting, please type "see previous section".	



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5d. Delivering Therapies and Supports	
The following questions ask about decisions related to the delivery of therapies and supports (i.e., the setting, the format [individual, group], the people involved [practitioner, parents, siblings/peers, others], the amount). Would you like to:	<ul> <li>Skip this section</li> <li>Provide your general thoughts on this</li> <li>Answer our specific questions</li> <li>Exit the survey</li> </ul>
From your perspective, what are the most important considerations for practitioners when delivering therapies and supports for children on the autism spectrum?	
How important do you think it is to deliver therapies and supports in ways that are appropriate for children on the autism spectrum and their families?	<ul> <li>Not at all important</li> <li>Slightly important</li> <li>Moderately important</li> <li>Very important</li> <li>Extremely important</li> </ul>
Is there a standard amount of practitioner-delivered therapy and support that you think children on the autism spectrum should have access to?	○ Yes ○ No
This includes therapies and supports provided directly to the child, supports provided to upskill parents/caregivers to support the child, and supports to upskills other members of the community (e.g., a child's teacher) to support the child.	
What is this standard amount of therapy?	
What is an appropriate amount of practitioner-delivered therapy and support you think that children on the autism spectrum should have access to?	
In what settings do you think it is appropriate to deliver therapies and supports?	
Who is important to involve (e.g., parents, practitioners, the child) in the delivery of therapies and supports?	
If your response is the same as previous sections (goal setting, planning), please indicate "see previous sections" here.	
What can practitioners do to ensure that appropriate therapies and supports are delivered? Provide up to three suggestions.	
If your response is the same as previous sections (goal setting, planning), please indicate "see previous sections" here.	



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5e. Monitoring of therapies and supports	
The following questions ask about monitoring progress and outcomes of therapies and supports. By this we mean the things that those working with the child and family do to evaluate how the service is delivered and the child and family's experience and outcomes. Would you like to:	<ul> <li>Skip this section</li> <li>Provide your general thoughts on this</li> <li>Answer our specific questions</li> <li>Exit the survey</li> </ul>
-	
From your perspective, what are the most important considerations for practitioners when monitoring progress and outcomes of therapies and supports for children on the autism spectrum?	
How important do you think it is to monitor the delivery of therapies and supports for children on the autism spectrum and their families? This includes ensuring the goals, therapies, and supports continue to be appropriate.	<ul> <li>Not at all important</li> <li>Slightly important</li> <li>Moderately important</li> <li>Very important</li> <li>Extremely important</li> </ul>
What aspects of therapies and supports provided, and the child and family's experience, should be monitored by practitioners?	
What can practitioners do to ensure the appropriate monitoring of goals, therapies and supports? Please provide up to three suggestions.	



5f. Safety and wellbeing		
The following questions ask about how the safety and wellbeing of children on the autism spectrum and their families can be ensured.	<ul> <li>Skip this section</li> <li>Provide your general thoughts on this</li> <li>Answer our specific questions</li> <li>Exit the survey</li> </ul>	
Would you like to?		
From your perspective, what are the most important things for practitioners to consider in order to ensure the safety and wellbeing of children on the autism spectrum and their families		
How important to do you think it is to ensure that the safety and wellbeing of children on the autism spectrum and their families is ensured when accessing therapies and supports?	<ul> <li>Not at all important</li> <li>Slightly important</li> <li>Moderately important</li> <li>Very important</li> <li>Extremely important</li> </ul>	
How can practitioners support the safety and wellbeing of children on the autism spectrum and their families when accessing therapies and supports?		
Please describe any risks you see for children and families in accessing therapies and supports.		
Before you go, did you complete the whole survey?	○ Yes ○ No	
Are you happy for us to use the information you provided?	○ Yes ○ No	
If you are willing, please tell us why you did not complete the whole survey? Select all that apply	<ul> <li>It was too long</li> <li>I did not understand the questions</li> <li>It was not relevant to me</li> <li>I have other things I need to do</li> <li>I prefer not to say</li> <li>Other</li> </ul>	

A note from the research team

Thank you very much for answering the questions. The information that you and others provide will directly inform the recommendations in the guideline.

The next step for the research team will be to analyse all of the information provided. The Guideline Development Group will then formulate recommendations.

If you have not already done so, please register with Autism CRC to receive updates about the guideline. You can do so here.

Before we finish, we want to take a moment to acknowledge the time it takes to complete surveys like this. While we are not able to send a personal response to each person who completes it, please know that we genuinely value the information you have provided and will be reading every word.

We also acknowledge that if you are an autistic person, a parent, or other family member of a child on the autism spectrum, you will have shared in the survey insights from your own life, your experience, and your expertise. It is likely that you will have been asked to do this many times before, and we warmly thank you for being willing to do so again here, to help make the guideline the best it can be. We simply could not do this piece of important work, without your insights. Thank you.

If you have any final comments, please feel welcome to share them below.

We look forward to sharing updates, and the guideline in due course, via Autism CRC's website. 07/08/2022 1:48pm projectredcap.org



Sincerely,

Rhylee, Kandice, Hannah, Sarah, David, and Andrew, on behalf of the Guideline Development Group.

Please provide any final comments below.

National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia

 Appendix 7.2
 Online survey – Young people





## Supporting Children National Guideline

[Attachment: "Online Survey - Explanation for Young People - Transcipt.docx"]

[Attachment: "Voice-to-text instructions.doc"]

Thank you again for your interest in this research.

As a reminder, you will have the opportunity to save your responses and return at a later time to complete this survey. To assist us in our data collection, we ask that you please finalise your responses within one week of starting the survey. We will not analyse any additional answers provided after this time.

THIS SURVEY WILL CLOSE AT 11:59 PM ON 30TH APRIL, 2022.

Please indicate if you are:

Completing this yourself

 Completing this with the help of a parent or caregiver

Would you like to tell us your story about getting support?

Yes
 No - skip to next section



Type your answers to the questions below, or upload a three (3) minute video file answering them here.	
When thinking about getting autism specific support:	
What has been good?	
What has been bad?	
What should have been done better?	
2. Your thoughts about the development of the Guideline	
What do you think are the three most important things that should be addressed in the Guideline?	
What are the possible benefits of having a Guideline?	
What concerns, if any, do you have about the development of a Guideline?	
At the moment, where do you get information about therapies and supports (select all that apply)?	<ul> <li>Online searches</li> <li>Social media</li> <li>Family and friends</li> <li>Autistic people (e.g., personal accounts published online)</li> <li>Teachers</li> <li>Medical practitioners</li> <li>Allied health practitioners</li> <li>Word of mouth</li> <li>Research articles</li> <li>Other</li> </ul>

Please specify if other.



## 3. Language preferences in relation to autism

The following questions ask about language preferences in relation to autism. Would you like to provide responses to these questions? Yes
 No - skip to next section
 No - exit survey

Autism CRC understands that different people have different views and preferences about terminology used to describe autism and people on the autism spectrum (see here for Autism CRC statement).

For this guideline, we will make decisions about language and terminology based on feedback from you and other members of the community, collected in this survey.

Our goal is to choose terminology that:

Is preferred by the majority of the autistic community. Is acceptable to the majority of parents/caregivers and practitioners, in that the term/s used would not stop them making use of the Practice Guideline. We are talking here only about the use of terminology in the Guideline document itself, and when Autism CRC and the project team are communicating about the Guideline. We understand that people may have different preferences about terminology, depending on the situation (for example when referring to themselves versus others), but we are focusing only on the Guideline in this survey.

To help us choose terminology, please answer the following questions.

1. Please tell us what term/s you would like to see used in the Guideline by giving each a rating.

	Strongly dislike	Dislike	Somewhat dislike	Neutral	Somewhat like	Like	Strongly like
Autistic	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	0
Autistic person (e.g., autistic children)	0	0	0	0	$\bigcirc$	0	$\bigcirc$
Person with autism (e.g., children with autism)	0	$\bigcirc$	0	$\bigcirc$	0	0	0
Person on the autism spectrum (e.g., children on the autism spectrum)	0	0	0	0	0	0	0
Person with autism spectrum disorder (e.g., children with ASD)	0	0	0	0	0	0	0
Person with autism spectrum condition (e.g., children with ASC)	0	0	0	0	0	0	0

2. Please now tell us if you think each of these terms are acceptable for use in the Guideline.

When we say acceptable, we mean that the term would not stop you supporting and/or using the Guideline, even if it is not your personal preference.

	Unacceptable: I would not support and/or use the guideline if this term is used	Acceptable: I would support and/or use the guideline if this term is used, even if it is not my personal preference
Autistic	0	0
Autistic child	0	0



Child with autism Child on the autism spectrum	0 0	0 0
Child with autism spectrum disorder (child with ASD)	0	0
Child with autism spectrum condition (child with ASC)	0	0



#### 4. Underlying Principles

The following set of questions ask you to provide your thoughts on principles that are important to the delivery of therapies and supports for children on the autism spectrum and their families. Would you like to provide responses to these questions? ○ Yes
 ○ No - skip to next section
 ○ No - exit survey



The following statements describe principles that have been identified by research as having importance for all aspects of providing therapies and supports for children and their families on the autism spectrum. While some principles refer to both children and their families in the same item to acknowledge the family unit, we do so noting that the individual preferences, needs, and rights of each person are always to be considered and maintained.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Holistic: When providing therapy and supports, we should consider an individual's life history, culture, strengths and challenges, goals and preferences, and environmental factors that impact their learning, participation, and quality of life.	0	0	0	0	0
Child and family-centred: The child and their family members should be considered equal partners with practitioners in the therapy process.	0	0	0	0	0
Supported: The child and their family should be supported to include people they feel are relevant in the therapy process, including for advocacy and support.	0	0	0	0	0
Lifespan perspective: When providing therapies and supports, decision making should account for the current stage of life of the child, as well as appropriate planning for both the short and longer term.	0	0	0	0	0
Developmental perspective: Decision-making should account for, and be responsive to, the individual, family and social changes that occur through childhood.	0	0	0	0	0



Empirically-supported: Therapies and supports should be underpinned by published, peer-reviewed scientific evidence demonstrating their effectiveness and safety.	0	0	0	0	0
Evidence-based practice approach: Decision-making should draw on and combine research and clinical evidence alongside the preferences and values of the child and their family.	0	0	0	0	0
Ethical practice: The provision of therapies and supports should be underpinned by an ethical framework that follows the principles of beneficence, non-maleficence, autonomy and fairness.	0	0	0	0	0
Culturally aware and responsive: The values, knowledge, preferences and cultural perspectives of the child and family should be sought, respected, and evident in the provision of therapies and supports.	0	0	0	0	0
Equity: All children and families, regardless of age, gender, cultural background, socioeconomic status or geographical location should be able to access timely, safe, desirable and effective therapies and supports.	0	0	0	0	0
Strengths-focused: Therapies and supports should focus on understanding, embracing and developing the strengths of an individual and their family.	0	0	0	0	0
Coordinated: A coordinated approach across practitioners, organisations, and agencies should be taken.	0	0	0	0	0



Personalised: Therapies and supports should be tailored to the unique strengths, needs, and preferences of each child and family.	0	0	0	0	0
Accessible: The process of planning, delivering, and monitoring therapies and support, including interactions and documentation, should be accessible.	0	0	0	0	0
Informed consent (parents): Informed parental consent should be obtained for therapies and supports provided.	0	0	0	0	0
Assent (children): Children's assent (expression of approval) should be obtained, wherever possible, for therapies and supports provided.	0	0	0	0	0
Qualified practitioners: People involved in the provision of therapies and supports should have relevant qualifications and professional regulation, and only engage in goal setting and the delivery of therapies and supports that are within their scope of practice.	0	0	0	0	0

What other principles not listed above, are important to the delivery of therapies and supports?



5a. Understanding the child, family, and context	
The following set of questions ask you to provide your thoughts on understanding children, their family, and their context, in the provision of therapies and supports. Would you like to:	<ul> <li>Skip this section</li> <li>Provide your general thoughts on this</li> <li>Answer our specific questions</li> <li>Exit the survey</li> </ul>
In clinical practice, assessment involves collecting information t family, and the broader context. Assessment may involve a ran practitioners), include the use of a range of tools (e.g., observat assessments), and draw on both current and historical informat	ge of people (e.g., the child, family, other ion, interviewing, functional assessment, dynamic
From your perspective, what are the most important considerations for practitioners trying to understand the child, family, and their context?	
How important do you think it is to understand the child, their family, and their context when making decisions about therapies and supports for children on the autism spectrum?	<ul> <li>Not at all important</li> <li>Slightly important</li> <li>Moderately important</li> <li>Very important</li> <li>Extremely important</li> </ul>
What information do you think is most important to collect to understand the child, their family, and their context?	
What would you suggest practitioners (i.e., people working directly with the child on the autism spectrum) do to ensure they understand the child, their family, and their context? Provide up to three suggestions.	



5b. Goal Setting	
The following questions ask about the process of planning, selecting and prioritising goals for therapy for young children on the autism spectrum. Would you like to:	<ul> <li>Skip this section</li> <li>Provide your general thoughts on this</li> <li>Answer our specific questions</li> <li>Exit the survey</li> </ul>
From your perspective, what are the most important considerations for practitioners when planning, selecting, and prioritising goals for children?	
How important do you think it is to select appropriate goals for therapy when working with children on the autism spectrum and their families?	<ul> <li>Not at all important</li> <li>Slightly important</li> <li>Moderately important</li> <li>Very important</li> <li>Extremely important</li> </ul>
Who is important to involve (e.g., child, parents, practitioners, others) in planning, selecting, and prioritising goals to support the learning and participation of children on the autism spectrum and their families?	
What types of goals are likely to be relevant to supporting the learning and participation of children on the autism spectrum and their families?	
What can practitioners do to ensure appropriate goals are selected? Provide up to three suggestions.	



5c. Selecting Therapies and Supports	
The following questions ask about the process of planning and selecting specific therapies and supports for young children on the autism spectrum. Would you like to:	<ul> <li>Skip this section</li> <li>Provide your general thoughts on this</li> <li>Answer our specific questions</li> <li>Exit the survey</li> </ul>
From your perspective, what are the most important considerations for practitioners when planning and selecting therapies and supports for children?	
How important do you think it is to select appropriate therapies and supports when working with children on the autism spectrum and their families?	<ul> <li>Not at all important</li> <li>Slightly important</li> <li>Moderately important</li> <li>Very important</li> <li>Extremely important</li> </ul>
Who is important to involve (e.g., parents, practitioners, the child) in selecting therapies and supports for children on the autism spectrum and their families?	
If your response is the same as goal setting, please type "See previous section" here.	
What types of therapies and supports are relevant to supporting the learning and participation of children on the autism spectrum and their families?	
What can practitioners do to ensure that appropriate therapies and supports are selected? Provide up to three suggestions.	
If your response is the same as for goal setting, please type "see previous section".	



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5d. Delivering Therapies and Supports	
The following questions ask about decisions related to the delivery of therapies and supports (i.e., the setting, the format [individual, group], the people involved [practitioner, parents, siblings/peers, others], the amount). Would you like to:	<ul> <li>Skip this section</li> <li>Provide your general thoughts on this</li> <li>Answer our specific questions</li> <li>Exit the survey</li> </ul>
From your perspective, what are the most important considerations for practitioners when delivering therapies and supports for children on the autism spectrum?	
How important do you think it is to deliver therapies and supports in ways that are appropriate for children on the autism spectrum and their families?	<ul> <li>Not at all important</li> <li>Slightly important</li> <li>Moderately important</li> <li>Very important</li> <li>Extremely important</li> </ul>
Is there a standard amount of practitioner-delivered therapy and support that you think children on the autism spectrum should have access to?	○ Yes ○ No
This includes therapies and supports provided directly to the child, supports provided to upskill parents/caregivers to support the child, and supports to upskills other members of the community (e.g., a child's teacher) to support the child.	
What is this standard amount of therapy?	
What is an appropriate amount of practitioner-delivered therapy and support you think that children on the autism spectrum should have access to?	
In what settings do you think it is appropriate to deliver therapies and supports?	
Who is important to involve (e.g., parents, practitioners, the child) in the delivery of therapies and supports?	
If your response is the same as previous sections (goal setting, planning), please indicate "see previous sections" here.	
What can practitioners do to ensure that appropriate therapies and supports are delivered? Provide up to three suggestions.	
If your response is the same as previous sections (goal setting, planning), please indicate "see previous sections" here.	



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5e. Monitoring of therapies and supports	
The following questions ask about monitoring progress and outcomes of therapies and supports. By this we mean the things that those working with the child and family do to evaluate how the service is delivered and the child and family's experience and outcomes. Would you like to:	<ul> <li>Skip this section</li> <li>Provide your general thoughts on this</li> <li>Answer our specific questions</li> <li>Exit the survey</li> </ul>
-	
From your perspective, what are the most important considerations for practitioners when monitoring progress and outcomes of therapies and supports for children on the autism spectrum?	
How important do you think it is to monitor the delivery of therapies and supports for children on the autism spectrum and their families? This includes ensuring the goals, therapies, and supports continue to be appropriate.	<ul> <li>Not at all important</li> <li>Slightly important</li> <li>Moderately important</li> <li>Very important</li> <li>Extremely important</li> </ul>
What aspects of therapies and supports provided, and the child and family's experience, should be monitored by practitioners?	
What can practitioners do to ensure the appropriate monitoring of goals, therapies and supports? Please provide up to three suggestions.	



5f. Safety and wellbeing	
The following questions ask about how the safety and wellbeing of children on the autism spectrum and their families can be ensured. Would you like to?	<ul> <li>Skip this section</li> <li>Provide your general thoughts on this</li> <li>Answer our specific questions</li> <li>Exit the survey</li> </ul>
From your perspective, what are the most important things for practitioners to consider in order to ensure the safety and wellbeing of children on the autism spectrum and their families	
How important to do you think it is to ensure that the safety and wellbeing of children on the autism spectrum and their families is ensured when accessing therapies and supports?	<ul> <li>Not at all important</li> <li>Slightly important</li> <li>Moderately important</li> <li>Very important</li> <li>Extremely important</li> </ul>
How can practitioners support the safety and wellbeing of children on the autism spectrum and their families when accessing therapies and supports?	
Please describe any risks you see for children and families in accessing therapies and supports.	
Before you go, did you complete the whole survey?	○ Yes ○ No
Are you happy for us to use the information you provided?	○ Yes ○ No
If you are willing, please tell us why you did not complete the whole survey? Select all that apply	<ul> <li>It was too long</li> <li>I did not understand the questions</li> <li>It was not relevant to me</li> <li>I have other things I need to do</li> <li>I prefer not to say</li> <li>Other</li> </ul>
If you have any final comments, please feel welcome to share them here.	

#### A note from the research team

Thank you very much for answering the questions. The information that you and others provide will directly inform the recommendations in the guideline.

The next step for the research team will be to analyse all of the information provided. The Guideline Development Group will then formulate recommendations.

If you have not already done so, please register with Autism CRC to receive updates about the guideline. You can do so here.

Before we finish, we want to take a moment to acknowledge the time it takes to complete surveys like this. While we are not able to send a personal response to each person who completes it, please know that we genuinely value the information you have provided and will be reading every word.

We look forward to sharing updates, and the guideline in due course, via Autism CRC's website.

Sincerely,

ይካለምም2Kangigg, Hannah, Sarah, David, and Andrew, on behalf of the Guideline Development Group.



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# National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia

 Appendix 7.3
 Code Book

#### Appendix 7.3 Code Book

#### Instructions for coders

- 1. Before starting coding for the day, please review the 'Coding Questions & Comments' Tab in Teams to see if there have been any updates
- 2. Find the file you have been allocated in Teams. Your file will be located in your own Teams folder located in the *'Data Files NVIVO'* folder. Your files will be dated, so please take note to select the most recent file (This should be the file available)
- 3. Save the file in a folder on your computer that is safe and can be easily found and deleted when coding is complete.
- 4. Open NVIVO (If you have not already setup your NVIVO settings, please ensure the settings are set to remind you to save the file at least every 15 minutes and add a two letter initials for identifying purposes. For example, David would add DT in the initial sections.)
- 5. Check which questions you are required to code (see colour coding below, the upload notification will confirm the questions requiring coding) and have a printed copy of the code book beside you for your reference.
- 6. Review the codes and definitions to clarify your understanding.
- 7. You might find coding one column (i.e., participants' responses to a question) at a time to be easier, as each column will have a specific set of codes to consider within the coding framework. Therefore, double check you are coding each response to the correct codes assigned.
- 8. In situations where the participant's response appears relevant to the question they were asked, but does not clearly meet the definition of one or more codes, then code as 'other.'
- 9. Please write a journal/reflection on the process, during each coding session. This should be done in NVIVO memo feature. Please reflect on any patterns you are seeing in the data (e.g., prominent themes); differences, contrasts, and/or contradictions in the responses; any challenges you experienced in assigning codes; suggestions for possible new or revised codes; reasons for why you may have coded a specific way or anything else that you, at that time, felt was important. These memos not only provide you with a great way to document the process and a source for recalling what you did and why, but are also a key aspect of the methodology and thus important to analysing and interpreting the data.
- 10. Once you have finished coding all responses in your file, save the file and upload into your Teams Data Files NVIVO Return folder. There is no need to change the file name.

- 11. Please notify Emma, in the Teams channel '*Data Management*' or in chat when you have completed and uploaded your assigned response. Likewise, this channel also notifies when a new data file for coding ready for each coder.
- 12. *IMPORTANT* Please <u>DO NOT</u> change any of the comments and responses. Only assign codes, as any changes to the text will impact file merging.

If you have any questions with coding, please ask via the "Coding Questions & Comments' Tab in Teams in the first instance, as this will provide us with a central and consistent way of documenting and responding to these questions. You can share a chat message via the Teams chat or contact Emma/David directly if you want to alert them to the new question/comment. Please do not hesitate to any questions or share comments as this is an important part of the process.

Part A: Coding Guide

- The sections and corresponding questions to be coded are outlined below
- See column 'D' for codes to be applied to each section
- Codes are further described in Part B of this manual
- Please ensure you are coding the correct codes according to the coding framework to be applied (D) as they can and do change for most questions.

A. Section	B. Question Number	C. Question Label	D. Coding framework to be applied	Coding Instructions
Your Story (parents/ caregivers)	1	What has been good?	Code for principles in first instance	Code these three questions at the same time for each participant
Your Story (parents/ caregivers)	2	What has been bad?	Code for principles in first instance	

Your Story (parents/ caregivers)	3	What could have been done better?	Code for principles in first instance	
Your Story (autistic adults)	1	What has been good?	Code for principles in first instance	Code these three questions at the same time for each participant
Your Story (autistic adults)	2	What has been bad?	Code for principles in first instance	
Your Story (autistic adults)	3	What could have been done better?	Code for principles in first instance	
4: Underlying Principles	2	What other principles not listed above, are important to the delivery of therapies and supports?	<ul> <li>If responses to S4.2 align with an existing principle, code at principles node</li> <li>If responses do not map to existing principles, code as "S4.2 Principles - other"</li> </ul>	Code this question for all participants at one time
5a: Understanding the child, family, and context	1a	From your perspective, what are the most important considerations for practitioners trying to understand the child, family, and their context?	<ul> <li>Code for principles</li> <li>If unsure, code as "S5 Understanding - other"</li> </ul>	
5a: Understanding the child, family, and context	2	What information do you think is most important to collect to understand the child, their family, and their context?	<ul> <li>Code as either "S5 understanding - child", "S5 understanding: family", or "S5 understanding: context"</li> </ul>	

_			<ul> <li>If unsure, code as "S5Understanding - other"</li> </ul>
5a: Understanding the child, family, and context	3	What would you suggest practitioners (i.e., people working directly with the child on the autism spectrum) do to ensure they understand the child, their family, and their context? Provide up to three suggestions.	<ul> <li>Code as either "S5 understanding: child", "S5 understanding: family", or "S5 understanding: context"</li> <li>If unsure, code as "S5Understanding - other"</li> </ul>
5b. Goal Setting	1a	From your perspective, what are the most important considerations for practitioners when planning, selecting, and prioritising goals for children?	<ul> <li>Code for principles</li> <li>If unsure, code as "S5b Goal setting - other"</li> </ul>
5b. Goal Setting	2	Who is important to involve (e.g., child, parents, practitioners, others) in selecting goals to support the learning and participation of children on the autism spectrum and their families?	<ul> <li>Code at "who" nodes (detailed below)</li> <li>If unsure, code as "S5b Goal setting - other"</li> </ul>
5b. Goal Setting	3	What types of goals are likely to be relevant to supporting the learning and participation of children on the autism spectrum and their families?	<ul> <li>Code as either "S5b.3 Child: mental/physical functions", "S5b.3 Child: activities/participation", or "S5b.3 Child: environment"</li> <li>If unsure, code as "S5b Goal setting - other"</li> </ul>
5b. Goal Setting	4	What would you suggest practitioners do to ensure appropriate goals are selected? Provide up to three suggestions.	<ul> <li>Code at "suggestions" nodes (more details below)</li> <li>If unsure, code as "S5b Goal setting - other"</li> </ul>

5c. Selecting Therapies and Supports 5c. Selecting Therapies and Supports	1a 2	From your perspective, what are the most important considerations for practitioners when planning and selecting therapies and supports for children? Who is important to involve (e.g., parents, practitioners, the child) in selecting therapies and supports for children on the autism spectrum and their families?	<ul> <li>Code for principles</li> <li>If unsure, code as "Q5c Selection - other"</li> <li>Code at "who" nodes</li> <li>If unsure, code as "S5c Selection - other"</li> </ul>
5c. Selecting Therapies and Supports	3	What types of therapies and supports are relevant to supporting the learning and participation of children on the autism spectrum and their families?	Specific - Supported: The         respondent names a specific         profession, technique, practice, or         category of practices that they         believe is appropriate to children         and/or families         Specific - Non-supported: The         respondent names a specific         profession, technique, practice, or         category of practices that they         believe is not appropriate for children         and/or families         Non-Specific - Supported: The         respondent refers to a type and/or         aspect of service delivery, that is         general in nature (i.e., does not meet         the specificity requirement to be         coded above) that they believe is         appropriate for children and/or         families

			Non-Specific - Non-supported: The respondent refers to a type and/or aspect of service delivery, that is general in nature (i.e., does not meet the specificity requirement to be coded above) that they believe is not appropriate for children and/or families
5c. Selecting Therapies and Supports	4	What can practitioners do to ensure that appropriate therapies and supports are selected? Provide up to three suggestions.	<ul> <li>Code at "suggestions" nodes (more details below)</li> <li>If unsure, code as "S5c Selection - other"</li> </ul>
5d. Delivering Therapies and Supports	1a	From your perspective, what are the most important considerations for practitioners when delivering therapies and supports for children?	<ul> <li>Code for principles</li> <li>If unsure, code as "Q5d Delivery - other"</li> </ul>
5d. Delivering Therapies and Supports	2a	What is this standard amount of therapy?	<ul> <li>Code as "S5d.2a Delivery – amount"</li> <li>New breakdown list is included below</li> </ul>
5d. Delivering Therapies and Supports	3	What is an appropriate amount of practitioner-delivered therapy and support you think that children on the autism spectrum should have access to?	<ul> <li>Code as "S5d.3 Delivery – amount"</li> <li>New breakdown list is included below</li> <li>2a and 3 use the same codes</li> </ul>
5d. Delivering Therapies and Supports	4	In what settings do you think therapies and supports should be delivered?	<ul> <li>Code as "S5d.4 Delivery – Clinic", "S5d.4 Delivery – home",</li> </ul>

			<ul> <li>"S5d.4 Delivery – educational setting", "S5d.4 Delivery – cultural setting", "S5d.4 Delivery –social setting", or "S5d.4 Delivery – recreational setting"</li> <li>If unsure, code as "S5d Delivery – other"</li> </ul>
5d. Delivering Therapies and Supports	5	Who is important to involve (e.g., parents, practitioners, the child) in the delivery of therapies and supports?	<ul> <li>Code at "who" nodes</li> <li>If unsure, code as "S5d Delivery - other"</li> </ul>
5d. Delivering Therapies and Supports	6	What would you suggest practitioners do to ensure that appropriate therapies and supports are delivered? Provide up to three suggestions.	<ul> <li>Code at "suggestions" nodes (more details below)</li> <li>If unsure, code as "S5d Delivery - other"</li> </ul>
5e. Monitoring of therapies and supports	1a	From your perspective, what are the most important considerations for practitioners when monitoring progress and outcomes of therapies and supports for children?	<ul> <li>Code for principles</li> <li>If unsure, code as "S5e Monitoring - other"</li> </ul>
5e. Monitoring of therapies and supports	2	What aspects of therapies and supports provided, and the child and family's experience, should be monitored?	<ul> <li>Code as either "S5e.2 Monitoring: fidelity", "S5e.2 Monitoring: progress", "S5e.2 Monitoring: impact", "S5e.2 Monitoring: maintenance", "S5e.2 Monitoring: Generalisation", "S5e.2 Monitoring: costs/benefits", or "S5e.2 Monitoring: unplanned outcomes"</li> </ul>

5e. Monitoring of therapies and supports	3	What can practitioners do to ensure the appropriate monitoring of goals, therapies, and supports? Provide up to three suggestions.	<ul> <li>If unsure, code as "S5e Monitoring - other"</li> <li>Code at "suggestions" nodes (more details below)</li> <li>If unsure, code as "S5e Monitoring - other"</li> </ul>
5f. Safety and wellbeing	1a	From your perspective, what are the most important considerations for practitioners to ensure the safety and wellbeing of children on the autism spectrum and their families?	<ul> <li>Code for principles</li> <li>If unsure, code as "S5f Safety - other"</li> </ul>
5f. Safety and wellbeing	2	How can practitioners support the safety and wellbeing of children on the autism spectrum and their families?	<ul> <li>Code as "S5f.2 Safety - Empirical Evidence", "S5f.2 Safety – Experience", "S5f.2 Safety- Supervision", "S5f.2 Safety – Research", "S5f.2 Safety – monitoring", "S5f.2 Safety – assessment", "S5f.2 Safety – rights", "S5f.2 Safety – practice standards", "S5f.2 Safety – concerns", "S5f.2 Safety – communication"</li> <li>If unsure, code as "S5f Safety - other"</li> </ul>
5f. Safety and wellbeing	3	Please describe any risks you see for children and families in accessing therapies and supports	<ul> <li>Code for principles</li> <li>If unsure, code as "S5f Safety - other"</li> </ul>

Part B: Code descriptions

- The following tables provide additional descriptors for some of the above codes to be used
- Codes are bolded

#### Section 4. Principles

Note: Code below at each principle label (bolded)

#### **Holistic:**

When providing therapy and supports, we should consider an individual's life history, culture, strengths and challenges, goals and preferences, and environmental factors that impact their learning, participation, and quality of life.

#### Child and family-centred:

The child on the autism spectrum and their family members should be considered equal partners with practitioners in the therapy process.

#### Supported:

The child and their family should be supported to include people they feel are relevant in the therapy process, including for advocacy and support.

#### Lifespan perspective:

Decision making should account for the current stage of life of the child, as well as appropriate planning for both the short and longer term.

#### **Developmental perspective:**

Decision-making should account for, and be responsive to, the individual, family and social changes that occur through childhood.

#### Empirically-supported:

Therapies and supports should be underpinned by published, peer-reviewed scientific evidence demonstrating their effectiveness and safety.

#### Evidence-based practice approach:

Decision-making should draw on and combine research and clinical evidence alongside the preferences and values of the child and their family.

#### Ethical practice:

The provision of therapies and supports should be underpinned by an ethical framework that follows the principles of beneficence, non-maleficence, autonomy and fairness.

#### Culturally aware and responsive:

The values, knowledge, preferences and cultural perspectives of the child and family should be sought, respected, and evident in the provision of therapies and supports.

#### Equity:

All children and families, regardless of age, gender, cultural background, socioeconomic status or geographical location should be able to access timely, safe, desirable and effective therapies and supports.

#### Strengths focused:

Therapies and supports should focus on understanding, embracing and developing the strengths of an individual and their family.

#### Coordinated:

A coordinated approach across practitioners, organisations, and agencies should be taken.

#### Personalised:

Therapies and supports should be tailored to the unique strengths, needs, and preferences of each child and family.

#### Accessible:

The process of planning, delivering, and monitoring therapies and support, including interactions and documentation, should be accessible.

#### Informed consent (parents):

Informed parental consent should be obtained for therapies and supports provided. **Assent (children)**:

Children's assent (expression of approval) should be obtained, wherever possible, for therapies and supports provided.

#### **Qualified practitioners:**

People involved in the provision of therapies and supports should have relevant qualifications and professional regulation, and only engage in goal setting and the delivery of therapies and supports that are within their scope of practice.

#### Section 5a. Understanding the child, family, and context

#### S5a Understanding: child

(use above code for any responses related to below)

The child's health (i.e., physical health, mental health, and health history).			
The child's developmental skills (i.e., gross and fine motor, social, emotional,			
cognitive, communication, and academic skills).			
The child's diagnostic characteristics (i.e., social communication skills,			
repetitive behaviours, focused/intense interests, and sensory behaviours).			
The child's activities and participation in home, educational, and community			
settings (this includes enablers and barriers to participation).			
The child's behaviour(s) of concern (including, (i) behaviours arising from the			
interaction of the person and their environment that risk the physical safety of			
the individual and/or others and (ii) behaviours that limit or deny participation in			
life activities).			
The child's perception of their quality of life (to the extent this is possible to			
obtain)			
The child's activity-related strengths and preferences (i.e., activities that bring			
the child joy and/or that they have expertise in).			
The child's preferences for therapies/supports (to the extent this is possible to			
obtain)			

4.2i	The child's expectations for the outcomes of therapy/support (to the extent this
	is possible to obtain)
4.2j	Other child factors

**S5a Understanding: family** (use above code for any responses related to below)

<b>1</b>	····· · · · · · · · · · · · · · · · ·
а	The family's physical and mental health (i.e., the presence of any conditions that
	may impact upon their capacity to participate, or need to be considered, in the
	provision of therapies/supports for their child).
b	The family's social-emotional resources and supports (i.e., resilience factors and
	the capacity to deal with stressful situations in life, along with social support via
	family, friends, and support groups).
С	The family's financial resources and supports (i.e., funding to pay for therapies
	and supports, capacity to purchase unfunded therapies and supports, and
	capacity to take time away from paid work to access therapies and supports).
d	The family's activities (i.e., work, social, cultural, sport and recreational, and
	educational activities).
е	The family's views, perspectives and preferences (i.e., views about their child's
	learning, participation and quality of life now and in the future, views on
	disability, the relevance of therapies/supports for their child, cultural perspectives
	on therapies/supports, preferences for therapies/supports, and expectations for
	outcomes).
f	The family's dynamics (i.e., the nature and strength of relationships between
	family members, the nature and distribution of roles and responsibilities, the
	positive and challenging impacts associated with the child's disability).

<b>S</b> 5	S5a Understanding: context		
(us	(use above code for any responses related to below)		
А	The nature of any services previously accessed, including goals and types of		
	services (e.g., allied health, mainstream supports).		
b	The child and family's experience of previously accessed services, including		
	their satisfaction with the service(s).		
С	The child and family's outcomes of accessing previous services, including the		
	progress made towards goals.		
D	Any arrangements that are in place to support the coordination of services and		
	supports accessed by the child and family (e.g., nominated case coordinator,		
	NDIS support coordination).		
Е	Family preferences for future arrangements to support the coordination of		
	services and supports accessed by the child and family.		

## Section 5b. Goal Setting

	S5b.3 Child: mental/physical functions				
(us	se above code for any responses related to below)				
Α	Mental functions (e.g., executive functioning)				
В	Physical functions (e.g., articulation of speech sounds, fine motor skills)				
S5	b.3 Child: activities/participation				
(us	se above code for any responses related to below)				
А	The acquisition of skills (e.g., social, communication, play, motor)				
В	The generalised use of skills in daily activities with others (e.g., social skills				
	used to help form relationships, communication skills used to have a				
	conversation, play skills used to engage in play with peers).				
С	The reduction of behaviours of concern (e.g., self-injurious behaviours)				
D	Learning and applying knowledge (e.g., learning to count, learning to read)				
Е	Carrying out daily routines (relative to age expectations)				
F	Supporting interpersonal interactions and relationships				
G	Participation in community, social, and civic life (e.g., recreation, leisure,				
	religion, spirituality)				
S5	b.3 Child: environment				
(us	se above code for any responses related to below)				
Α	Accessibility in the physical environment (e.g., sensory-safe spaces)				
В	Accessibility in the social environment (e.g., changing attitudes and increasing				
	knowledge and skills of others')				
С	Enhancement of services, systems, and policies (e.g., to improve coordination				
	of services, changing policies that create barriers to participation).				

A	S5c.3 Specific - Supported	The respondent names a specific profession, technique, practice, or category of practices that they believe is appropriate to children and/or families
В	S5c.3 Specific - Non- supported	The respondent names a specific profession, technique, practice, or category of practices that they believe is not appropriate for children and/or families
С	S5c.3 Non-Specific - Supported	The respondent refers to a type and/or aspect of service delivery, that is general in nature (i.e., does not meet the specificity requirement to be coded above) that they believe is appropriate for children and/or families
D	S5c.3 Non-Specific - Non-supported:	The respondent refers to a type and/or aspect of service delivery, that is general in nature (i.e., does not meet the specificity requirement to be coded above) that they believe is not appropriate for children and/or families

## Section 5c. Selecting and Planning

# Section 5d. Delivery

A	S5d.4 Delivery	– Clinic	Clinic
В	S5d.4 Delivery – home		The child's home
С	S5d.4 Delivery educational set		Educational settings (including school and early child education settings/day care)
D	S5d.4 Delivery cultural setting		Cultural settings (e.g., places of worship)
E	S5d.4 Delivery –social setting		Social settings (e.g., other people's homes, community spaces)
f	S5d.4 Delivery – recreational setting		Recreational settings (e.g., sports ovals, music/art/drama studios)
	S5d.2a and S5d.3: Delivery amount	Only allocate one code per the entire entry	
	Specified amount	The respondent specifies an amount (minimum, maximum, range, and or mean) of therapy/support in quantitative terms (e.g., hours, days, sessions, occasions of service). The respondent does not indicate that the amount should be individualised.	
	Individualised - Indicative amount.	People who can contribute to supporting the child's participation in community activities (e.g., sports coaches, art teachers, community members the child interacts with regularly including retail environments, community groups, and cultural activities)	
	Individualised - Amount not specified	The respondent indicates that amount should be individualised and does not specify an amount that children should receive. The respondent may imply that the amount should be individualised based on criticism of specific amount they mention (e.g., not XX hours).	
	Not Applicable	The respo the three	ondent's comments are inconsistent with each of codes.

# Section 5e. Monitoring of Therapies and Supports

S5	S5e.2 Monitoring: fidelity		
(us	(use above code for any responses related to below)		
8.2	8.2 Fidelity of therapy/support delivery		
А	Type: The extent to which the planned type of therapy/support was delivered.		
В	People: The extent to which the people who were intended to contribute to		
	progress towards the goal contributed.		

С	Settings: The extent to which the settings in which the goal was to be targeted			
	were included.			
D	Amount: The extent to which the intended amount of therapy/support was			
	delivered.			
S5	e.2 Monitoring: progress			
(us	se above code for any responses related to below)			
8.3	3 Children's progress towards therapy/support goals			
А	Amount of progress made towards the goal			
В	The child's satisfaction with progress towards the goal (to the extent possible)			
С	Parents' satisfaction with the child's progress towards the goal			
S5	e.2 Monitoring: impact			
(us	se above code for any responses related to below)			
8.4	Impact of progress towards therapy/support goals			
А	Changes in the child's skills			
В	Changes in the child's learning and participation			
С	Changes in the child's wellbeing			
D	Changes in the family's wellbeing			
Е	Changes in the environment that affect learning and participation			
S5	e.2 Monitoring: maintenance			
(us	se above code for any responses related to below)			
8.5	5 Maintenance			
А	Maintenance of change over the short term (i.e., 12 months – 2 years)			
В	Maintenance of change over the medium term (i.e., 2-3 years)			
С	Maintenance of change over the long term (i.e., 3+ years)			
S5	e.2 Monitoring: Generalisation			
(us	se above code for any responses related to below)			
А	Generalisation of change to interactions with other people			
В	Generalisation of change to other activities			
С	Generalisation of change to other settings			
S5	e.2 Monitoring: costs/benefits			
(us	se above code for any responses related to below)			
А	Costs for children (e.g., time, fatigue, not pursuing alternative goal or service			
	option)			
В	Costs for parents (e.g., time, financial)			
С	Benefits for children			
D	Benefits for family members			
S5e.2 Monitoring: unplanned outcomes				
(us	(use above code for any responses related to below)			
А	Positive unplanned outcomes that have arisen from the delivery of			
	therapy/support			
В	Adverse effects that have arisen from the delivery of the therapies/supports			

# Section 5f. Safety and Wellbeing

а.	S5f.2 Safety -	Ensuring practitioners have up-to-date knowledge of the
	Empirical Evidence	empirical evidence for therapies/supports (including
		research on the views and preferences of autistic
		people)
b.	S5f.2 Safety -	Ensuring practitioners have adequate experience and
	Experience	skills in the selection, delivery and assessment of
		therapies/supports
C.	S5f.2 Safety-	Ensuring that practitioners have access to clinical
	Supervision	supervision
d.	S5f.2 Safety -	Ensuring the effectiveness and safety of
	Research	therapies/supports being delivered by practitioners have
		been validated through well-designed research studies
e.	S5f.2 Safety –	Ongoing monitoring of therapy/support outcomes
	monitoring	
f.	S5f.2 Safety –	Ongoing assessment of support needs
	assessment	
g.	S5f.2 Safety –	Practitioners working in ways that are consistent with
	rights	relevant conventions, including the United Nations
		Convention on the Rights of Persons with Disabilities
		and the United Nations Convention on the Rights of the
		Child
h.	S5f.2 Safety –	Practitioners following relevant practice/ professional
	practice standards	processes and legislative requirements (e.g., Disability
		Discrimination Act, NDIS rules)
i.	S5f.2 Safety –	Ensuring that children and their families have a clear
	concerns	method and pathway for raising concerns
j.	S5f.2 Safety -	Ensuring the provision of clear, appropriate, and
	communication	accurate information between practitioners and families
		at all stages (including to ensure informed consent is
		validly obtained)

# Across Section Codes

### 'Who' codes

2.1	Who: family	The child, family, and family-like people (i.e., family friends,
		peers)
2.2	Who:	People who provide formal support for the child's health and
	support	development (e.g., educators, medical and allied health
	providers	practitioners)
2.3	Who:	People who can contribute to supporting the child's
	participation	participation in community activities (e.g., sports coaches, art
	-	teachers, community members the child interacts with

		regularly including retail environments, community groups, and cultural activities)
2.4	Who: agencies	Agencies that support the provision and/or access to services (e.g., NDIS planners, child safety officers)

'Suggestion' Codes

a.	Suggestions -	A theoretical rationale for why the goal/therapy/support is
	Theoretical	likely to lead to an increase in the child's learning and
	Rationale	participation.
b.	Suggestions –	Research evidence (from published, peer-reviewed
	research	research) that the goal/therapy/support is likely to lead to
	evidence	an increase in the child's learning and participation.
C.	Suggestions –	Clinical evidence gathered through practice that the
	clinical evidence	goal/therapy/support is likely to lead to an increase in the
		child's learning and participation, including evidence drawn
		from the experiences/outcomes of other children and
		families the practitioner has supported.
d.	Suggestions –	Perspectives expressed by autistic people regarding the
	autistic	goal/therapy/support.
	perspectives	
		ut child/family/context
		any suggestions that relate to below (e through o)
e.		bout the child, family, and their context that is relevant to this
_	goal/therapy/s	
f.		n of whether the child/family have the time required for the
	goal/therapy/s	
g.		n of whether the child/family have the social support required
<u> </u>		herapy/support (e.g., family members willing to assist).
h.	Consideration of whether the child/family have the financial resources	
		ne goal/therapy/support
i.	Consideration of whether the child/family have the emotional support	
	required for the goal/therapy/support	
j.	Consideration of whether the goal/therapy/support is consistent with the	
	•	cultural background.
k.		n of whether the goal/therapy/support is consistent with the
	parent/s views on child-rearing.	
١.		n of whether the goal/therapy/support is consistent with the
	parent/s views on child development.	
m.		n of whether the goal/therapy/support is consistent with the
		s on disability (and the need to focus on the child versus the
n	environment)	
n.		n of whether the child supports the goal/therapy/support (to
	the extent pos	

0.	Consideratior	of whether the parent/s support the goal/therapy/support
р.	Suggestions –	Consideration of the potential benefits associated with the
	benefits	goal/therapy/support.
q.	Suggestions -	Consideration of the potential risks associated with the
	risks	goal/therapy/support.
r.	Suggestions –	Consideration of the alternative options to this
	alternatives	goal/therapy/support.
S.	Suggestions –	Consideration of how this goal/ /therapy/support may
	enhance	enhance progress towards other goals.
	progress	
t.	Suggestions –	Consideration of how this goal/therapy/support may impede
	impede progress	progress towards other goals.
u.	Suggestions –	Consideration of the relevance of this goal/therapy/support
	relevance	currently for the child and family.
	(current)	
۷.	Suggestions –	Consideration of the relevance of this goal/therapy/support
	relevance (future)	in the future for the child and family.

National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia

 Appendix 8.1
 Focus Group – Demographics survey





# Supporting Children National Guideline

Thank you for registering to participate in the Supporting Children Guideline focus groups. The following short survey will ask for some basic information about you, which will help us describe the individuals who participated in the publication of the guideline.

While we do ask for your name and email address, this information will only be used for administrative purposes and will not be published in any format.

Please provide your first and last name.

Please provide your contact email you used to register for the focus groups.





Information About You	
Please indicate which perspectives you bring to this focus group (select all that apply)	<ul> <li>Autistic individual/person on the autism spectrum</li> <li>Parent/primary caregiver of someone on the autism spectrum</li> <li>Family member of person on the autism spectrum</li> <li>An individual who provides services to children (0-12 years) on the autism spectrum</li> <li>A member of an organisation or service which provides services to children (0-12 years) on the autism spectrum</li> </ul>
With which gender do you identify?	<ul> <li>Female</li> <li>Male</li> <li>Non-binary</li> <li>Prefer not to say</li> <li>Other</li> </ul>
Please specify if other	
Which state or territory of Australia do you currently reside in?	<ul> <li>Australian Capital Territory</li> <li>New South Wales</li> <li>Northern Territory</li> <li>Queensland</li> <li>South Australia</li> <li>Tasmania</li> <li>Victoria</li> <li>Western Australia</li> <li>Do not currently reside in Australia</li> </ul>
Which of the following best describes where you live?	<ul> <li>Major city</li> <li>Regional and/or remote area</li> </ul>
Do you self-identify as Aboriginal and/or Torres Strait Islander?	<ul> <li>No</li> <li>Yes, Aboriginal</li> <li>Yes, Torres Strait Islander</li> <li>Yes, both Aboriginal and Torres Strait Islander</li> </ul>
Are you of Aboriginal and/or Torres Strait Islander heritage?	<ul> <li>No</li> <li>Yes, Aboriginal</li> <li>Yes, Torres Strait Islander</li> <li>Yes, both Aboriginal and Torres Strait Islander</li> </ul>
Were you born in Australia?	○ No ○ Yes
In what country were you born?	
Do you speak one or more languages other than English in the home?	○ No ○ Yes
How many languages, including English, do you speak at home?	



What is your age?	<ul> <li>0-17 years</li> <li>18-20 years</li> <li>21-30 years</li> <li>31-40 years</li> <li>41-50 years</li> <li>51-60 years</li> <li>61-70 years</li> <li>61-70 years</li> <li>71-80 years</li> <li>81-90 years</li> <li>91-100 years</li> <li>100+ years</li> </ul>
If you identify as an autistic adult, are you happy to tell us more about your experience of autism, in terms of your diagnosis?	<ul> <li>No</li> <li>Yes</li> <li>Does not apply to me</li> </ul>
Which of the following best describes your circumstances?	<ul> <li>I have been given a formal diagnosis of autism (or a related diagnosis e.g., Asperger's, Pervasive Developmental Disorder) by one or more qualified health practitioners (e.g., paediatrician, clinical psychologist, psychiatrist)</li> <li>I am currently being assessed for a possible diagnosis of autism</li> <li>I self-identify as autistic, but have not been given a formal diagnosis by a health professional.</li> </ul>
At what age did you receive a formal diagnosis? Please specify in years	
What was your diagnosis?	
Did you receive or access autism specific therapies and supports between the ages of 0-6 years?	○ No ○ Yes
Did you receive or access autism specific therapies and supports between the ages of 7-12 years?	○ No ○ Yes

The below table outlines the three levels of support required within the autism spectrum as described in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5).

Level

Social communication

Restricted, repetitive behaviors

Level 3 "Requiring very substantial support"

Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches

Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.

Level 2 "Requiring substantial support"

<sup>07</sup>/ዘቆብደረብ ଧିጅምድበቴ in verbal and nonverbal social communication skills; social impairmeries መንጭምድቡት even የፍርጉ በግን የመንግሥት

supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.

Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.

#### Level 1 "Requiring support"

Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.

Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

If you were diagnosed as a child under the DSM-5, please indicate which support level was associated with your diagnosis.	<ul> <li>Level 1 - Requires support</li> <li>Level 2 - Requires substantial support</li> <li>Level 3 - Required very substantial support</li> <li>I am unsure</li> <li>I would prefer not to say</li> </ul>
If you were not diagnosed as a child under the DSM-5, or you received a diagnosis in adulthood, please indicate which level would have best represented your support needs as a child.	<ul> <li>Level 1 - Requires support</li> <li>Level 2 - Requires substantial support</li> <li>Level 3 - Required very substantial support</li> <li>I am unsure</li> <li>I would prefer not to say</li> </ul>
If you identify as a parent, are you happy to tell us more about your child(ren) on the autism spectrum? This includes your children who are now teenagers or adults. We will ask you to focus on just one child at a time.	<ul> <li>No</li> <li>Yes</li> <li>This does not apply to me</li> </ul>
How old is your child (years)	
How old is your child (months)	
Has your child received a formal diagnosis of autism (or a related disorder e.g., Asperger's, Pervasive Developmental Disorder)?	○ No ○ Yes
At what age was your child diagnosed (please round to the nearest year)?	
Did you access therapies and/or supports for your child at some stage between the ages of 0-6 years?	○ No ○ Yes
Did you access therapies and/or supports for your child at some stage between the ages of 7-12 years?	○ No ○ Yes

The below table outlines the three levels of support required within the autism spectrum as described in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5).

Level

Social communication

Restricted, repetitive behaviors

Level 3 "Requiring very substantial support"

Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches

Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.

Level 2 "Requiring substantial support"

Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.

Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.

#### Level 1 "Requiring support"

Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.

Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

If your child was diagnosed under the DSM-5, please indicate which support level is associated with their diagnosis.	<ul> <li>Level 1 - Requires support</li> <li>Level 2 - Requires substantial support</li> <li>Level 3 - Required very substantial support</li> <li>I am unsure</li> <li>I would prefer not to say</li> </ul>
If your child has not yet received a formal diagnosis or was not diagnosed as a child under the DSM-5, please indicate which level you feel would have best represented their support needs as a child.	<ul> <li>Level 1 - Requires support</li> <li>Level 2 - Requires substantial support</li> <li>Level 3 - Required very substantial support</li> <li>I am unsure</li> <li>I would prefer not to say</li> </ul>
Do you wish to provide details for another child on the autism spectrum?	○ No ○ Yes



How old is your child (years)	
How old is your child (months)	
Has your child received a formal diagnosis of autism (or a related disorder e.g., Asperger's, Pervasive Developmental Disorder)?	○ No ○ Yes
At what age was your child diagnosed (please round to the nearest year)?	
Did you access therapies and/or supports for your child at some stage between the ages of 0-6 years?	○ No ○ Yes
Did you access therapies and/or supports for your child at some stage between the ages of 7-12 years?	○ No ○ Yes

The below table outlines the three levels of support required within the autism spectrum as described in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5).

Level

Social communication

Restricted, repetitive behaviors

Level 3 "Requiring very substantial support"

Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches

Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.

Level 2 "Requiring substantial support"

Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.

Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.

#### Level 1 "Requiring support"

Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.

Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching

If your child was diagnosed under the DSM-5, please indicate which support level is associated with their diagnosis.	<ul> <li>Level 1 - Requires support</li> <li>Level 2 - Requires substantial support</li> <li>Level 3 - Required very substantial support</li> <li>I am unsure</li> <li>I would prefer not to say</li> </ul>
If your child has not yet received a formal diagnosis or was not diagnosed as a child under the DSM-5, please indicate which level you feel would have best represented their support needs as a child.	<ul> <li>Level 1 - Requires support</li> <li>Level 2 - Requires substantial support</li> <li>Level 3 - Required very substantial support</li> <li>I am unsure</li> <li>I would prefer not to say</li> </ul>
Do you wish to provide details for another child on the autism spectrum?	○ No ○ Yes
How old is your child (years)	
How old is your child (months)	
Has your child received a formal diagnosis of autism (or a related disorder e.g., Asperger's, Pervasive Developmental Disorder)?	○ No ○ Yes
At what age was your child diagnosed (please round to the nearest year)?	
Did you access therapies and/or supports for your child at some stage between the ages of 0-6 years?	○ No ○ Yes
Did you access therapies and/or supports for your child at some stage between the ages of 7-12 years?	○ No ○ Yes

The below table outlines the three levels of support required within the autism spectrum as described in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5).

Level

Social communication

Restricted, repetitive behaviors

Level 3 "Requiring very substantial support"

Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches

Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.

Level 2 "Requiring substantial support"

Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special freeses, and more than a markedly odd nonverbal communication.

Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.

#### Level 1 "Requiring support"

Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.

Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

If your child was diagnosed under the DSM-5, please indicate which support level is associated with their diagnosis.	<ul> <li>Level 1 - Requires support</li> <li>Level 2 - Requires substantial support</li> <li>Level 3 - Required very substantial support</li> <li>I am unsure</li> <li>I would prefer not to say</li> </ul>
If your child has not yet received a formal diagnosis or was not diagnosed as a child under the DSM-5, please indicate which level you feel would have best represented their support needs as a child.	<ul> <li>Level 1 - Requires support</li> <li>Level 2 - Requires substantial support</li> <li>Level 3 - Required very substantial support</li> <li>I am unsure</li> <li>I would prefer not to say</li> </ul>

A note from the research team

Thank you very much for providing answers to these questions.

Following the completion of the focus groups, the next step for the research team will be to analyse all of the information provided. The Guideline Development Group will then formulate recommendations.

If you have not already done so, please register with the Autism CRC to receive updates about the guideline. You can do so here.

Before we finish, we want to take a moment to acknowledge, and thank you for the time you are committing to participate in these focus groups.

We also acknowledge that we are asking you to share insights during focus groups from your own life, your experience, and your expertise as an autistic person and/or a parent or caregiver of a child on the autism spectrum. It is likely that you will have been asked to do this many times before, and we warmly thank you for being willing to do so again here, to help make the guideline the best it can be. We simply could not do this piece of important work, without your insights. Thank you.

We look forward to sharing updates, and the guideline in due course, via the Autism CRC website.

Sincerely,

Rhylee, Kandice, Hannah, Sarah, David, and Andrew, on behalf of the Guideline Development Group.

National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia

 Appendix 8.2
 Focus Group – Presentation

### Supporting Children National Guideline Community Consultation

Focus Groups



### Acknowledgement of Country





#### Overview

- Housekeeping
- Introduction to guideline and focus groups
- Understanding and expectations

This focus group is being recorded so that we can transcribe and analyse the information the group provides.

The recording *will not* be used for any other purpose.

We *will not* use anyone's name or other identifying information when share the findings in the National Guideline.



## Housekeeping

- Introducing the facilitators
- Schedule
  - Introduction and house keeping (10 mins)
  - Focus questions (90 mins)
  - Summary and next steps (10 mins)
- Video/audio/chat options
- Tech Support
- Key ethical considerations (consent, privacy, seeking support)



## Introducing the Guideline

- 1. Why do we need a guideline?
- 2. How is it being developed?
- 3. How will my involvement today help?
- 4. What if I have other questions about the Guideline?



### Why do we need a Guideline?

- Therapies and supports during childhood can support children's early development, minimise disability, and maximise each child's strengths and opportunities.
- However, a wide variety are available, which differ according to:
  - Nature
  - How they are support to work
  - The goals they target
  - The places/settings in which they are delivered
  - The people who deliver them
  - Evidence for their effectiveness
  - And many other ways...



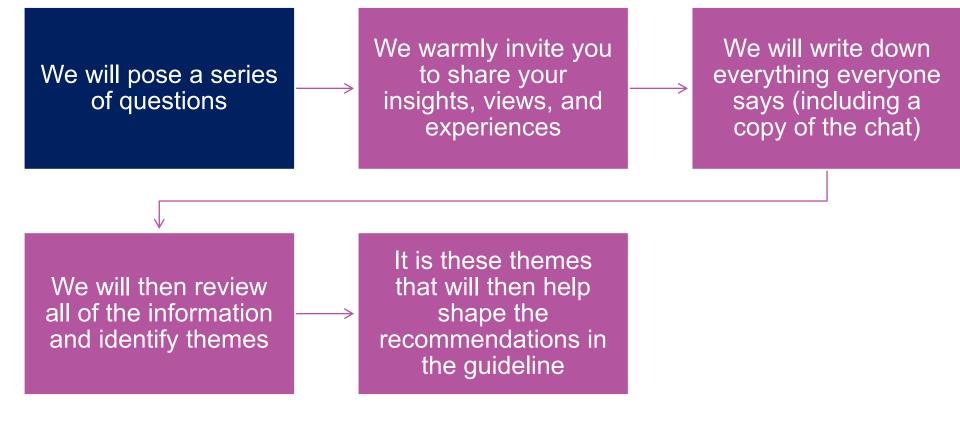
### Why do we need a Guideline

- Despite the complexity, there is not a yet a national guideline for the selection, delivery, and monitoring of therapies and supports for children on the autism spectrum and their families.
- The Autism CRC is addressing this need, and your involvement today will help shape the recommendations in the Guideline.

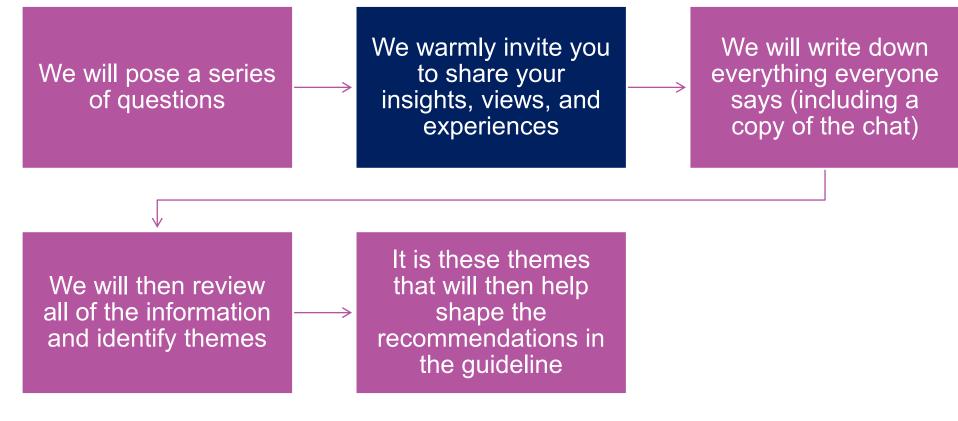


#### How is it being developed?

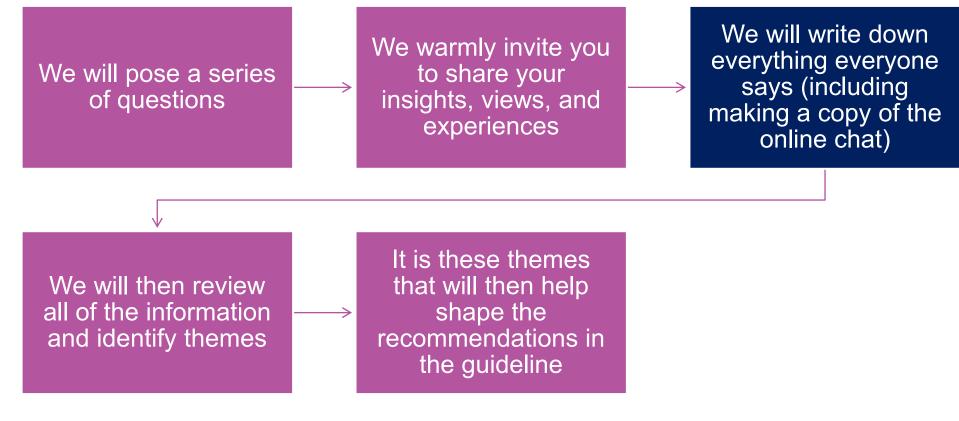




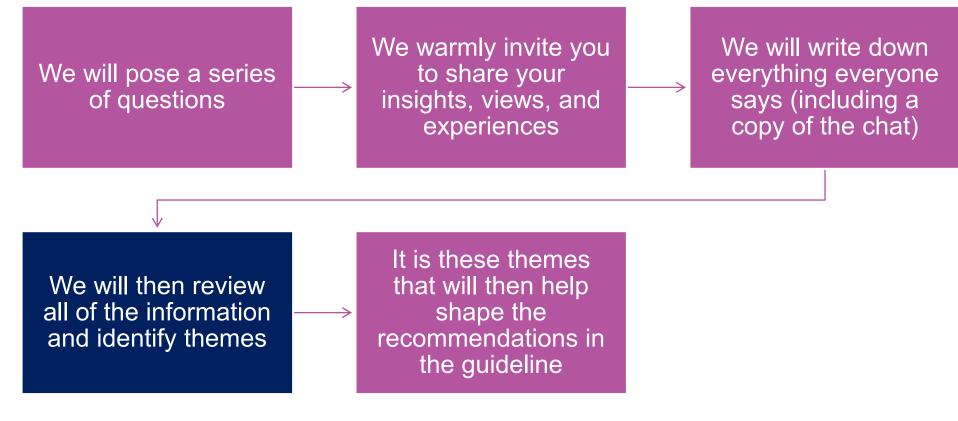


















#### What if I have questions about the Guideline?





Website: https://www.autismcrc.com.au /supporting-children Email: supportingchildren@autismcrc.c om.au



#### Understanding and Expectations







You have volunteered your time because you want to make a difference We are privileged to have people with diverse views and experiences joining

We want to ensure that everyone has the opportunity contribute and feels safe and supported



## A positive and productive focus group

- As facilitators we will ensure:
  - On topic
  - On time
  - Everyone has a chance to share
- As participants, we ask that you please:
  - Stay on topic
  - Keep your comments relatively brief, so that more people have a chance to talk/share
  - Help us create a safe and supportive space
  - Avoid naming specific people, practitioners, and service providers
  - Maintain the privacy of others during and following the group



### The questions we will ask

Understanding	Understanding the child, family, and their context?
Goal setting	Planning, selecting, and prioritising goals for children?
Selecting therapies and supports	Planning and selecting therapies and supports for children?
Delivering therapies and supports	Delivering therapies and supports for children?
Monitoring	Monitoring progress and outcomes of therapies and supports for children?
Quality and Safeguards	Ensuring the safety and wellbeing of children on the autism spectrum and their families?





- **Parent(s):** Refers to any individuals with parenting or caregiving responsibilities for a child (e.g., guardians, kinship, foster carers).
- Family: Refers to the child's parents/caregivers, siblings and any extended family (e.g., grandparents, aunts, uncles, cousins) involved in the child's care.
- Therapies: Refers to services that focus on supporting children to acquire or enhance functional skills aimed at ensuring their learning, participation, and quality of life in the community.
- Support: Refers to services that focus on adjustments, modifications, and enhancements to the environment aimed at ensuring their learning, participation, and quality of life in the community.
- **Practitioners:** People who are paid to provide services to children and families.





# What are the most important considerations for practitioners trying to **understand the child, family, and their context**?





From your perspective, what are the most important considerations for practitioners when **planning**, **selecting**, **and prioritising goals** for children?





From your perspective, what are the most important considerations for practitioners when **planning and selecting therapies and supports** for children?





From your perspective, what are the most important considerations for practitioners when **delivering therapies and supports** for children?





From your perspective, what are the most important considerations for practitioners when **monitoring progress and outcomes** of therapies and supports for children?





From your perspective, what are the most important considerations for practitioners to ensure the **safety and wellbeing** of children on the autism spectrum and their families?



## Summary and Next Steps

- Reflections on discussion
- Next steps
- Acknolwedgements





autismcrc.com.au

National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia

Appendix 9.1Delphi Survey – Round 1

#### Supporting Children Guideline - Delphi Survey (Round $1^{P_{age 1}}$

In this survey, we are interested in your views, as a practitioner, about the planning and delivery of therapies and supports aimed at enhancing the learning, participation, and quality of life of children on the autism spectrum (aged 0-12 years) and their families in community settings.

Part 1 of the survey will ask about your professional affiliation, your experience and practice working with children on the autism spectrum and their families, and the types and location of your current service setting(s). Part 2 of the survey (which contains nine sections) asks you to rate your agreement with various statements on what you consider to be best practice when supporting children on the autism spectrum and their families. You will also have the opportunity within each section of Part 2 to provide additional (optional) comments.

PLEASE NOTE: The survey will close at 11:59pm on March 20th (AEST)

For the purpose of this survey:

'Parent(s)' refers to any individuals with parenting or caregiving responsibilities for a child (e.g., guardians, kinship, foster carers)'Family' refers to the child's parents/caregivers, siblings and any extended family (e.g., grandparents, aunts, uncles, cousins) involved in the child's care'Therapies' refers to services that focus on supporting the children to acquire or enhance functional skills aimed at ensuring their learning, participation, and quality of life in the community'Support' refers to services that focus on adjustments, modifications, and enhancements to the environment aimed at ensuring their learning, participation, and quality of life in the community





#### Supporting Children National Guideline

Please provide your first name:

Please provide your last name:

Please provide the most appropriate email address to follow-up with your Round 2 survey:

You have been invited to participate in this survey through your links with a professional organisation.



Which professional organisation invited you to participate in this survey?	<ul> <li>Australian Psychological Society</li> <li>Australian Physiotherapy Association</li> <li>Neurodevelopmental and Behavioural Paediatrics Society of Australasia</li> <li>Occupational Therapy Australia</li> <li>Speech Pathology Australia</li> </ul>
What is your profession (select all that apply)?	<ul> <li>General Practitioner</li> <li>Occupational Therapist</li> <li>Paediatrician</li> <li>Physiotherapist</li> <li>Psychiatrist</li> <li>Psychologist</li> <li>Speech Pathologist</li> <li>None of the above</li> </ul>
How are you currently involved in clinical practice for children on the autism spectrum? (select all that apply)	<ul> <li>I provide therapies and supports to children and families on the autism spectrum</li> <li>I supervise others who provide therapies and supports to children on the autism spectrum</li> <li>I conduct research into clinical practice for children on the autism spectrum</li> <li>Other</li> </ul>
As you selected 'other', please specify how you are currently involved in clinical practice for children on the autism spectrum.	
How many years experience do you have working in clinical practice with children on the autism spectrum?	
In 2021, approximately what proportion of your caseload were children on the autism spectrum?	<ul> <li>○ 0-25%</li> <li>○ 26-50%</li> <li>○ 51-75%</li> <li>○ 76-100%</li> </ul>
In 2021, what age groups of individuals on the autism spectrum did you provide therapies and supports to (select all that apply)?	<ul> <li>0-3 years</li> <li>4-6 years</li> <li>7-9 years</li> <li>10-12 years</li> <li>13-15 years</li> <li>16-18 years</li> <li>19 years and older</li> <li>I did not provide any therapies or supports to individuals on the autism spectrum in 2021</li> </ul>
Across your career to date, what age groups of individuals on the autism spectrum have you predominately provided therapies and supports to (select all that apply)?	<ul> <li>0-3 years</li> <li>4-6 years</li> <li>7-9 years</li> <li>10-12 years</li> <li>13-15 years</li> <li>16-18 years</li> <li>19 years and older</li> </ul>
In 2021, did you provide therapies and supports for children on the autism spectrum and their families who identify as being Aboriginal and/or Torres Strait Islander peoples?	○ Yes ○ No



In 2021, did you provide therapies and supports for children on the autism spectrum and their families who were not born in Australia?	○ Yes ○ No
In 2021, did you provide therapies and supports for children on the autism spectrum and their families who did not speak English?	○ Yes ○ No
In which state/territory do you currently practice? (select all that apply)	<ul> <li>Australian Capital Territory</li> <li>New South Wales</li> <li>Northern Territory</li> <li>Queensland</li> <li>South Australia</li> <li>Tasmania</li> <li>Victoria</li> <li>Western Australia</li> </ul>
In which areas do you conduct your work with children on the autism spectrum and their families?	<ul> <li>Major cities</li> <li>Regional and remote areas</li> </ul>
In which of the following service settings do you currently provide therapies and supports for children on the autism spectrum and their families (select all that apply)?	<ul> <li>Private, including non-government organisations</li> <li>Government organisation</li> </ul>
In which of the following settings do you currently provide therapies and supports for children on the autism spectrum and their families? (select all that apply)	<ul> <li>Child's home</li> <li>Hospital (inpatient/outpatient)</li> <li>Community clinic (including private practice)</li> <li>University clinic (includes providing services as part of student training and research)</li> <li>Early childhood education centre (prior to formal schooling, and commonly referred to as day care/childcare)</li> <li>Early childhood education centre in a specialised setting (prior to formal schooling and catering only to children with additional learning needs)</li> <li>Mainstream school</li> <li>Support class/unit within a mainstream school</li> <li>School specifically for children with additional learning needs, that includes children on the autism spectrum</li> <li>Other</li> </ul>
Please specify the 'other' type(s) of settings that you currently provide therapies and supports for children on the autism spectrum.	
Please indicate how children on the autism spectrum and their families access your service (select all that apply)	<ul> <li>Face to face delivery</li> <li>Telepractice delivery</li> </ul>



#### SURVEY PART 2

There are nine sections to this survey.

First, we will ask you to reflect on overarching principles that should be adhered to at all stages of the clinical process when working with children on the autism spectrum and their families (Section 1).

We will then ask (i) who should be involved in the provision of therapies and supports (Section 2), and (ii) what sources of information should be considered when making decisions about therapies and supports (Section 3).

We will next ask you to offer your views across various stages of working with children on the autism spectrum and their families, which we have divided into (a) understanding the child, family and their context (Section 4), (b) goal setting (Section 5), (c) selecting therapies and supports (Section 6), (d) delivering therapies and supports (Section 7), and (e) monitoring outcomes (Section 8).

At the end, we will also ask you to offer your views about how quality and safety can be assured (Section 9).

PLEASE NOTE: the survey takes approximately 45-60 minutes to complete. At any stage, you can select the 'Save and Return Later' icon if you would prefer to complete the survey over multiple sittings.

The data you enter will be automatically saved on the Griffith University research server (via REDCap), so do not be concerned about it being lost. If you have any difficulties re-commencing the survey, you can contact the research team for help (k.varcin@griffith.edu.au).

The survey will close at 11:59pm on March 20th (AEST)



#### Section 1 of 9.

#### **Principles**

1.1 Please indicate the extent to which you agree each of the following are principles that are important to all aspects of providing therapies and supports to children on the autism spectrum.

\*While some principles refer to both children and their families to acknowledge the family unit, we do so noting that the individual preferences, needs, and rights of each person are always to be considered and maintained.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1.1a Holistic: The provision of therapies and supports should involve consideration of an individual's life history, culture, strengths and challenges, goals and preferences, and environmental factors that act as facilitators or barriers to learning, participation, and quality of life.	0	0	0	0	0
1.1b Child and family-centred: The child and their family members should be considered equal partners with practitioners in the therapy process.	0	0	0	0	0
1.1c Supported: The child and their family should be supported to include people they feel are relevant in the therapy process, including for advocacy and support.	0	0	0	0	0
1.1d Lifespan perspective: Clinical decision-making regarding the provision of therapies and supports should account for the current stage of life of the individual, as well as appropriate planning for both the short and longer term.	0	0	0	0	0

1.1e



	Developmental perspective: Clinical decision-making regarding the provision of therapies and supports should account for, and be responsive to, the individual, family and social changes that occur through childhood.	0	0	0	0	0
1.1f	Empirically supported: Therapies and supports should be underpinned by the best available published, peer-reviewed scientific evidence demonstrating their effectiveness and safety.	0	0	0	0	0
1.1g	Evidence-based practice approach: Clinical decision-making regarding the provision of therapies and supports should draw on, and integrate, research and clinical evidence alongside the preferences and values of the child and their family.	0	0	0	0	0
1.1h	Ethical practice: The provision of therapies and supports should be underpinned by an ethical framework that follows the principles of beneficence (i.e., to act for the benefit of others), non-maleficence (i.e., do no harm), autonomy and fairness.	0	0	0	0	0
1.1i	Culturally aware and responsive: The values, knowledge, preferences and cultural perspectives of the child and family should be sought, respected, and evident in the provision of therapies and supports.	0	0	0	0	0

1.1j

07/08/2022 2:33pm



	Equity: All children and families, regardless of age, gender, cultural background, socioeconomic status or geographical location should be able to access timely, safe, desirable and effective therapies and supports.	0	0	0	0	0
1.1k	Strengths-focused: Therapies and supports should focus on understanding, embracing and developing the strengths of an individual and their family.	0	0	0	0	0
1.11	Coordinated: A coordinated approach to the provision of therapies and supports for the child and family across practitioners, organisations, and agencies should be taken.	0	0	0	0	0
1.1m	Personalised: Therapies and supports should be tailored to the unique strengths, needs, and preferences of each child and family.	0	0	0	0	0
1.1n	Accessible: The process of planning, delivering, and monitoring therapies and supports, including interactions and documentation, should be accessible.	0	0	0	0	0
1.10	Informed consent (parents): Informed parental consent should be obtained for the provision of therapies and supports.	0	0	0	0	0
1.1p	Assent (children): Children's assent (expression of approval) should be obtained, wherever possible, for the provision of therapies and supports.	0	0	0	0	0

1.1q



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Qualified practitioners: People involved in the provision of therapies and supports should have relevant qualifications and professional regulation, and only engage in goal setting and the delivery of therapies and supports that are within their scope of practice.	0	0	0	0	0
1.2. Are there other overarching princip relevant to the provision of therapies a for children on the autism spectrum?		⊖ Yes ⊖ No			
To help us understand your suggestion the name of the principle that has not b					
Principle name:					
Please explain why this principle is imp have done in the table above.	ortant, as we				
Principle explanation:					-
Are there other overarching principles t relevant to the provision of therapies a for children on the autism spectrum?		⊖ Yes ⊖ No			
To help us understand your suggestion the name of the principle that has not b					
Principle name:					
Please explain why this principle is imp have done in the table above.	ortant, as we				
Principle explanation:					-
Are there other overarching principles to relevant to the provision of therapies a for children on the autism spectrum?		⊖ Yes ⊖ No			
To help us understand your suggestion the name of the principle that has not b					
Principle name:					
Please explain why this principle is imp have done in the table above.	ortant, as we				
Principle explanation:					-



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Are there other overarching principles that are relevant to the provision of therapies and supports for children on the autism spectrum?	○ Yes ○ No
To help us understand your suggestion, please provide the name of the principle that has not been covered.	
Principle name:	
Please explain why this principle is important, as we have done in the table above.	
Principle explanation:	
Are there other overarching principles that are relevant to the provision of therapies and supports for children on the autism spectrum?	○ Yes ○ No
To help us understand your suggestion, please provide the name of the principle that has not been covered.	
Principle name:	
Please explain why this principle is important, as we have done in the table above.	
Principle explanation:	
Section 2 of 9.	

Who should be involved in the provision of therapies and supports?

We are interested to know who you think should be involved in the provision of therapies and supports for children on the autism spectrum. This includes when:

Working to understand the child, family, and context Setting goals Selecting therapies and supports Delivering therapies and supports Monitoring outcomes Below, we have indicated a range of people who might be involved in the provision of therapies and supports.

Please tell us the extent to which you agree with these statements.

Page 9



2.1. The child, family, and family-like people (i.e., family friends, peers) should be involved in:									
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree				
2.1a Working to understand the child, family, and their context	0	0	0	$\bigcirc$	0				
2.1b Setting goals	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$				
2.1c Selecting therapies and supports	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$				
2.1d Delivering therapies and	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$				
2.1e Monitoring outcomes	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$				



### 2.2. People who provide formal support for the child's health and development (e.g., educators, medical and allied health practitioners) should be involved in:

	•	•			
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
2.2a Working to understand th family, and their context	he child, $\bigcirc$	0	$\bigcirc$	0	$\bigcirc$
2.2b Setting goals	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
2.2c Selecting therapies and s	upports O	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
2.2d Delivering therapies and	0	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
2.2e Monitoring outcomes	0	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$



2.3. People who can contribute to supporting the child's participation in community activities (e.g., sports coaches, art teachers, community members the child interacts with regularly including retail environments, community groups, and cultural activities) should be involved in:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
2.3a Working to understand the child, family, and their context	0	0	0	$\bigcirc$	0
2.3b Setting goals	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
2.3c Selecting therapies and supports	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
2.3d Delivering therapies and	0	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
2.3e Monitoring outcomes	$\bigcirc$	0	$\bigcirc$	$\bigcirc$	0



REDCap

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
2.4a Working to understand the child, family, and their context	0	0	0	$\bigcirc$	0
2.4b Setting goals	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
2.4c Selecting therapies and supports	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
2.4d Delivering therapies and	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
2.4e Monitoring outcomes	0	$\bigcirc$	$\bigcirc$	0	$\bigcirc$
2.5. Are there any other people or a should be involved in service delive		0	Yes No		
Please indicate (i) any other people who/that should be involved in serv in what aspect(s) of service delivery involved in (e.g., assessment, goal and delivering therapies/supports, r (iii) to what extent they should be in	ice delivery, (ii)				

### Section 3 of 9.

Sources of information

We are interested to know what factors are important for practitioners to consider when making recommendations for goals, and the selection and delivery of therapies and supports when working with children on the autism spectrum and their families.



3.1 Please indicate the extent to which you believe the following factors are important:							
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree		
3.1a A theoretical rationale for why the chosen goal/therapy/support is likely to lead to an increase in the child's learning and participation.	0	0	0	0	0		
3.1b Research evidence (from published, peer-reviewed research) that the goal/therapy/support is likely to lead to an increase in the child's learning and participation.	0	0	0	0	0		
3.1c Clinical evidence gathered through practice that the goal/therapy/support is likely to lead to an increase in the child's learning and participation, including evidence drawn from the experiences/outcomes of other children and families the practitioner has supported.	0	0	0	0	0		
3.1d Perspectives expressed by autistic people regarding the goal/therapy/support.	0	0	0	0	0		
3.1e Information about the child, family, and their context that is relevant to the goal/therapy/support.	0	0	0	0	0		
3.1f Consideration of whether the child/family have the time required for the goal/therapy/support	0	0	0	0	0		
3.1g Consideration of whether the child/family have the social support required for the goal/therapy/support (e.g., family members willing to assist).	0	0	0	0	0		
3.1h Consideration of whether the child/family have the financial resources required for the goal/therapy/support.	0	0	0	0	0		

3.1i



	Consideration of whether the child/family have the emotional support required for the goal/therapy/support.	0	0	0	0	0
3.1j	Consideration of whether the goal/therapy/support is consistent with the child/family's cultural background.	0	0	0	0	0
3.1	Consideration of whether the goal/therapy/support is consistent with the parent/s views on child-rearing.	0	0	0	0	0
3.11	Consideration of whether the goal/therapy/support is consistent with the parent/s views on child development.	0	0	0	0	0
3.1r	nConsideration of whether the goal/therapy/support is consistent with the parent/s views on disability (and the need to focus on the child versus the environment).	0	0	0	0	0
3.1r	Consideration of whether the child supports the goal/therapy/support (to the extent possible).	0	0	0	0	0
3.10	Consideration of whether the parent/s supports the goal/therapy/support.	0	0	0	0	0
3.1µ	Consideration of the potential benefits associated with the goal/therapy/support.	0	0	0	0	0
3.10	Consideration of the potential risks associated with the goal/therapy/support.	0	0	0	0	0
3.1r	Consideration of the alternative options to this goal/therapy/support.	0	0	0	0	0
3.19	Consideration of how this goal/therapy/support may enhance progress towards other goals.	0	0	0	0	0

3.1t





Consideration of how this goal/therapy/support may impede progress towards other goals.	0	0		0	0	0
3.1u Consideration of the relevance of this goal/therapy/support currently for the child and	0	0		0	0	0
family. 3.1v Consideration of the relevance of this goal/therapy/support in the future for the child and family.	0	0		0	0	0
3.1w Are there any other factors that regarding goal setting and therapy/s and delivery, should be based on?			⊖ Yes ⊖ No			
Please describe any other factors th regarding goal setting and therapy/s and delivery should be based on.						



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#### Understanding the child, family and their context

In clinical practice, assessment involves collecting information that helps the practitioner understand the child, their family, and the broader context. Assessment may involve a range of people (e.g., the child, family, other practitioners), include the use of a range of tools (e.g., observation, interviewing, functional assessment, dynamic assessments), and draw on both current and historical information.

	Not at all important	Slightly important	Moderately important	Very important	Extremely important
4.1 How important do you think it is to understand the child, their family, and their context when making decisions about therapies and supports for children on the autism spectrum?	0	0	0	0	0



# 4.2 Please indicate the extent to which you agree that the planning of therapies and supports should be informed by assessment of the following aspects of children's health, development, and wellbeing:

and wellbeing:					
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
4.2a The child's health (i.e., physical health, mental health, and health history).	0	0	0	0	0
4.2b The child's developmental skills (i.e., gross and fine motor, social, emotional, cognitive, communication, and academic skills).	0	0	0	0	0
4.2c The child's diagnostic characteristics (i.e., social communication skills, repetitive behaviours, focused/intense interests, and sensory behaviours).	0	0	0	0	0
4.2d The child's activities and participation in home, educational, and community settings (this includes enablers and barriers to participation).	0	0	0	0	0
4.2e The child's behaviour(s) of concern (including, (i) behaviours arising from the interaction of the person and their environment that risk the physical safety of the individual and/or others and (ii) behaviours that limit or deny participation in life activities).	0	0	0	0	0
4.2f The child's perception of their quality of life (to the extent this is possible to obtain).	0	0	0	0	0
4.2g The child's activity-related strengths and preferences (i.e., activities that bring the child joy and/or that they have expertise in).	0	0	0	0	0
4.2h The child's preferences for therapies/supports (to the extent this is possible to obtain).	0	0	0	0	0

4.2i



The child's expectations for the outcomes of therapy/support (to the extent this is possible to obtain).	0	0	0	0	0
4.2j Are there any other child-related should inform the planning of therapi	U U	Yes No			
Please describe any other child-relate should be assessed to inform the pla and supports.					



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#### 4.3 Please indicate the extent to which you agree that the planning of therapies and supports should be informed by assessment of the following aspects of the family: Strongly agree Stronaly Disagree Neutral Aaree disagree Ο 4.3a The family's physical and mental $\bigcirc$ $\bigcirc$ $\bigcirc$ $\bigcirc$ health (i.e., the presence of any conditions that may impact upon their capacity to participate, or need to be considered, in the provision of therapies/supports for the child). $\bigcirc$ $\bigcirc$ $\bigcirc$ $\bigcirc$ $\bigcirc$ 4.3b The family's social-emotional resources and supports (i.e., resilience factors and the capacity to deal with stressful situations in life, along with social support via family, friends, and support groups). $\bigcirc$ $\bigcirc$ $\bigcirc$ $\bigcirc$ $\bigcirc$ 4.3c The family's financial resources and supports (i.e., funding to pay for therapies and supports, capacity to purchase unfunded therapies and supports, and capacity to take time away from paid work to access therapies and supports). $\bigcirc$ $\bigcirc$ $\bigcirc$ $\bigcirc$ Ο 4.3d The family's activities (i.e., work, social, cultural, sport and recreational, and educational activities). $\bigcirc$ $\bigcirc$ $\bigcirc$ $\bigcirc$ $\bigcirc$ 4.3e The family's views, perspectives, and preferences (i.e., views about their child's learning, participation, and quality of life now and in the future, views on disability, the relevance of therapies/supports for their child, cultural perspectives on therapies/supports, preferences for therapies/supports, and expectations for outcomes).

4.3f



The family's dynamics (i.e., the nature and strength of relationships between family members, the nature and distribution of roles and responsibilities, and the positive and challenging impacts associated with the child's disability).	0	0	0	0	0
4.3g Are there any other family-rela should inform the planning of thera		○ Yes ○ No			

Please describe any other family-related factors that should be assessed to inform the planning of therapies

and supports.

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## 4.4 Please indicate the extent to which you agree that the planning of therapies and supports should be informed by assessment of the following aspects of a family's PREVIOUS

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
4.4a The nature of any services previously accessed, including goals and types of services (e.g., allied health, mainstream supports).	0	0	0	0	0
4.4b The child and family's experience of previously accessed services, including their satisfaction with the service(s).	0	0	0	0	0
4.4c The child and family's outcomes of accessing previous services, including the progress made towards goals.	0	0	0	0	0



## 4.5 Please indicate the extent to which you agree that the planning of therapies and supports should be informed by assessment of the following aspects of a family's CURRENT

engagement with other services:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
4.5a The nature of any services and funding/support (e.g., NDIS plan, education department) currently accessed, including goals and types of services (e.g., allied health, mainstream supports)	0	0	0	0	0
4.5b The child and family's experience of currently accessed services, including their satisfaction with the service(s).	0	0	0	0	0
4.5c The child and family's outcomes of accessing current services, including the progress made towards goals.	0	0	0	0	0
4.5d Any arrangements that are in place to support the coordination of services and supports accessed by the child and family (e.g., nominated case coordinator, NDIS support coordination)	0	0	0	0	0
4.5e Family preferences for future arrangements to support the coordination of services and supports accessed by the child and family	0	0	0	0	0
4.5f Are there any other factors re family's engagement with services the planning of therapies and supp		) Yes ) No			
Please describe any other factors family's engagement with services the planning of therapies and supp	s that should inform	_			
[OPTIONAL] 4.6 Please provide any you would like to help explain you you believe is relevant to consider child, their family and their contex provision of therapies/supports.	r responses, or that in understanding a				



#### Section 5 of 9.

#### **Goal-setting**

### In this section we ask you to rate your agreement with statements about goal setting,

including what the goals should target, and how decisions about goal setting should be made.								
	Not at all important	Slightly important	Moderately important	Very important	Extremely important			
5.1 How important do you think it is to select appropriate goals for therapy when working with children on the autism spectrum and their families?	0	0	0	0	0			



### 5.2 When relevant, goals for children on the autism spectrum and their families should consider focusing on the child's:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
5.2a Mental functions (e.g., executive functioning)	0	0	0	0	0
5.2b Physical functions (e.g., articulation of speech sounds, fine motor skills)	0	0	0	0	0



# 5.3 When relevant, goals for children on the autism spectrum and their families should consider focusing on the following skills/behaviours related to the child's activities and participation:

participation					
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
5.3a The acquisition of skills (e.g., social, communication, play, motor).	0	0	0	0	0
5.3b The generalised use of skills in daily activities with others (e.g., social skills used to help form relationships, communication skills used to have a conversation, play skills used to engage in play with peers).	0	0	0	0	0
5.3c The reduction of behaviours of concern (e.g., self-injurious behaviours).	0	0	0	0	0
5.3d Learning and applying knowledge (e.g., learning to count, learning to read).	0	0	0	0	0
5.3e Carrying out daily routines (relative to age expectations).	0	$\bigcirc$	0	0	0
5.3f Supporting interpersonal interactions and relationships.	0	0	0	0	0
5.3g Participation in community, social, and civic life (e.g., recreation, leisure, religion, spirituality).	0	0	0	0	0



5.4 When relevant, goals for children on the autism spectrum and their families should									
consider focusing on the fol	consider focusing on the following aspects of the child's environment:								
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree				
5.4a Accessibility in the physical environment (e.g., sensory-safe spaces).	0	0	0	0	0				
5.4b Accessibility in the social environment (e.g., changing attitudes and increasing knowledge and skills of others).	0	0	0	0	0				
5.4c Enhancement of services, systems, and policies (e.g., to improve coordination of services, changing policies that create barriers to participation).	0	0	0	0	0				
5.5 Are there any other domains the focused on for children on the autist their families?		Yes No							
Please describe any other domains that goals should be focused on for children on the autism spectrum and their families.									



5.6 In working with children and families to set goals, practitioners should:							
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree		
5.6a Ensure goals are specific	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$		
5.6b Ensure goals are measureable	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$		
5.6c Ensure goals are achievable	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$		
5.6d Ensure goals are relevant to the child, family and their context	0	0	$\bigcirc$	0	0		
5.6e Ensure goals are understood by the family and relevant stakeholders	0	0	0	0	0		
5.6f Ensure goals are documented	$\bigcirc$	0	$\bigcirc$	0	0		
5.6g Ensure goals have a clear timeframe	0	0	0	0	0		



	Strongly disagree	Disagree	Neutral	Agree	Strongly agre
a Short-term i.e., for goal attainment over 12 months-2 years.	0	0	0	0	0
o Medium term i.e., for goal attainment over 2-3 years.	0	0	0	0	0
Long-term i.e., for goal attainment over 3+ years.	0	0	0	0	0
5.7d Are there other timeframe goals should cover?	es that therapy/supp		) Yes ) No		
Please describe any other time therapy/support goals should o					
[OPTIONAL] 5.8 Please provide you would like to help explain you believe is relevant to cons and selection of goals.	your responses, or t	hat			
Section 6 of 9.					
Selecting therapies and suppo	orts				
	Not at all important	Slightly important	Moderately important	Very important	Extremely important
6.1 How important do you thin it is to select appropriate therapies and supports when working with children on the autism spectrum and their families?	Not at all important			Very important	•
6.1 How important do you thin it is to select appropriate therapies and supports when working with children on the autism spectrum and their	Not at all important		important	Very important	important
6.1 How important do you thin it is to select appropriate therapies and supports when working with children on the autism spectrum and their	Not at all important k O Strongly disagree	important	important	0	important

Delivering therapies and supports

The following items focus on decisions about therapy/support delivery (e.g., settings, amount, timing).



					Page 30
	Not at all important	Slightly important	Moderately important	Very important	Extremely important
7.1 How important do you think it is to deliver therapies and supports in ways that are appropriate for children on the autism spectrum and their families?	0	0	0	0	0



#### In what settings should therapies/supports be delivered?

### 7.2 Where relevant, the following settings may be appropriate for the delivery of therapies/supports:

		Strongly disagree	Disagree	Neutral	Agree	Strongly agree
7.2a	Clinic	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
7.2b	The child's home	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
7.2c	Educational settings (including school and early child education settings/day care)	0	0	0	0	0
7.2d	Cultural settings (e.g., places of worship)	0	0	0	0	0
7.2e	Social settings (e.g., other people's homes, community spaces)	0	0	0	0	0
7.2f	Recreational settings (e.g., sports ovals, music/art/drama studios)	0	0	0	0	0
		2g Are there any other settings that may be propriate for the delivery of therapies and pports?		Yes No		
	Please describe any other settings appropriate for the delivery of ther supports.		_			

#### In what amount(s) should therapies/supports be delivered?

In this section we will ask you for your views regarding the amount of therapy/support children on the autism spectrum should receive.

First, we want to acknowledge that children's learning and participation may be supported through a combination of mainstream services (e.g., health and education), practitioner services (e.g., allied health therapies), and upskilling parents and other family members to deliver therapies and supports. We provide an opportunity to comment on the relevance of mainstream services and parent-mediated therapies and supports in other sections.

Here, we want to focus on your views about the amount of practitioner-delivered support children and families should receive.



7.3 When relevant, children	Strongly	Disagree	Neutral	Agree	Strongly agree
	disagree	-		-	
7.3a Child-directed services (i.e., a practitioner working primarily with the child as 1:1 or in a small group)	0	0	0	0	0
7.3b Parent-directed services (i.e., a practitioner working primarily to upskill the parent(s) to support the child's learning and participation)	0	0	0	0	0
7.3c Community-directed services (i.e., a practitioner working primarily to upskill other members of the community [e.g., educators] to support the child's learning and participation)	0	0	0	0	0



	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
.4a Services provided to children should be predominately child-directed (i.e., a practitioner working primarily with the child as 1:1 or in a small group)	0	0	0	0	0
.4b Services provided to children should be predominately parent-directed (i.e., a practitioner working primarily to upskill the parent/s)	0	0	0	0	0
.4c Services provided to children should be predominately community-directed (i.e., a practitioner working primarily to upskill other members of the community [e.g., educators])	0	0	0	0	0
.4d The proportion of child-directed, parent-directed, and community-directed services should be personalised	0	0	0	0	0



7.5 Please rate your agreeme	ent with the	following stat	ements:		
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
7.5a There is a minimum number of practitioner-delivered therapy/support hours that all children on the autism spectrum should receive	0	0	0	0	0
7.5b There is a maximum number of practitioner-delivered therapy/support hours that all children on the autism spectrum should receive	0	0	0	0	0
7.5c All children on the autism spectrum should receive a set number of hours per week of practitioner-delivered therapy/support services	0	0	0	0	0
7.5d The amount of therapy/support hours should be based on individual factors related to the child and family, including the child's functional difficulties, the therapy goals, and the broader family needs.	0	0	0	0	0
7.5e The number of hours of practitioner-delivered therapy/support a child receives should be personalised	0	0	0	0	0
As you agreed that there should be practitioner-delivered therapy/supp children, please indicate the minimu per week you think children on the should receive.	ort hours for um number of l	nours			
As you agreed that there should be practitioner-delivered therapy/supp children, please indicate the maxim per week you think children on the should receive.	ort hours for um number of	hours			
As you agreed that all children on the should receive a set number of hou practitioner-delivered therapy/supp please (i) indicate the number of how would recommend, and (ii) provide	rs per week of ort services, ours per week y	ou —			
Please provide your reasoning as to that all children on the autism spec receive a set number of hours per v practitioner-delivered therapy/supp	trum should veek of	ree —			



Please provide your reasoning as to why you agree that the amount of therapy/support hours should be based on individual factors related to the child and family.

Please provide your reasonining as to why you disagree that the amount of therapy/support hours should be based on individual factors related to the child and family.



disagree	Strongly agree
apies/supports should be O O O O e available as soon as a port need is identified	0

Section 8 of 9.

Monitoring

In this section we seek your views on how progress towards goals and the broader impacts of therapies and supports should be monitored, including who should be consulted; what sources of information should be considered; and how, and how often, the findings should be shared with child, family, and key stakeholders.

	Not at all important	Slightly important	Moderately important	Very important	Extremely important
8.1 How important do you think it is to monitor the delivery of therapies and supports for children on the autism spectrum and their families? This includes ensuring the goals, therapies, and supports continue to be appropriate.	0	0	0	0	0



#### 8.2 When relevant, progress and the outcomes of therapy/support provision should include monitoring of the following aspects of therapy fidelity/support delivery: Strongly agree Strongly Disagree Neutral Agree disagree $\bigcirc$ $\bigcirc$ Ο $\bigcirc$ 8.2a Type: the extent to which the $\bigcirc$ planned type of therapy/support was delivered Ο $\bigcirc$ $\bigcirc$ Ο $\bigcirc$ 8.2b People: the extent to which the people who were intended to contribute to progress towards the goal, contributed $\bigcirc$ Ο Ο Ο Ο 8.2c Settings: the extent to which the settings in which the goal was to be targeted were included 8.2d Amount: the extent to which the $\bigcirc$ Ο Ο Ο Ο intended amount of therapy/support was delivered



8.3 When relevant, progress and the outcomes of therapy/support provision should include monitoring of children's progress towards therapy/support goals across the following domains:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
8.3a Amount of progress made towards the goal	0	0	0	$\bigcirc$	0
8.3b The child's satisfaction with progress towards the goal (to the extent possible)	0	0	0	0	0
8.3c Parent's satisfaction with the child's progress towards the goal	0	0	0	0	0



REDCap

### 8.4 When relevant, progress and the outcomes of therapy/support provision should include monitoring of:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
8.4a Changes in the child's skills	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
8.4b Changes in the child's learning and participation	0	0	$\bigcirc$	0	0
8.4c Changes in the child's wellbeing	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
8.4d Changes in the family's	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
8.4e Changes in the environment that affect learning and participation	0	0	0	0	0



### 8.5 When relevant, progress and the outcomes of therapy/support provision should include monitoring of:

3					
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
8.5a Maintenance of change over the short-term (i.e., 12 months-2 years)	0	0	0	$\bigcirc$	0
8.5b Maintenance of change over the medium term (i.e., 2-3 years)	0	0	0	0	0
8.5c Maintenance of change over the long-term (i.e., 3+ years)	0	0	0	0	0



### 8.6 When relevant, progress and the outcomes of therapy/support provision should include monitoring of:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
8.6a Generalisation of change to interactions with other people	0	0	0	$\bigcirc$	0
8.6b Generalisation of change to other activities	0	0	0	$\bigcirc$	0
8.6c Generalisation of change to other settings	0	0	0	0	0



REDCap

### 8.7 When relevant, progress and the outcomes of therapy/support provision should include monitoring of:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
8.7a Costs for children (e.g., time, fatigue, not pursuing alternative goal or service option)	0	0	0	0	0
8.7b Costs for parents (e.g., time, financial)	0	0	0	0	0
8.7c Benefits for children 8.7d Benefits for family members	0 0	0 0	0 0	0 0	0 0



8.8 When relevant, progress and the outcomes of therapy/support provision should include monitoring of:						
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	
8.8a Positive unplanned outcomes that have arisen from the delivery of therapies/supports	0	0	0	0	0	
8.8b Adverse effects that have arisen from the delivery of therapies/supports	0	0	0	0	0	



8.9 The following assessme	nt/evaluation	tools and sou	rces of inform	ation should	d be				
considered when monitoring therapy/support progress and outcomes: OBSERVATIONS									
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree				
8.9a Observations of the child's progress towards goals during the delivery of therapy/support	0	0	0	0	0				
8.9b Observations of the child's progress towards goals in contexts outside of those in which the therapy/support is being delivered	0	0	0	0	0				
8.9c Observations of the child's reaction (positive, negative, mixed) to engaging in the therapy/support	0	0	0	0	0				



# 8.10 The following assessment/evaluation tools and sources of information should be considered when monitoring therapy/support progress and outcomes: DIRECT AND PARENT REPORT

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
8.10Direct report from the child about progress towards goals (to the extent possible)	0	0	0	0	0
8.10 <sup>b</sup> Parent report of the child's progress towards the goals	0	0	0	0	0
8.10Direct report from the child about their experience (positive, negative, mixed) of engaging with the therapy/support (to the extent possible)	0	0	0	0	0
8.10 Parent report of what they perceive to be the child's experience (positive, negative, mixed) of engaging with the therapy/support	0	0	0	0	0



8.11 The following assessment/evaluation tools and sources of information should be								
considered when monitoring therapy/support progress and outcomes: REPORTS FROM OTHERS								
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree			
8.11 Reports from people who are involved in the delivery of the therapy/support	0	0	0	0	0			
8.11bReports from people who can provide insight into the child's progress towards the goals and/or general learning, participation, and wellbeing	0	0	0	0	0			



8.12 The following assessment/evaluation tools and sources of information should be									
considered when monitoring therapy/support progress and outcomes: PROGRESS DATA									
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree				
8.12aClinician collected progress data	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$				
8.12hChild collected progress data (to the extent possible) (e.g. self-report)	0	0	0	0	0				
8.12@arent-collected progress data	$\bigcirc$	$\bigcirc$	$\bigcirc$	0	$\bigcirc$				
8.12 <b>P</b> rogress data collected from other stakeholders (e.g. teacher checklist)	0	0	0	0	0				



	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
13aNorm-referenced assessments comparing a child's skills and functioning with neurotypical children of the same age	0	0	0	0	0
13bNorm-referenced assessments comparing a child's skills and functioning with a cohort of children on the autism spectrum	0	0	0	0	0
13Criterion-referenced assessment comparing a child's skills and functioning with pre-defined criteria such as developmental milestones	0	0	0	0	0
13 <b>c</b> Curriculum-based assessments comparing a child's progress towards a pre-specified set of goals	0	0	0	0	0
13@Ethnographic interviewing to gather child/family views regarding progress and	0	0	0	0	0
outcomes L3fNaturalistic sampling (e.g., recording and analysis of communication interactions, change in self-injurious behaviour)	0	0	0	0	0



	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
8.14aAt each occasion of service	$\bigcirc$	$\bigcirc$	$\bigcirc$	0	$\bigcirc$
8.14 <b>E</b> very month	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
8.14Œvery 2 months	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
8.14 <b>在</b> very 3 months	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
8.14€very 6 months	$\bigcirc$	$\bigcirc$	$\bigcirc$	0	$\bigcirc$
8.14fEvery 12 months	0	0	0	0	0
8.14g Are there other time intervalue appropriate for reviewing therap		0	Yes No		

Please describe other time intervals that are more appropriate for reviewing therapy/support goals.



8.15 Therapy/support goals	Strongly	Disagree	Neutral	Agree	Strongly agree
	disagree	Disayiee	inculiai	Ayree	Scrongly agree
.15aThe child achieves a goal	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
15b he child and/or their family request new goals	$\bigcirc$	$\bigcirc$	0	0	$\bigcirc$
.15cThe practitioner identifies new goals relevant to the child and/or their family	0	0	0	0	0
.15d here are significant changes in the life of the child and/or family (e.g., transition to school, parental supervision, moving house)	0	0	0	0	0
.15& a frequency, and in a manner, specified by the child and family	0	0	0	0	0
.15fAt a frequency, and in a manner, that is sufficient for the practitioner delivering the therapy/support to make evidence-based decisions and recommendations	0	0	0	0	0
.15gThere is a change in the funding for services for the child and family	0	0	0	0	0
8.15h Are there other occasions/evo lead to a review of therapy/support			Yes No		



	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
8.16At each occasion of service	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
8.16 <b>E</b> very month	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
8.16 Every 2 months	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
8.16œvery 3 months	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
8.16∉very 6 months	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
8.16fEvery 12 months	0	0	0	0	0
8.16g Are there other time inter appropriate for monitoring thera and outcomes?		ss O	Yes No		

appropriate for monitoring therapy/support progress and outcomes



# **8.17** The information gained through monitoring should:

## \*It is assumed that people providing services will adhere to relevant rules and legislation (e.g., privacy, freedom of information)

(e.g., privacy, needoni or ini	ormation)				
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
8.17 Be shared and discussed with the child receiving the therapies/supports, if appropriate	0	0	0	0	0
8.17be shared and discussed with the parents of the child receiving the therapies/supports*	0	0	0	0	0
8.17 Be shared and discussed with other community members (nominated by the family) as the basis for supporting the child and/or family*	0	0	0	0	0
8.17 Be shared with other practitioners/specialists that support the child, as the basis for informing them of progress and/or inviting consultation*	0	0	0	0	0
8.17 Be shared with other organisations that support the child, as the basis for informing them of progress and/or inviting consultation (e.g., schools/day care)*	0	0	0	0	0
8.17fNot be disclosed	0	0	0	0	0



\*Responses will only appear to this item if you agreed, in the previous item, that information should be shared

8.18 The focus of this item is on the mode by which monitoring information may be shared. The manner in which this would then occur would account for individual and cultural preferences regarding the nature of the interaction.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
8.18æe shared during a telephone conversation	$\bigcirc$	$\bigcirc$	$\bigcirc$	0	0
8.18bBe shared during a face-to-face conversation	0	0	0	0	0
8.18ße shared during a videoconference conversation	0	0	0	0	0
8.18dBe shared in a written report	$\bigcirc$	$\bigcirc$	0	0	0
8.18&Be shared via a graphical mode (i.e., drawing, art)	0	0	0	0	0
8.18fBe shared and discussed in the manner preferred by the child and/or family	0	0	0	0	0
8.18 Be shared by a combination of different modes preferred by the child and/or family	0	0	0	0	0
8.18h Are there other modes in whi information should be shared?	ch monitoring		Yes No		
Please describe other modes by wh information should be shared.	ich monitoring				
[OPTIONAL] 8.19 Please provide an you would like to help explain your you believe is relevant to consider of therapies/supports.	responses, or t	hat			

#### Section 9 of 9.

Quality and Safeguards

In this section, we are seeking your views about how the safety, comfort, and wellbeing of individuals on the autism spectrum can be best supported. This includes approaches for acknowledging and maintaining people's rights and reducing the risk of adverse effects that can occur any time therapies and supports are delivered.



					Page 54
	Not at all important	Slightly important	Moderately important	Very important	Extremely important
9.1 How important do you think it is that the safety of children on the autism spectrum and their families is ensured when accessing therapies and supports?	0	0	0	0	0



# 9.2 Please indicate the extent to which you agree each of the following are approaches that should be incorporated in clinical practice to ensure the safety, comfort, and wellbeing of individuals on the autism spectrum and their families:

individuals on the autism spectrum and their families:							
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree		
9.2a Ensuring practitioners have up-to-date knowledge of the empirical evidence for therapies/supports (including research on the views and preferences of autistic people)	0	0	0	0	0		
9.2b Ensuring practitioners have adequate experience and skills in the selection, delivery and assessment of therapies/supports	0	0	0	0	0		
9.2c Ensuring that practitioners have access to clinical supervision	0	0	0	0	0		
9.2d Ensuring the effectiveness and safety of therapies/supports being delivered by practitioners have been validated through well-designed research studies	0	0	0	0	0		
9.2e Ongoing monitoring of therapy/support outcomes	0	0	0	$\bigcirc$	0		
9.2f Ongoing assessment of support needs	0	0	0	0	0		
9.2g Practitioners working in ways that are consistent with relevant conventions, including the United Nations Convention on the Rights of Persons with Disabilities and the United Nations Convention on the Rights of the Child	0	0	0	0	0		
9.2h Practitioners following relevant practice/ professional processes and legislative requirements (e.g., Disability Discrimination Act, NDIS rules)	0	0	0	0	0		
9.2i Ensuring that children and their families have a clear method and pathway for raising concerns	0	0	0	0	0		

9.2j



 $\bigcirc$ Ο Ο Ο Ο Ensuring the provision of clear, appropriate, and accurate information between practitioners and families at all stages (including to ensure informed consent is validly obtained) ⊖ Yes ⊖ No 9.2k Are there other approaches that should be incorporated into clinical practice to ensure the safety, comfort, and wellbeing of individuals on the autism spectrum and their families? Please describe other approaches that should be incorporated into clinical practice to ensure the safety, comfort, and wellbeing of individuals on the autism spectrum and their families. [OPTIONAL] 9.3 Please provide any further information you would like to help explain your responses, or that you believe is relevant to consider for how the safety and quality of therapy/support provision can be

ensured.



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National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia

Appendix 9.2Delphi Survey – Round 2

# Supporting Children Guideline Delphi Round 2

Thank you for your participation in the Round 1 Delphi Survey. The outcomes of this Delphi process will directly inform the recommendations in the National Practice Guideline for supporting children on the autism spectrum and their families in Australia.

The results of the Round 1 survey showed strong consensus amongst practitioners for most items. This Round 2 survey presents the results from Round 1 for all items. For those items that did achieve consensus, we have presented the results for your information. For those items that did not achieve consensus, we are presenting the item again for you to rate your agreement/disagreement. Some of the items are being presented exactly as they appeared in Round 1. Others have been modified slightly according to the qualitative feedback provided from practitioners in Round 1.

In addition, there are three new items that did not appear in Round 1 for you to rate your agreement. These new items were informed by feedback from our community consultation process, including focus groups, an online survey, and qualitative feedback provided on the Delphi Round 1 survey.

For this Round 2 survey, we are once again interested in your views, as a practitioner, about the planning and delivery of therapies and supports aimed at enhancing the learning, participation, and quality of life of children on the autism spectrum (aged 0-12 years) and their families in community settings.

The Round 2 survey contains ten sections. However, since consensus was achieved on most items in the Round 1 survey, there are only six sections with items to rate your agreement on what you consider to be best practice when supporting children on the autism spectrum and their families.

Please note: the survey will close at 11:59pm on May 5th (AEST).

As a reminder, for the purpose of this survey:

'Parent(s)' refers to any individuals with parenting or caregiving responsibilities for a child (e.g., guardians, kinship, foster carers). 'Family' refers to the child's parents/caregivers, siblings and any extended family (e.g., grandparents, aunts, uncles, cousins) involved in the child's care. 'Therapies' refers to services that focus on supporting children to acquire or enhance functional skills aimed at ensuring their learning, participation, and quality of life in the community.'Support' refers to services that focus on adjustments, modifications, and enhancements to the environment aimed at ensuring their learning, participation, and guality of life in the community.

Please provide your first name:

Please provide your last name:

Please provide the most appropriate email address to follow-up with feedback from Round 2:

Survey Part 1

Overview of practitioners participating in Round 1

Seventy-two practitioners representing six professions, from five professional organisations, participated in the Round 1 Delphi survey for the National Practice Guideline.

Practitioners had, on average, 15 years' experience in working in clinical practice with children on the autism spectrum (Mean = 15 years, SD = 9.60; Range: 1.5 - 41 years).

All states and territories were represented in the Round 1 survey. The distribution of practitioners working in major cities versus regional/remote areas was broadly consistent with the distribution of the Australian population (ABS 2019) whereby 70% of practitioners worked with families in major cities, and 30% worked with families in regional/remote areas.

The pdf below contains a breakdown of:

The number of practitioners from each professional organisation Professions represented The broad geographical distribution of practitioners that participated in Round 1 07/08/2022 2:36pm projectredcap.org



#### Survey Part 2

There are ten sections to this survey, however, there are only six sections that contain items for you to rate. The first nine sections are the same as those in Round 1. In this version, there is also one new section (Section 10). For some sections, consensus was achieved across all items in Round 1. For those sections, we have presented the results for your information, even if there are no items to rate in Round 2.

Below is a table of all ten sections in the survey, including if the section contains items for you to rate.

Section

Section Name

Outcome

#### 1

Principles

Consensus achieved

#### 2

Who should be involved in the provision of therapies and supports?

Items to rate

#### 3

Sources of information

Items to rate

#### 4

Understanding the child, family, and their context

Consensus achieved

#### 5

Goal setting

Consensus achieved

#### 6

Selecting therapies and supports Items to rate

#### 7

Delivering therapies and supports

Items to rate

#### 8

Monitoring outcomes

Items to rate

#### 9

Quality and safeguards

Consensus achieved

10

Knowledge, skills, and/or experience of practitioners providing therapies and supports

Items to rate

Items in Round 1 were rated on a scale from 1 (Strongly Disagree) to 5 (Strongly Agree).

To determine if consensus had been achieved for items, two criteria were applied:

For agreement with statements, we used a median rating of  $\geq 4$  (i.e., agree or strongly agree) and an interquartile range (IQR) of  $\leq 1$  for agreement with the item; for disagreement with statements, we used median  $\leq 2$  (i.e., disagree or strongly disagree) and an interquartile range (IQR) of  $\leq 1$  for disagreement with the item For agreement with statements,  $\geq 70\%$  of practitioners rated the item as  $\geq 4$  (i.e., agree or strongly agree) for agreement with the item; for disagreement with statements,  $\geq 70\%$  of practitioners rated the item as  $\geq 4$  (i.e., agree or strongly agree) for agreement with the item; for disagreement with statements,  $\geq 70\%$  of practitioners rated the item as median  $\leq 2$  (i.e., disagree or strongly disagree) for disagreement with the item Consensus agreement or consensus disagreement was achieved if both of the above criteria were met. If only one of the criteria was met, it was considered to be partial consensus agreement/disagreement and the item was retained for the Round 2 survey. If neither criteria were met, the item was considered to not have consensus agreement or consensus disagreement and it was retained for the Round 2 survey. For those items without consensus agreement/disagreement, the item was reviewed and, where relevant, revised based on the qualitative feedback you provided in Round 1.

Please note: the survey takes approximately 20-40 minutes to complete. At any stage, you can select the 'Save and Return Later' icon if you would prefer to complete the survey over multiple sittings. The data you enter will be automatically saved on the Griffith University research server (via REDCap), so do not be concerned about it being lost, and if you have any difficulties re-commencing the survey, you can contact the research team for help (k.varcin@griffith.edu.au).

The survey will close at 11:59pm on May 5th (AEST).

The first section of this survey refers to 'Principles' that are relevant to all aspects of therapy/support provision. There was consensus agreement for all items in this section in Round 1.

As such, what would you like to do?

See the feedback from Round 1
 Skip to the next section

Section 1 of 10.

Principles

Round 1: Items with consensus achieved

There was consensus agreement amongst practitioners in Round 1 that all of the below principles are important to all aspects of providing therapies and supports to children on the autism spectrum. Consensus agreement was reached on all items. Data are provided below for your interest.

\*Agreement = the proportion of practitioners who rated their agreement for the statement as 4 (agree) or 5 (strongly agree).

1.1 Please indicate the extent to which you agree each of the following are principles that are important to all aspects of providing therapies and supports to children on the autism spectrum:

Outcome

Median (IQR)

a.

Holistic: The provision of therapies and supports should involve consideration of an individual's life history, culture, strengths and challenges, goals and preferences, and environmental factors that act as facilitators or barriers to learning, participation, and quality of life.

100% agreement

5 (0)

b.

Child and family-centred: The child and their family members should be considered equal partners with practitioners in the therapy process.

99%

agreement

5 (0)

c.

Supported: The child and their family should be supported to include people they feel are relevant in the therapy process, including for advocacy and support.

100% agreement

5 (0)

d.

Lifespan perspective: Clinical decision-making regarding the provision of therapies and supports should account for the current stage of life of the individual, as well as appropriate planning for both the short and longer term.

99%

agreement

5 (0) 07/08/2022 2:36pm



e.

Developmental perspective: Clinical decision-making regarding the provision of therapies and supports should account for, and be responsive to, the individual, family and social changes that occur through childhood.

100% agreement

5 (0)

f.

Empirically supported: Therapies and supports should be underpinned by the best available published, peer-reviewed scientific evidence demonstrating their effectiveness and safety.

90%

agreement

5 (1)

g.

Evidence-based practice approach: Clinical decision-making regarding the provision of therapies and supports should draw on, and integrate, research and clinical evidence alongside the preferences and values of the child and their family.

98%

agreement

5 (0)

h.

Ethical practice: The provision of therapies and supports should be underpinned by an ethical framework that follows the principles of beneficence (i.e., to act for the benefit of others), non-maleficence (i.e., do no harm), autonomy and fairness.

100% agreement

5 (0)

i.

Culturally aware and responsive: The values, knowledge, preferences and cultural perspectives of the child and family should be sought, respected, and evident in the provision of therapies and supports.

100% agreement

5 (0)

j.

Equity: All children and families, regardless of age, gender, cultural background, socioeconomic status or geographical location should be able to access timely, safe, desirable and effective therapies and supports.

100% agreement

5 (0)

k.

Strengths-focused: Therapies and supports should focus on understanding, embracing and developing the strengths of an individual and their family.

#### 97%

#### agreement

5 (0)

I.

Coordinated: A coordinated approach to the provision of therapies and supports for the child and family across practitioners, organisations, and agencies should be taken.

97%

#### agreement

5 (0)

m.

Personalised: Therapies and supports should be tailored to the unique strengths, needs, and preferences of each child and family.

96%

agreement

5 (0)

n.

Accessible: The process of planning, delivering, and monitoring therapies and support, including interactions and documentation, should be accessible.

100% agreement

5 (0)

0.

Informed consent (parents): Informed parental consent should be obtained for the provision of therapies and supports.

96%

#### agreement

5 (0)

p.

Assent (children): Children's assent (expression of approval) should be obtained, wherever possible, for the provision of therapies and supports.

89%

#### agreement

5 (1)

q.

Qualified practitioners: People involved in the provision of therapies and supports should have relevant qualifications and professional regulation, and only engage in goal setting and the delivery of therapies and supports that are within their scope of practice.

99%

#### agreement

5 (0)

Section 2 of 10.

Who should be involved in the provision of therapies and supports?

Round 1: Items with conensus achieved

Items 2.1, 2.2: There was consensus agreement amongst practitioners in Round 1 that (i) the child, family, and family-like people (i.e., family, friends, peers), and (ii) people who provide formal support to the child's health and development (e.g., educators, medical and allied health practitioners) should be involved in all aspects of therapy/support provision for children on the autism spectrum.

\*Agreement = the proportion of practitioners who rated their agreement for the statement as 4 (agree) or 5 (strongly agree).

2. Below, we have indicated a range of people who might be involved in therapy/support provision. Please tell us the extent to which you agree with these statements.

Outcome

Mdn (IQR)

2.1 The child, family, and family-like people (i.e., family, friends, peers)

a. Working to understand the child, family, and their context

100% agreement

5 (0)

b. Setting goals

100% agreement

5 (0)

c. Selecting therapies and supports

91% agreement

5 (1)

d. Delivering therapies and supports

86% agreement

5 (1)

e. Monitoring outcomes

92% agreement

4.5 (1)

2.2. People who provide formal support to the child's health and development (e.g., educators, medical and allied health practitioners)

a. Working to understand the child, family, and context

100% agreement

5 (0)

b. Setting goals

99% agreement

5 (1)

c. Selecting therapies and supports

90% agreement

5 (1)

d. Delivering therapies and supports

100% agreement

5 (1)

e. Monitoring outcomes

97% agreement

5 (0)

Who should be involved in the provision of therapies and supports? (continued)

Please read the below statement and view the attached file, as it is relevant for the next item we will ask you to rate.

Item 2.3 - With regard to people who can contribute to supporting the child's participation in community activities (e.g., sports coaches, art teachers, community members the child interacts with regularly including retail environments, community groups, and cultural activities), there was no consensus agreement or consensus disagreement for their involvement in all aspects of therapy/support provision.

The results from Round 1 for these items are presented in the attached file.

[Attachment: "Round 1 results\_Item 2.3.pdf"]

Based on the quantitative ratings and qualitative feedback provided in Round 1, we have revised item 2.3. A key change relates to the use of 'may' where 'should' was used previously. Please tell us the extent to which you now agree with this statement:

2.3. Where relevant and desired by the child and family, people who can contribute to supporting the child's participation in community activities (e.g., sports coaches, art teachers, community members the child interacts with regularly including retail environments, community groups, and cultural activities) may be involved in one or more aspects of:

community groups, and cultural activities) may be involved in one or more aspects of:						
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	
<ul> <li>(i) Working to understand the child, family, and their context,</li> <li>(ii) setting goals, (iii) selecting therapies and supports, (iv) delivering therapies and supports, and supports, (v) monitoring outcomes</li> </ul>	0	0	0	0	0	

Who should be involved in the provision of therapies and supports? (continued)

Please read the below statement and view the attached file, as it is relevant for the next item we will ask you to rate.

Item 2.4 - With regard to agencies that support the provision and/or access to services (e.g., NDIS planners, safety officers), there was no consensus agreement or consensus disagreement for their involvement in all aspects of therapy/support provision. The results from Round 1 for these items are presented in the attached pdf.

[Attachment: "Round 1 results\_Item 2.4.pdf"]



Based on the quantitative ratings and qualitative feedback provided in Round 1, we have revised this item. A key change relates to the use of 'may' where 'should' was used previously. Please tell us the extent to which you agree with this statement:

2.4. Where relevant and desired by the child and family, staff in agencies that support the provision and/or access to services (e.g., NDIS planners, child safety officers) may be involved in one or more aspects of:

		Strongly disagree	Disagree	Neutral	Agree	Strongly agree
2.4	<ul> <li>(i) Working to understand the child, family, and their context,</li> <li>(ii) setting goals, (iii) selecting therapies and supports, (iv) delivering therapies and supports, (v) monitoring outcomes</li> </ul>	0	0	0	0	0

#### Section 3 of 10.

#### Sources of information

Round 1: Items with conensus achieved

Item 3.1 There was consensus agreement amongst practitioners in Round 1 that the factors listed below are important for practitioners to consider when making recommendations for goals and the selection and delivery of therapies and supports when working with children on the autism spectrum and their families.

\*Agreement = the proportion of practitioners who rated their agreement for the statement as 4 (agree) or 5 (strongly agree).

3.1 Please indicate the extent to which you believe the following factors are important:

Outcome

Mdn (IQR)

#### a.

A theoretical rationale for why the goal/therapy/support is likely to lead to an increase in the child's learning and participation.

86% agreement

4 (1)

b.

Research evidence (from published, peer-reviewed research) that the goal/therapy/support is likely to lead to an increase in the child's learning and participation.

85% agreement

4 (1)

c.

Clinical evidence gathered through practice that the goal/therapy/support is likely to lead to an increase in the ৫৮/৩৪/২০ ফ্রেন্ট্রাক্সান্বা participation, including evidence drawn from the experiences/outcointesdof potter child contains and participation. families the practitioner has supported.

94% agreement

5 (1)

d.

Perspectives expressed by autistic people regarding the goal/therapy/support.

90% agreement

5 (1)

e.

Information about the child, family, and their context that is relevant to this goal/therapy/support.

100% agreement

5 (0)

f.

Consideration of whether the child/family have the time required for the goal/therapy/support

98% agreement

5 (1)

g.

Consideration of whether the child/family have the social support required for the goal/therapy/support (e.g., family members willing to assist).

99% agreement

5 (1)

h.

Consideration of whether the child/family have the financial resources required for the goal/therapy/support.

90% agreement

5 (1)

i.

Consideration of whether the child/family have the emotional support required for the goal/therapy/support,

100% agreement

5 (0)

j.

Consideration of whether the goal/therapy/support is consistent with the child/family's cultural background.

97% agreement

m.

Consideration of whether the goal/therapy/support is consistent with the parent/s views on disability (and the need to focus on the child versus the environment).

76% agreement

4 (1)

n.

Consideration of whether the child supports the goal/therapy/support (to the extent possible).

89% agreement

5 (1)

о.

Consideration of whether the parent/s support the goal/therapy/support.

98% agreement

5 (1)

p.

Consideration of the potential benefits associated with the goal/therapy/support.

100% agreement

5 (1)

q.

Consideration of the potential risks associated with the goal/therapy/support.

98% agreement

5 (1)

r.

Consideration of the alternative options to this goal/therapy/support.

97% agreement

4 (1)

s.

Consideration of how this goal/ /therapy/support may enhance progress towards other goals.

96% agreement

5 (1)

t.

Consideration of how this goal/therapy/support may impede progress towards other goals.

90% agreement

5 (1)

u.

Consideration of the relevance of this goal/therapy/support currently for the child and family.

98% agreement

5 (1)

v.

Consideration of the relevance of this goal/therapy/support in the future for the child and family.

95% agreement

5 (1)

Sources of information (continued)

Please read the below statements and view the attached file, as it is relevant for the next item we will ask you to rate.

Consensus was not achieved on two items.

Item 3k - 'Consideration of whether the goal/therapy/support is consistent with the parent/s views on child-rearing' - showed partial consensus agreement amongst practitioners.

Item 3I - 'Consideration of whether the goal/therapy/support is consistent with the parent/s views on child development' - did not meet consensus agreement or consensus disagreement thresholds amongst practitioners.

The distributions of ratings for these items is presented in the attached image.

[Attachment: "Round 1 results\_3k\_l.png"]

Having reviewed these results from Round 1, we would like to ask you to rate these items again. We are interested to know what factors are important for practitioners to CONSIDER when making recommendations for goals and the selection and delivery of therapies and supports when working with children on the autism spectrum and their families.

#### **3.1** Please indicate the extent to which you believe the following factors are important:

	-				
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
3.1k Consideration of whether the goal/therapy/support is consistent with the parent/s views on child-rearing.	0	0	0	0	0
3.11 Consideration of whether the goal/therapy/support is consistent with the parent/s views on child development.	0	0	0	0	0

The next section of this survey refers to 'Understanding the child, family, and their context'. There was consensus agreement for all items in this section in Round 1.

As such, what would you like to do?

 $\bigcirc$  See the feedback from Round 1

 $\bigcirc$  Skip to the next section



Section 4 of 10.

Understanding the child, family, and their context

Round 1: Items with consensus achieved

Item 4.1 There was consensus agreement amongst practitioners in Round 1 that it is important to understand the child, their family, and their context when making decisions about therapies and supports.

\*Agreement = the proportion of practitioners who rated the statement as 4 (important) or 5 (very important).

Outcome

Mdn (IQR)

How important do you think it is to understand the child, their family, and their context when making decisions about therapies and supports for children on the autism spectrum?

98% agreement

5 (0)

Item 4.2 There was consensus agreement amongst practitioners in Round 1 that the planning of therapies and supports should be informed by assessment of the following aspects of children's health, development, and wellbeing:

\*Agreement = the proportion of practitioners who rated their agreement for the statement as 4 (agree) or 5 (strongly agree).

4.2 Please indicate the extent to which you agree that the planning of therapies and supports should be informed by assessment of the following aspects of children's health, development, and wellbeing:

Outcome

Mdn (IQR)

а

The child's health (i.e., physical health, mental health, and health history).

100% agreement

5 (1)

b

The child's developmental skills (i.e., gross and fine motor, social, emotional, cognitive, communication, and academic skills).

97% agreement

5 (0)

С

interests, and sensory behaviours).

92% agreement

5 (1)

d

The child's activities and participation in home, educational, and community settings (this includes enablers and barriers to participation).

100% agreement

5 (1)

e

The child's behaviour(s) of concern (including, (i) behaviours arising from the interaction of the person and their environment that risk the physical safety of the individual and/or others and (ii) behaviours that limit or deny participation in life activities).

98% agreement

5 (1)

f

The child's perception of their quality of life (to the extent this is possible to obtain)

90% agreement

5(1)

g

The child's activity-related strengths and preferences (i.e., activities that bring the child joy and/or that they have expertise in).

97% agreement

5 (1)

h

The child's preferences for therapies/supports (to the extent this is possible to obtain)

95% agreement

4 (1)

i

The child's expectations for the outcomes of therapy/support (to the extent this is possible to obtain)

86% agreement

4 (1)

Item 4.3 There was consensus agreement amongst practitioners in Round 1 that the planning of therapies and supports should be informed by assessment of the following aspects of the family:

\*Agreement = the proportion of practitioners who rated their agreement for the statement as 4 (agree) or 5

(strongly agree).

4.3 Please indicate the extent to which you agree that the planning of therapies and supports should be informed by assessment of the following aspects of the family:

Outcome

Mdn (IQR)

а

The family's physical and mental health (i.e., the presence of any conditions that may impact upon their capacity to participate, or need to be considered, in the provision of therapies/supports for their child).

98% agreement

5 (1)

b

The family's social-emotional resources and supports (i.e., resilience factors and the capacity to deal with stressful situations in life, along with social support via family, friends, and support groups).

99% agreement

5 (1)

С

The family's financial resources and supports (i.e., funding to pay for therapies and supports, capacity to purchase unfunded therapies and supports, and capacity to take time away from paid work to access therapies and supports).

89% agreement

5(1)

d

The family's activities (i.e., work, social, cultural, sport and recreational, and educational activities).

90% agreement

4 (1)

е

The family's views, perspectives and preferences (i.e., views about their child's learning, participation and quality of life now and in the future, views on disability, the relevance of therapies/supports for their child, cultural perspectives on therapies/supports, preferences for therapies/supports, and expectations for outcomes).

92% agreement

5 (1)

f

The family's dynamics (i.e., the nature and strength of relationships between family members, the nature and distribution of roles and responsibilities, the positive and challenging impacts associated with the child's disability).

96% agreement

4.5 (1)

Item 4.4 There was consensus agreement amongst practitioners in Round 1 that the planning of therapies and supports should be informed by assessment of the following aspects of a family's previous engagement with other services:

\*Agreement = the proportion of practitioners who rated their agreement for the statement as 4 (agree) or 5 (strongly agree).

4.4 Please indicate the extent to which you agree that the planning of therapies and supports should be informed by assessment of the following aspects of a family's previous engagement with other services:

Outcome

Mdn (IQR)

а

The nature of any services previously accessed, including goals and types of services (e.g., allied health, mainstream supports).

73% agreement

4 (1)

b

The child and family's experience of previously accessed services, including their satisfaction with the service(s).

86% agreement

4 (1)

С

The child and family's outcomes of accessing previous services, including the progress made towards goals.

83% agreement

4 (1)

Item 4.5 There was consensus agreement amongst practitioners in Round 1 that the planning of therapies and supports should be informed by assessment of the following aspects of a family's current engagement with other clinical services and mainstream supports:

\*Agreement = the proportion of practitioners who rated their agreement for the statement as 4 (agree) or 5 (strongly agree).

4.5 Please indicate the extent to which you agree that the planning of therapies and supports should be informed by assessment of the following aspects of a family's current engagement with other clinical services and mainstream supports:

Outcome

Mdn (IQR)

The nature of any services and funding/support (e.g., NDIS plan, education department) currently accessed, including goals and types of services (e.g., allied health, mainstream supports).

93% agreement

4 (1)

b

The child and family's experience of currently accessed services, including their satisfaction with the service(s).

96% agreement

4 (1)

С

The child and family's outcomes of accessing current services, including the progress made towards goals.

94% agreement

4 (1)

d

Any arrangements that are in place to support the coordination of services and supports accessed by the child and family (e.g., nominated case coordinator, NDIS support coordination).

86% agreement

4 (1)

e

Family preferences for future arrangements to support the coordination of services and supports accessed by the child and family.

87% agreement

4 (1)

The next section of this survey refers to 'Goal-setting'. There was consensus agreement for all items in this section in Round 1.  $\bigcirc$  See the feedback from Round 1  $\bigcirc$  Skip to the next section

As such, what would you like to do?

Section 5 of 10.

Goal-setting

Round 1: Items with consensus achieved

Iten 5.1 There was consensus agreement amongst practitioners in Round 1 that it is important to select appropriate goals for therapy when working with children on the autism spectrum and their families.

\*Agreement = the proportion of practitioners who rated the statement as 4 (important) or 5 (very important).

Outcome

Mdn (IQR)

How important do you think it is to select appropriate goals for therapy when working with children on the autism spectrum and their families?

96% agreement

5 (0)

Items 5.2-5.4 There was consensus agreement amongst practitioners in Round 1 that, when relevant, goals for children on the autism spectrum and their families should consider focusing on the following:

\*Agreement = the proportion of practitioners who rated their agreement for the statement as 4 (agree) or 5 (strongly agree).

Items 5.2-5.4. When relevant, goals for children on the autism spectrum and their families should consider focusing on:

Outcome

Mdn (IQR)

5.2 Child's mental and physical functions

а

Mental functions (e.g., executive functioning)

95% agreement

5 (1)

b

Physical functions (e.g., articulation of speech sounds, fine motor skills)

92% agreement

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#### 5.3 Child's activities and participation

а

The acquisition of skills (e.g., social, communication, play, motor)

94% agreement

5 (1)

b

The generalised use of skills in daily activities with others (e.g., social skills used to help form relationships, communication skills used to have a conversation, play skills used to engage in play with peers).

96% agreement

5 (1)

С

The reduction of behaviours of concern (e.g., self-injurious behaviours)

89% agreement

5 (1)

d

Learning and applying knowledge (e.g., learning to count, learning to read)

78% agreement

4 (1)

е

Carrying out daily routines (relative to age expectations)

96% agreement

5 (1)

f

Supporting interpersonal interactions and relationships

94% agreement

### g

Participation in community, social, and civic life (e.g., recreation, leisure, religion, spirituality) 95% agreement

5 (1)

5.4 Child's environment

#### а

Accessibility in the physical environment (e.g., sensory-safe spaces)

96% agreement

4.5 (1)

b

Accessibility in the social environment (e.g., changing attitudes and increasing knowledge and skills of others')

98% agreement

5 (1)

С

Enhancement of services, systems, and policies (e.g., to improve coordination of services, changing policies that create barriers to participation).

91% agreement

5 (1)

Item 5.6 There was consensus agreement amongst practitioners in Round 1 that, when working with children and families to set goals, practitioners should do the following:

\*Agreement = the proportion of practitioners who rated their agreement for the statement as 4 (agree) or 5 (strongly agree).

5.6 In working with children and families to set goals, practitioners should:

Outcome

Mdn (IQR)

а

Ensure goals are specific

93% agreement

5 (1)

b

Ensure goals are measurable

95% agreement

5 (1)

С

Ensure goals are achievable

96% agreement

5 (1)

# d

Ensure goals are relevant to the child, family and their context

100% agreement

5 (0)

е

Ensure goals are understood by the family and relevant stakeholders

100% agreement

5 (0)

f

Ensure goals are documented

97% agreement

5 (1)

g

Ensure goals have a clear timeframe

81% agreement

4 (1)

Item 5.7 There was consensus agreement amongst practitioners in Round 1 that, therapy/support goals should be selected in relation to how they support the child's functioning, activities, and participation over the following timeframes:

\*Agreement = the proportion of practitioners who rated their agreement for the statement as 4 (agree) or 5 (strongly agree).

5.7 Therapy/support goals should be selected in relation to how they support the child's functioning, activities, and participation over the:

Outcome

Mdn (IQR)

а

Short-term i.e., for goal attainment over 12 months - 2 years.

90% agreement

5 (1)

b

Medium term i.e., for goal attainment over 2 - 3 years.

77% agreement

4 (0)

С

Long-term i.e., for goal attainment over 3+ years

71% agreement

4 (1)

Section 6 of 10.

Selecting therapies and supports

Round 1: Items with consensus achieved

Item 6.1 There was consensus agreement amongst practitioners in Round 1 that it is important to select appropriate therapies and supports when working with children on the autism spectrum and their families.

\*Agreement = the proportion of practitioners who rated the statement as 4 (important) or 5 (very important).

Outcome

Mdn (IQR)

How important do you think it is to select appropriate therapies and supports when working with children on the autism spectrum and their families?

95% agreement

Item 6.2 There was consensus agreement amongst practitioners in Round 1 that the selection of therapies and supports should be informed by the goals for therapy.

\*Agreement = the proportion of practitioners who rated their agreement for the statement as 4 (agree) or 5 (strongly agree).

Outcome

Mdn (IQR)

The selection of therapies and supports should be informed by the goals for therapy.

93% agreement

5 (1)

Selecting therapies and supports (continued)

New item in Round 2

This section contains one new item that was developed based on qualitative feedback from the Round 1 Delphi and our additional community consultations activities, including focus groups and an online survey.

We are interested in your views on how therapies and supports should be selected. In this question, we ask about practices and techniques. We have defined what we mean by 'practice' and 'technique' in the below table. To do that, we also refer to 'categories'. Please familiarise yourself with these definitions.

Term

Category

Example

Category

One or more practices that share similar theoretical underpinnings.

'Behavioural interventions'

Practice

A combination of techniques evaluated and implemented together to target the acquisition of one or more skills

Early Intensive Behavioural Intervention; the Picture Exchange Communication System

Technique

A discrete clinical strategy, targeting the acquisition of a discrete skill

Prompting; modelling; shaping

# 6.3 - NEW ITEM: Please rate your agreement with the following statements.

# Where relevant, and assuming that the therapy program is tailored to the individual child and their family, practitioners may:

2 · 1					
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
6.3a Select and deliver a single intervention practice	0	0	0	0	0
6.3b Select and deliver a range of practices or techniques (i.e., a so called 'eclectic approach').	0	0	0	0	Ο

Section 7 of 10.

Delivering therapies and supports

Round 1: Items with consensus achieved

Item 7.1 There was consensus agreement amongst practitioners in Round 1 that it is important to deliver therapies and supports in ways that are appropriate for children on the autism spectrum and their families.

\*Agreement = the proportion of practitioners who rated the statement as 4 (important) or 5 (very important).

Outcome

Mdn (IQR)

How important do you think it is to deliver therapies and supports in ways that are appropriate for children on the autism spectrum and their families?

97% agreement

5 (0)

In what settings should therapies/supports be delivered?

Item 7.2 There was consensus agreement amongst practitioners in Round 1 that an array of settings may be appropriate for the delivery of therapies/supports.

\*Agreement = the proportion of practitioners who rated their agreement for the statement as 4 (agree) or 5 (strongly agree).

7.2 Where relevant, the following settings may be appropriate for the delivery of therapies/supports:

Outcome

Mdn (IQR)

а

Clinic



### b

The child's home

96% agreement

5 (1)

с

Educational settings (including school and early child education settings/day care)

97% agreement

5 (1)

е

Social settings (e.g., other people's homes, community spaces)

81% agreement

4 (0)

f

Recreational settings (e.g., sports ovals, music/art/drama studios)

79% agreement

4 (1)

In what settings should therapies/supports be delivered? (continued)

Please read the below statement and view the attached file, as it is relevant for the next item we will ask you to rate.

Consensus was not achieved on one item in this sub-section.

Item 7.2d - 'Cultural settings (e.g., places of worship)' - did not meet consensus agreement or consensus disagreement thresholds amongst practitioners in Round 1. The distribution of ratings is presented in the attachment below.

[Attachment: "Round 1 results\_7.2d.png"]

We would like to ask you to rate this item again. However, please note that the preceding phrase 'where relevant' implies that a setting may be appropriate depending on the individual child, their family, and their context. It does not require this setting to be part of the provision of all therapies/supports for all children and their families.

# 7.2 Where relevant, the following setting may be appropriate for the delivery of therapies/supports:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
7.2d Cultural settings (e.g., places of worship)	0	0	0	0	0

In what amount(s) should therapies/supports be delivered?

Item 7.3 There was consensus agreement amongst practitioners in Round 1 that, when relevant, children should have access to the following services:

\*Agreement = the proportion of practitioners who rated their agreement for the statement as 4 (agree) or 5 (strongly agree).

7.3 When relevant, children should have access to:

### Outcome

Mdn (IQR)

### а

Child-directed services (i.e., a practitioner working primarily with the child as 1:1 or in a small group)

92% agreement

5 (1)

### b

Parent-directed services (i.e., a practitioner working primarily to upskill the parent(s) to support the child's learning and participation)

98% agreement

5 (1)

# С

Community-directed services (i.e., a practitioner working primarily to upskill other members of the community [e.g., educators] to support the child's learning and participation)

#### 94% agreement



For item 7.4, there was consensus agreement amongst practitioners (based on both quantitative ratings and qualitative feedback) that the proportion of child-directed, parent-directed, and community-directed services should be personalised.

7.4 Please rate your agreement with the following statements:

Outcome

Mdn (IQR)

d

The proportion of child-directed, parent-directed, and community-directed services should be personalised

95% agreement

5 (0)

As such, we have not presented items 7.4a-c for rating again in Round 2.

The distributions of ratings for items 7.4a-d are presented in the attached file.

[Attachment: "Round 1 results\_7.4a-d.png"]

In what amount(s) should therapies/supports be delivered? (continued)

Round 1: Items with consensus achieved

Item 7.5 The majority of practitioners in Round 1 disagreed with the statement that all children on the autism spectrum should receive a set number of hours per week of practitioner-delivered therapy/support services.

There was consensus agreement amongst practitioners in Round 1 that (i) the amount of therapy/support hours a child received should be based on individual factors related to the child and family and (ii) the number of hours of practitioner-delivered therapy/support a child receives should be personalised.

\*Agreement = the proportion of practitioners who rated their agreement for the statement as 4 (agree) or 5 (strongly agree).

\*Disagreement = the proportion of practitioners who rated their agreement for the statement as 1 (strongly disagree) or 2 (disagree).

7.5 Please rate your agreement with the following statements:

Outcome

Mdn (IQR)

С

All children on the autism spectrum should receive a set number of hours per week of practitioner-delivered therapy/support services.

#### 87% disagreement

# d

The amount of therapy/support hours should be based on individual factors related to the child and family, including the child's functional difficulties, the therapy goals, and broader family needs.

100% agreement

5 (0)

е

The number of hours of practitioner-delivered therapy/support a child receives should be personalised.

100% agreement

5 (0)

In what amount should therapies/supports be delivered? (continued)

Please read the below statement and view the attached file, as it is relevant for the next item we will ask you to rate.

Two items achieved partial consensus disagreement.

Item 7.5a - 'There is a minimum number of practitioner-delivered therapy/support hours that all children on the autism spectrum should receive' - showed partial consensus disagreement amongst practitioners.

Item 7.5b - 'There is a maximum number of practitioner-delivered therapy/support hours that all children on the autism spectrum should receive' - showed partial consensus disagreement amongst practitioners.

The distributions of ratings are presented in the attached file.

[Attachment: "Round 1 results\_7.5a-b.png"]

# Having reviewed these results from Round 1, including the qualitative feedback provided, we have revised these items and would like to ask you to rate these items again.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
.5a All children on the autism spectrum should receive a minimum number of practitioner-delivered therapy/support hours, irrespective of child and family contextual factors.	0	0	0	0	0
.5b All children on the autism spectrum should receive a maximum number of practitioner-delivered therapy/support hours, irrespective of child and family contextual factors.	0	0	0	0	0

#### When should therapies and supports be delivered?

Round 1: Items with consensus achieved

Item 7.6 There was consensus agreement amongst practitioners in Round 1 that therapies/supports should be made available as soon as a support need is identified.

\*Agreement = the proportion of practitioners who rated their agreement for the statement as 4 (agree) or 5 (strongly agree).

7.6 Please rate your agreement with the following statement:

Outcome

Mdn (IQR)

Therapies/supports should be made available as soon as a support need is identified.

92% agreement



#### Section 8 of 10.

Monitoring

In this section we sought your views on how progress towards goals and the broader impacts of therapies and supports should be monitored, including who should be consulted; what sources of information should be considered; and how, and how often, the findings should be shared with child, family, and key stakeholders.

Round 1: Items with consensus achieved

Item 8.1 There was consensus agreement amongst practitioners in Round 1 that it is important to monitor the delivery of therapies and supports for children on the autism spectrum and their families.

\*Agreement = the proportion of practitioners who rated the statement as 4 (important) or 5 (very important).

Outcome

Mdn (IQR)

How important do you think it is to monitor the delivery of therapies and supports for children on the autism spectrum and their families? This includes ensuring the goals, therapies, and supports continue to be appropriate.

95% agreement

5(1)

Item 8.2-8.8 There was consensus agreement amongst practitioners in Round 1 that, when relevant, progress and the outcomes of therapy/support provision should include monitoring of the following aspects:

\*Agreement = the proportion of practitioners who rated their agreement for the statement as 4 (agree) or 5 (strongly agree).

8.2-8.8 When relevant, progress and the outcomes of therapy/support provision should include monitoring of the following aspects:

Outcome

Mdn (IQR)

8.2 Fidelity of therapy/support delivery

а

Type: The extent to which the planned type of therapy/support was delivered.

94% agreement



b

People: The extent to which the people who were intended to contribute to progress towards the goal contributed.

92% agreement

4 (1)

С

Settings: The extent to which the settings in which the goal was to be targeted were included.

91% agreement

4 (1)

d

Amount: The extent to which the intended amount of therapy/support was delivered.

90% agreement

4 (1)

8.3 Children's progress towards therapy/support goals

а

Amount of progress made towards the goal

94% agreement

4 (1)

b

The child's satisfaction with progress towards the goal (to the extent possible)

95% agreement

5 (1)

С

Parents' satisfaction with the child's progress towards the goal

97% agreement

8.4 Impact of progress towards therapy/support goals

а

# Changes in the child's skills

96% agreement

5 (1)

# b

Changes in the child's learning and participation

97% agreement

5 (1)

С

Changes in the child's wellbeing

100% agreement

5 (0)

# d

Changes in the family's wellbeing

99% agreement

5 (1)

е

Changes in the environment that affect learning and participation

97% agreement

5 (1)

8.5 Maintenance

### а

Maintenance of change over the short term (i.e., 12 months – 2 years)

91% agreement

# b

Maintenance of change over the medium term (i.e., 2-3 years)

72% agreement

4 (1)

# 8.6 Generalisation

# а

Generalisation of change to interactions with other people

86% agreement

4 (1)

# b

Generalisation of change to other activities

87% agreement

4 (1)

С

Generalisation of change to other settings

91% agreement

4 (1)

8.7 Costs and Benefits

# а

Costs for children (e.g., time, fatigue, not pursuing alternative goal or service option)

94% agreement

b

Costs for parents (e.g., time, financial)

94% agreement

4 (1)

С

Benefits for children

100% agreement

5 (1)

d

Benefits for family members

96% agreement

5 (1)

8.8 Unplanned Outcomes

а

Positive unplanned outcomes that have arisen from the delivery of therapy/support

93% agreement

4 (1)

b

Adverse effects that have arisen from the delivery of the therapies/supports

100% agreement

5 (1)

Monitoring (continued)

Please read the below statement and view the attached file, as it is relevant for the next item we will ask you to rate.

One item did not achieve consensus.

This item was item 8.5c - 'Maintenance of change over the long term (i.e., 3+ years)'.

The distribution of ratings for this item is presented in the attached file.

[Attachment: "Round 1 results\_8.5c.png"]

We would like to ask you to rate this item again. However, please note that the preceding phrase 'when relevant' implies that the monitoring of maintenance over this timeframe should only be considered when it is feasible and appropriate.

# 8.5 When relevant, progress and the outcomes of therapy/support provision should include monitoring of:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
8.5c Maintenance of change over the long-term (i.e., 3+ years)	0	0	0	0	0

### Monitoring (continued)

Items 8.9-8.13 There was consensus agreement amongst practitioners in Round 1 that the following assessment/evaluation tools and sources of information should be considered when monitoring therapy/support progress and outcomes:

\*Agreement = the proportion of practitioners who rated their agreement for the statement as 4 (agree) or 5 (strongly agree).

8.9-8.13 The following assessment/evaluation tools and sources of information should be considered when monitoring therapy/support progress and outcomes.

### Outcome

Mdn (IQR)

8.9 Observations

а

Observations of the child's progress towards goals during the delivery of the therapy/support

94% agreement

4 (1)

b

Observations of the child's progress towards goals in contexts outside of those in which the therapy/support is being delivered

90% agreement

4 (1)

### С

Observations of the child's reaction (positive, negative, mixed) to engaging in the therapy/support

90% agreement



а

Direct report from the child about progress towards goals (to the extent possible)

94% agreement

5 (1)

b

Parent report of the child's progress towards the goals

96% agreement

5 (1)

С

Direct report from the child about their experience (positive, negative, mixed) of engaging with the therapy/support (to the extent possible)

96% agreement

5(1)

d

Parent report of what they perceive to be the child's experience (positive, negative, mixed) of engaging with the therapy/support

95% agreement

5(1)

8.11 Reports from others

а

Reports from people who are involved in the delivery of the therapy/support

97% agreement

4 (1)

b

Reports from people who can provide insight into the child's progress towards the goals and/or general learning, participation, and wellbeing.

98% agreement

4 (1)

8.12 Progress data

а

Clinician collected progress data

94% agreement

b

Child collected progress data (to the extent possible) (e.g. self-report)

93% agreement

4 (1)

С

Parent-collected progress data

94% agreement

4 (1)

d

Progress data collected from other stakeholders (e.g., teacher checklist)

91% agreement

4 (1)

8.13 Assessment tools

е

Ethnographic interviewing to gather child/family views regarding progress and outcomes

71% agreement

4 (1)

f

Naturalistic sampling (e.g., recording and analysis of communication interactions, change in self-injurious behaviour)

83% agreement

4 (1)

Monitoring (continued)

Please read the below statement and view the attached file, as it is relevant for the next item we will ask you to rate.

Four items (regarding Assessment tools) did not have clear consensus agreement from practitioners in Round 1. These items were:

Item 8.13a - 'Norm-referenced assessments comparing child's skills and functioning with neurotypical children of the same age' - did not meet consensus agreement or consensus disagreement thresholds. Item 8.13b - 'Norm-referenced assessments comparing child's skills and functioning with a cohort of children on the autism spectrum' - had only partial consensus agreement from practitioners in Round 1. Item 8.13c - 'Criterion-references assessments comparing child's skills and functioning with pre-defined criteria such as developmental milestones' - had only partial consensus agreement from practitioners in Round 1. Item 8.13d - 'Curriculum-based assessments comparing child's progress towards a pre-specified set of goals' - had only partial consensus agreement from practitioners in Round 1. The distributions of ratings for these items is presented in the attached file.

[Attachment: "Round 1 results\_8.13a-d.png"]

We would like to ask you to rate these items again. Please note that these statements refer to POSSIBLE options that practitioners can select as a way of monitoring therapy/support progress and outcomes. It is not expected that these assessments would be required on every occasion or with every child.

# 8.13 The following assessment/evaluation tools and sources of information should be considered when monitoring therapy/support progress and outcomes: ASSESSMENT TOOLS

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
8.13aNorm-referenced assessments comparing a child's skills and functioning with neurotypical children of the same age	0	0	0	0	0
8.13bNorm-referenced assessments comparing a child's skills and functioning with a cohort of children on the autism spectrum	0	0	0	0	0
8.13Criterion-referenced assessment comparing a child's skills and functioning with pre-defined criteria such as developmental milestones	0	0	0	0	0
8.130 Curriculum-based assessments comparing a child's progress towards a pre-specified set of goals	0	0	0	0	0

### Monitoring (continued)

Round 1: Items with consensus achieved

Item 8.14 There was consensus agreement amongst practitioners in Round 1 that therapy/support goals should be reviewed every 6 months (8.14e) and every 12 months (8.14f).

\*Agreement = the proportion of practitioners who rated their agreement for the statement as 4 (agree) or 5 (strongly agree).

8.14 Therapy/support goals should be reviewed:

Outcome
---------

Mdn (IQR)

е

Every 6 months

87% agreement



Every 12 months

89% agreement

5 (1)

Monitoring (continued)

Please read the below statement and view the attached file, as it is relevant for the next item we will ask you to rate.

While there was clear consensus agreement that therapy/support goals should be reviewed every 6-12 months, there was no clear consensus over shorter timeframes.

Specifically, four items did not achieve consensus:

Item 8.14a – 'At each occasion of service' – did not achieve consensus agreement or disagreement Item 8.14b – 'Every month' - did not achieve consensus agreement or disagreement Item 8.14c – 'Every 2 months' - did not achieve consensus agreement or disagreement Item 8.14d – 'Every 3 months' – had partial consensus agreement The distributions of ratings for these items are presented in the attached file.

[Attachment: "Round 1 results\_8.14.png"]

# Having reviewed these results from Round 1, we would like to ask you to rate these items again.

8.14 Therapy/support goals should be reviewed:							
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree		
8.14aAt each occasion of service	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$		
8.14 Every month	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$		
8.14Œvery 2 months	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$		
8.14 Every 3 months	$\bigcirc$	0	$\bigcirc$	0	0		

Monitoring (continued)

Round 1: Items with consensus achieved

Item 8.15 There was consensus agreement amongst practitioners in Round 1 that therapy/support goals should be reviewed if/when the following occur:

\*Agreement = the proportion of practitioners who rated their agreement for the statement as 4 (agree) or 5 (strongly agree).

8.15 Therapy/support goals should be reviewed if/when:

Outcome

Mdn (IQR)

а

The child achieves a goal

94% agreement

4 (1)

b

The child and/or their family request new goals

95% agreement

4 (1)

С

The practitioner identifies new goals relevant to the child and/or their family

91% agreement



d

There are significant changes in the life of the child and/or family (e.g., transition to school, parental supervision, moving house)

95% agreement

4(1)

f

At a frequency, and in a manner, that is sufficient for the practitioner delivering the therapy/support to make evidence-based decisions and recommendations.

77% agreement

4 (1)

Monitoring (continued)

Please read the below statement and view the attached file, as it is relevant for the next item we will ask you to rate.

Two items did not achieve consensus.

Item 8.15e - 'At a frequency, and in a manner, specified by the child and family' – had partial consensus agreement from practitioners.

Item 8.15g - 'There is a change in the funding for services for the child and family' - had only partial consensus agreement from practitioners.

The distributions of ratings for these items are presented in the attached file.

[Attachment: "Round 1 results\_8.15e-g.png"]

# Having reviewed these results from Round 1, including the qualitative feedback, we have revised these items and would like to ask you to rate them again.

## 8.15 Therapy/support goals should be reviewed:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
3.15At a frequency, and in a manner, that is appropriate to the child and family.	0	0	0	0	0
3.15gf/when there is a change in the family's financial capacity to access services, including changes in available funding.	0	0	0	0	0

#### Monitoring (continued)

Round 1: Items with consensus achieved

Item 8.16 There was consensus agreement amongst practitioners in Round 1 that monitoring of therapy/support progress and outcomes should occur every 6 months (8.16e) and every 12 months (8.16f).

\*Agreement = the proportion of practitioners who rated their agreement for the statement as 4 (agree) or 5 (strongly agree).

8.16 At a minimum, the monitoring of therapy/support progress and outcomes should occur:

Outcome

Mdn (IQR)

e.

Every 6 months

77% agreement

4 (1)

# f.

Every 12 months

76% agreement



### Monitoring (continued)

Please read the below statement and view the attached file, as it is relevant for the next item we will ask you to rate.

While there was consensus agreement that monitoring of therapy/support progress and outcomes should occur every 6-12 months, there was no clear consensus over shorter timeframes.

Specifically, four items did not achieve consensus agreement disagreement amongst practitioners in Round 1:

Item 8.16a – 'At each occasion of service' Item 8.16b – 'Every month' Item 8.16c – 'Every 2 months' Item 8.16d – 'Every 3 months'

The distributions of ratings for these items are presented in the attached file.

[Attachment: "Round 1 results\_8.16a-d.png"]



# Having reviewed these results from Round 1, we would like to ask you to rate these items again.

8.16 At a minimum, the monitoring of therapy/support progress and outcomes should occur:						
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	
8.16aAt each occasion of service	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	
8.16 <b>E</b> very month	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	
8.16Œvery 2 months	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	
8.16 Every 3 months	0	0	0	0	0	

### Monitoring (continued)

Round 1: Items with consensus achieved

Item 8.17 There was consensus agreement amongst practitioners that the information gained through monitoring should be shared and discussed with the child, parents, other community members, other practitioners/specialists, and other organisations (8.17a-e). The majority of practitioners in Round 1 disagreed with the statement that information gained through monitoring should not be shared.

\*Agreement = the proportion of practitioners who rated their agreement for the statement as 4 (agree) or 5 (strongly agree).

\*Disagreement = the proportion of practitioners who rated their agreement for the statement as 1 (strongly disagree) or 2 (disagree).

8.17 The information gained through monitoring should:

Outcome

Mdn (IQR)

a.

Be shared and discussed with the child receiving the therapies/supports, if appropriate

98%

### agreement

5 (1)

b.

Be shared and discussed with the parents of the child receiving the therapies/supports\*

100%

agreement

5 (1)

c.

Be shared and discussed with other community members (nominated by the family) as the basis for supporting the child and/or family.



#### agreement

4 (1)

### d.

Be shared with other practitioners/specialists that support the child, as the basis for informing them of progress and/or inviting consultation\*

92%

### agreement

4 (1)

e.

Be shared with other organisations that support the child, as the basis for informing them of progress and/or inviting consultation (e.g., schools/day care)\*

84%

### agreement

4 (1)

```
f.
```

Not be disclosed

83% disagreement

2 (1)

\*At all times, it is assumed that people providing services will adhere to relevant rules and legislation (e.g., privacy, freedom of information).

Item 8.18 There was consensus agreement amongst practitioners in Round 1 that the information gained through monitoring may be shared during a face-to-face conversation (8.18b), in a written report (8.18d), in the manner preferred by the child and/or family (8.18f), and by a combination of different modes preferred by the child and/or family (8.18g).

8.18 The outcome of monitoring should:

Outcome

Mdn (IQR)

b.

Be shared during a face-to-face conversation

73% agreement

Be shared in a written report

72% agreement

4 (1)

f.

Be shared and discussed in the manner preferred by the child and/or family

89% agreement

5 (1)

g.

Be shared by a combination of different modes preferred by the child and/or family

94% agreement

5 (1)

Monitoring (continued)

Please read the below statement and view the attached file, as it is relevant for the next item we will ask you to rate.

Three items did not achieve consensus.

Item 8.18a – 'Be shared during a telephone conversation' – achieved partial consensus agreement Item 8.18c – 'Be shared during a videoconference conversation' – achieved partial consensus agreement Item 8.18e – 'Be shared via graphical mode (i.e., drawing, art)' – did not achieve consensus agreement or disagreement. The distributions of ratings for these items are presented in the attached file.

[Attachment: "Round 1 results\_8.18a c e.png"]

Having reviewed these results from Round 1, including the qualitative feedback, we have reviewed these items and would like to ask you to rate these items again. Please note that these are listed as potential options that should be considered for sharing monitoring information - the manner in which information is ultimately shared would be tailored to the particular circumstances of the child and family.

8.18 The focus of this item is on the mode by which monitoring information may be shared. The manner in which this would then occur would account for individual and cultural preferences regarding the nature of the interaction.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
8.18&Be shared during a telephone conversation	0	$\bigcirc$	0	0	0
8.18ße shared during a videoconference conversation	0	0	0	0	0
8.18& shared in other ways that may be meaningful to the child and/or family (e.g., graphical mode such as drawing, art)	0	0	0	0	0
The next section of this survey refe Safeguards'. There was consensus items in this section in Round 1. As such, what would you like to do	agreement for a		See the feedbac Skip to the next		L
Section 9 of 10.					
Quality and Safeguards					
Round 1: Items with consensus ac	hieved				
Item 9.1 There was consensus agr children on the autism spectrum a					
*Agreement = the proportion of p	ractitioners who	rated the statem	ent as 4 (importa	ant) or 5 (very i	important).
Outcome					

Mdn (IQR)

How important do you think it is that the safety of children on the autism spectrum and their families is ensured when accessing therapies and supports?

100% agreement

5 (0)

autism spectrum and their families:

\*Agreement = the proportion of practitioners who rated their agreement for the statement as 4 (agree) or 5 (strongly agree)

9.2 Please indicate the extent to which you agree each of the following are approaches that should be incorporated in clinical practice to ensure the safety, comfort, and wellbeing of individuals on the autism spectrum and their families:

Outcome

Mdn (IQR)

a.

Ensuring practitioners have up-to-date knowledge of the empirical evidence for therapies/supports (including research on the views and preferences of autistic people)

100% agreement

5 (0)

b.

Ensuring practitioners have adequate experience and skills in the selection, delivery and assessment of therapies/supports

98.5% agreement

5 (0)

c.

Ensuring that practitioners have access to clinical supervision

97% agreement

5 (0)

d.

Ensuring the effectiveness and safety of therapies/supports being delivered by practitioners have been validated through well-designed research studies

89% agreement

5 (1)

e.

Ongoing monitoring of therapy/support outcomes

97% agreement

5 (1)

# f.

Ongoing assessment of support needs

96% agreement

5(1)

# g.

Practitioners working in ways that are consistent with relevant conventions, including the United Nations Convention on the Rights of Persons with Disabilities and the United Nations Convention on the Rights of the Child

100% agreement

5 (0)

# h.

Practitioners following relevant practice/ professional processes and legislative requirements (e.g., Disability Discrimination Act, NDIS rules)

98.5% agreement

5 (0)

i.

Ensuring that children and their families have a clear method and pathway for raising concerns

100% agreement

5 (0)

j.

Ensuring the provision of clear, appropriate, and accurate information between practitioners and families at all stages (including to ensure informed consent is validly obtained)

100% agreement

5 (0)

Section 10 of 10.

Knowledge, skills and/or experiences of practitioners providing therapies and supports

This section contains two new questions that were developed based on qualitative feedback from the Round 1 Delphi and our additional community consultations activities, including focus groups and an online survey.

In this section, we ask you to rate your agreement with statements about what knowledge, skills, and/or experience you believe are required of practitioners who provide therapies and supports to children on the autism spectrum and their family.

# **NEW ITEM**

# 10.1 It is important that practitioners providing therapies and supports to children on the autism spectrum and their families obtain relevant knowledge, skills and/or experience in the following areas:

following areas:					
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
10.1aTypical and atypical development across the age ranges of children with whom they conduct their clinical work	0	0	0	0	0
10.1bThe impact of other important considerations, such as intellectual and/or communication capacity, culturally, linguistically and/or socioeconomically diverse background, regional or remote location, or complex psychosocial factors, on the provision of therapy/support	0	0	0	0	0
10.1cThe range of therapies and supports appropriate for children on the autism spectrum and other neurodevelopmental disorders, within their scope of practice	0	0	0	0	0
10.1dThe theoretical principle(s) underpinning the therapies and supports that that they provide ('Theoretical principles' refers to the purported reasons that the therapies and supports deliver the intended therapeutic effect, i.e., how and why the therapy/support works).	0	0	0	0	0
10.1eThe current best available research that the therapies and supports they provide delivers the intended therapeutic effect	0	0	0	0	0
10.1fThe circumstances when therapies and supports may and may not be appropriate for a given child and family	0	0	0	0	0

10.1g



Clinical reasoning in evaluating evidence, integrating information and decision-making	0	0	0	0	0
10.1IClinical documentation and reporting	0	$\bigcirc$	0	0	$\bigcirc$
10.1iCommunicating with children on the autism spectrum and their family members	0	0	0	0	0
10.1jUnderstanding of neurodiversity affirming practices	0	0	0	0	$\bigcirc$
('Neurodiversity affirming' here refers to practices that affirm the child's neurodivergent identity, rather than seeking to fix or cure their neurotype.)					
10.1k Are there other areas in whic providing therapies and supports to autism spectrum and their families relevant training, expertise, and kn		Yes No			
Please describe the other areas in v practitioners providing therapies an children on the autism spectrum an should have relevant training, expe knowledge.	_				



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# **NEW ITEM**

10.2 In addition to the foundation qualification(s) relevant to their professional discipline, it is important that practitioners providing therapies and supports to children on the autism spectrum and their families obtain and/or maintain their skills and expertise through:					
spectrum and their familie	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
10.2æeer observation	$\bigcirc$	$\bigcirc$	$\bigcirc$	0	$\bigcirc$
10.2bPeer supervision	$\bigcirc$	$\bigcirc$	$\bigcirc$	0	$\bigcirc$
10.2 Peer mentoring	$\bigcirc$	$\bigcirc$	$\bigcirc$	0	$\bigcirc$
10.2 <b>F</b> ormal training courses	$\bigcirc$	$\bigcirc$	$\bigcirc$	0	$\bigcirc$
10.2 <b>&amp;</b> urther qualifications	0	0	$\bigcirc$	0	$\bigcirc$
10.2f Are there other types of rel expertise practitioners should ob therapies and supports to childre spectrum and their families? Please describe the other types of	tain when providin n on the autism		Yes No		

providing therapies and supports to children on the autism spectrum and their families.



National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia

 Appendix 10.1
 Brief Online Survey





# Supporting Children National Guideline

[Attachment: "Brief Survey Video Script.docx"]





Development of a National Practice Guideline for Supporting Children on the Autism Spectrum and their Families: Three Questions about Therapies and Supports

(GU ref no:2021/843)

Part 1: Participation Information

#### What is this project about?

The Autism CRC is leading the development of a National Practice Guideline for supporting children on the autism spectrum and their families in Australia. The Guideline will be developed based on both research and consultation with the community. The result will be a set of recommendations to guide the delivery of therapy and support services for children on the autism spectrum and their families.

Why are you being invited to participate?

We want to hear the voices of all community members with an interest in the Guideline, including those of children and young people, as well as those of adults who communicate mainly in ways other than speech. We are inviting you to give consent for your child, young person, or adult person to complete a three-question survey about their views on accessing therapies and supports.

Who can participate in the research?

#### We want to hear from:

Parents of children, young people, and adult people on the autism spectrum. The children, young people, and adults themselves.

What is this activity? It is a set of three questions that you would ask your child, young person, or adult person. They can write their response or you can write down what they say. The questions ask for their opinion about their most and least favourite things about accessing therapies and supports, and what they think could be done better.

Who is it designed for? We have designed this activity with children, young people, and adults who are able to ask and answer questions in mind.

How long will it take? This should take between 5-15 minutes to complete, depending on how much information they want to share.

What will you need to do? We will provide you with the questions on screen, and the child, young person, or adult person (with or without your help) can type in their responses. It is important to note that although you can help with typing, the answers for this activity need to be their own words (a voice to text option may be available to you, depending on the device you use).

Can you have a look first? Yes, you can click on the pdf link below to see the instructions and questions you will be asked.



Participation is voluntary for you and your child. If you decide not to participate, this decision will not disadvantage you or impact your relationship with Griffith University or any other institutions affiliated with this research.

### What happens if you/they have a change of mind?

If you and your child begin participating but then change your mind:

There is a button at the end of the questionnaire that you/your child can select to indicate that you no longer want the information you provided to be used in the project. If you decide to withdraw consent after submitting the survey, your individual responses will not be able to identified, due to the anonymous nature of data collection. If you are unsure, you can contact the research team at supportingchildren@griffith.edu.au What are the benefits of participating?

We hope that it will be a positive experience for you and your child, young person, or adult person in helping to inform the Guideline. While you may not receive any direct benefits from participating in this research, the benefits of the research more broadly include an increase in knowledge and understanding regarding the most important factors relevant to the delivery of therapies and supports for young children on the autism spectrum.

#### Are there any potential risks?

We do not believe there are any direct risks associated with participation in this research. However, we understand that for some people thinking and talking about their experiences, can lead to a mixture of emotions, including sadness. There is also the possibility that the person completing the survey may respond in ways that you were not expecting, such as sharing negative experiences about accessing therapies and supports. If you, the person completing the survey, or anyone close to you, participates in this research and experiences any distress, we ask that you contact Lifeline on 13 11 14 and Kidshelpline on 1800 55 1800. If the person answering the survey raises any issues that require further investigation, please contact the relevant authorities such as the police or Government department responsible for services and safety in your State or Territory.

Who are the researchers?

A/Professor David Trembath, Menzies Health Institute Queensland, Griffith University

Professor Andrew Whitehouse, Bennett Chair of Autism & Director, CliniKids, Telethon Kids Institute

Dr Kandice Varcin, Research Fellow, Menzies Health Institute Queensland, Griffith University

Dr Rhylee Sulek, Research Fellow, School of Health Sciences and Social Work, Griffith University

Dr Hannah Waddington, Lecturer, School of Education, Victoria University of Wellington

Ms Sarah Pillar, Integration Project Manager, CliniKids, Telethon Kids Institute

### Who can you contact for further information?

You might be unsure if you are able to participate or unsure about how the research process works. We encourage you to contact A/Prof David Trembath at supportingchildren@griffith.edu.au

to discuss this and anything else you might wish to talk about in relation to the project.

How can you receive information about the research results?

Regular updates regarding the progress of the Guideline including a summary of the outcomes of this set of consultation activities, will be provided on the National Practice Guideline Community Hub website. Participants will be able to access a copy of the Guideline, once published. If you would like to discuss this further with the research team, you can do so via email.

How can you trust this research is safe for me and/or my child/young person/adult person?

This research is being conducted by skilled research staff and supported by a Guideline Development Group that includes people with a range of knowledge and experience, including autistic adults and parents raising children on the autism spectrum. The team has carefully designed the activities to include only questions that are relevant and to ensure that different activities can cater for all children, young people, and adults who communicate mainly in ways other than speech. Only anonymous, summarised and combined information will be used and reported.

Part 2: Ethical Information we must provide you.

#### What will be done with the information collected?

We will use the information you and others provide to help develop a set of draft recommendations for supporting children and their families, and then share these with the community for feedback. The information will be published and presented in public, including through the Guideline document but also potentially in presentations, academic journals, online newspapers and newsletters, and social media.

#### When we share our findings, we will:

Present a summary of de-identified information about who participated (e.g., ages, communication skills). Present the themes that emerge from responses, and use direct quotes from participants to help explain what the themes are about. Any quotes will be presented anonymously, not using their real name. It is possible that if you or the person who completes the survey reads the findings or sees them presented at a workshop or seminar they might recognise their quotes, but we will never attach real names to these quotes.

#### How will privacy be protected?

The conduct of this research involves the collection, access, storage and/or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. Your anonymity will at all times be safeguarded. For further information consult the University's Privacy Plan at http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan or telephone (07) 3735 4375.

To further explain how your privacy will be protected, all of the data that is collected through the survey will be completely confidential. All data will be stored securely on an encrypted and password protected storage drive that will be accessible only by the members of the research team. This data will be stored securely for five years.

#### The ethical conduct of this research

Griffith University conducts research in accordance with the National Statement on Ethical Conduct in Human Research. Please feel free to contact the researchers if you have any questions (A/Prof David Trembath, supportingchildren@griffith.edu.au). If you have any additional questions or concerns about ethical issues, please contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee (research-ethics@griffith.edu.au; 07 3735 4375).

#### THIS SURVEY WILL CLOSE AT 11:59 PM ON 30TH APRIL, 2022.

[Attachment: "Brief survey\_Participant Information statement.docx"]

Please click on the pdf attachment if you would like to view a copy of the instructions and survey before deciding to participate.

[Attachment: "Brief survey\_activity and questions.pdf"]

[Attachment: "Voice-to-text instructions.doc"]

#### **Consent to Participate**

Consent Form for the Research Project:

Development of a National Practice Guideline for Supporting Children on the Autism Spectrum and their Families: Three Questions about Therapies and Supports

(GU ref no:2021/843)

By selecting the check box below, I confirm that I have read and understood the information sheet and I have noted that:

I understand that my child's/young person's/adult person's participation in this research will involve them completing a three question survey about therapies and supports. I understand that I will be responsible for providing informed consent, and then sharing/facilitating their access to or completion of the task. I understand that the information collected will be used to inform the development of National Practice Guideline for supporting children on the autism spectrum and their families in Australia. I understand that written responses they provide in this activity may be reproduced in the Guideline and related research activities (e.g., community presentations, research articles, online news and newsletters, social media), provided they contain no personally identifying information. I have read the Information Statement, or someone has read it to me in a language that I understand. I understand why this research is being conducted and what participating will involve. I understand any risks as described above. I have had an opportunity to ask questions and I am satisfied with the answers I have received. I understand that I am free, and my child/young person/adult person is free, to withdraw at any time during the project without question or consequence. I understand that I can contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee if I have any concerns about the ethical conduct of this project I agree to participate in the research.

I agree for my child and/or young person to take part	⊖ No	
in this research	⊖ Yes	

Thank you again for your interest in this research.

As a reminder, you will have the opportunity to save your responses and return at a later time to complete this survey. To assist us in our data collection, we ask that you please finalise your responses within one week of starting the survey. We will not analyse any additional answers provided after this time.

Your young person's first and last name:

(Note: this information is only collected to obtain
consent and is not used in the research)

Your first and last name:

(Note: this information is only collected to obtain consent and is not used in the research)



#### **Parent and Child Demographics**

Please answer the following questions so that we can describe, in general terms, children and adults who participated in this aspect of the study. All questions are optional, but it is very helpful to us if you complete them as this helps us interpret the information provided.

About you:	○ Yes ○ No
Are you the parent/primary caregiver/legal guardian of a child on the autism spectrum?	
About your child:	
How old is your child (years)	
With what gender does you child identify?	<ul> <li>Female</li> <li>Male</li> <li>Non-binary</li> <li>Prefer not to say</li> <li>Other</li> </ul>
Please specify if other	
Are they of Aboriginal and/or Torres Strait Islander origin?	<ul> <li>No</li> <li>Yes, Aboriginal</li> <li>Yes, Torres Strait Islander</li> <li>Yes, both Aboriginal and Torres Strait Islander</li> </ul>
Were they born in Australia?	○ No ○ Yes
Are they living in a home where a language other than English is spoken?	○ No ○ Yes
Has your child received a formal diagnosis of autism (or a related condition e.g., Asperger's, Pervasive Developmental Disorder)?	○ No ○ Yes
At what age was your child diagnosed (please round to the nearest year)?	
Did you access therapies and/or supports for your child at some stage between the ages of 0-6 years?	○ No ○ Yes
Did you access therapies and/or supports for your child at some stage between the ages of 7-12 years?	○ No ○ Yes

projectredcap.org

The below table outlines the three levels of support required within the autism spectrum as described in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5).

Level

Social communication

Restricted, repetitive behaviors

Level 3 "Requiring very substantial support"

Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches

Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.

Level 2 "Requiring substantial support"

Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.

Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.

#### Level 1 "Requiring support"

Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.

Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

If your child was diagnosed under the DSM-5, please indicate which support level is associated with their diagnosis.	<ul> <li>Level 1 - Requires support</li> <li>Level 2 - Requires substantial support</li> <li>Level 3 - Required very substantial support</li> <li>I am unsure</li> <li>I would prefer not to say</li> </ul>
If your child has not yet received a formal diagnosis or was not diagnosed as a child under the DSM-5, please indicate which level you feel would have best represented their support needs as a child.	<ul> <li>Level 1 - Requires support</li> <li>Level 2 - Requires substantial support</li> <li>Level 3 - Required very substantial support</li> <li>I am unsure</li> <li>I would prefer not to say</li> </ul>



Three Questions – Task Instructions/Survey Development of a National Practice Guideline for Supporting Children on the Autism Spectrum and their Families:

Three Questions about Therapies and Supports

#### Instructions

Please explain this activity to your child, young person, or adult person in a way that matches their understanding and gives you confidence that they are comfortable to be involved.

If your child or young person is 0-12 years of age, please ask them to talk/write about therapies and supports they are currently accessing.

If the young person or adult person is older than 12 years, please ask them to talk/write about what it was like accessing therapies and supports when they were under 12 years of age.

They can complete the survey independently or with help. For example, they can type their answers, they can use a voice-to-text option if your device allows it, or you can offer to type their responses. However, if you are typing, please type exactly what they say. Do not change, correct, or add words or ideas. For this survey, we really want to hear what they have to say in their own words, including any errors or profanities.

You can call the therapies or supports that your child, young person, or adult person has accessed and/or is accessing whatever will make the most sense to that person, and use any other materials that might be helpful. For example, some people refer to 'speech therapy' while others refer to the name of the person of the speech pathologist. Some people may be able to respond based just on the name, but others may find it helpful to refer to a picture of the person, the organisation's website, a visual support, or any other object or artefact that is helpful to them.

They can answer the questions for one or more therapies and supports, either by talking about them together in one response or by answering the questions multiple times (up to 5 times).

Question for you, the parent/caregiver

What type of therapies/supports will you ask about?

Questions for the autistic child, young person, or adult person on the autism spectrum:

1. What was/is your most favourite thing about.... [please use the name of the therapy/support that will make the most sense to the person]

For example, you might ask "What is your most favourite thing about going to occupational therapy?" Alternatively, you could say the name of the person they see, such as "What is your most favourite thing about seeing Jessica?" (the occupational therapist)



2. What was/is your least favourite thing about.... [please use the name of the therapy/support that will make the most sense to the person] For example, you might ask, "What is your least favourite thing about going to occupational therapy?" Alternatively, you could say the name of the person they see, such as "What is your least favourite thing about seeing Jessica?" (the occupational therapist) 3. What could make it better?.... [please use the name of the therapy/support that will make the most sense to the person] For example, you might ask, "What could make going to occupational therapy better?" Alternatively, you could say the name of the person they see, such as "What could make seeing Jessica (the occupational therapist) better?" ⊖ Yes Would you like to enter another response ⊖ No 1. What was/is your most favourite thing about.... [please use the name of the therapy/support that will make the most sense to the person] For example, you might ask "What is your most favourite thing about going to occupational therapy?" Alternatively, you could say the name of the person they see, such as "What is your most favourite thing about seeing Jessica?" (the occupational therapist) 2. What was/is your least favourite thing about.... [please use the name of the therapy/support that will make the most sense to the person] For example, you might ask, "What is your least favourite thing about going to occupational therapy?" Alternatively, you could say the name of the person they see, such as "What is your least favourite thing about seeing Jessica?" (the occupational therapist)



3. What could make it better? [please use the name of the therapy/support that will make the most sense to the person]	
For example, you might ask, "What could make going to occupational therapy better?" Alternatively, you could say the name of the person they see, such as "What could make seeing Jessica (the occupational therapist) better?"	
Would you like to enter another response	○ Yes ○ No
<ol> <li>What was/is your most favourite thing about</li> <li>[please use the name of the therapy/support that will make the most sense to the person]</li> </ol>	
For example, you might ask "What is your most favourite thing about going to occupational therapy?" Alternatively, you could say the name of the person they see, such as "What is your most favourite thing about seeing Jessica?" (the occupational therapist)	
2. What was/is your least favourite thing about [please use the name of the therapy/support that will make the most sense to the person]	
For example, you might ask, "What is your least favourite thing about going to occupational therapy?" Alternatively, you could say the name of the person they see, such as "What is your least favourite thing about seeing Jessica?" (the occupational therapist)	
3. What could make it better? [please use the name of the therapy/support that will make the most sense to the person]	
For example, you might ask, "What could make going to occupational therapy better?" Alternatively, you could say the name of the person they see, such as "What could make seeing Jessica (the occupational therapist) better?"	
Would you like to enter another response	○ Yes ○ No

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1. What was/is your most favourite thing about
[please use the name of the therapy/support that will
make the most sense to the person]

For example, you might ask "What is your most favourite thing about going to occupational therapy?" Alternatively, you could say the name of the person they see, such as "What is your most favourite thing about seeing Jessica?" (the occupational therapist)

2. What was/is your least favourite thing about.... [please use the name of the therapy/support that will make the most sense to the person]

For example, you might ask, "What is your least favourite thing about going to occupational therapy?" Alternatively, you could say the name of the person they see, such as "What is your least favourite thing about seeing Jessica?" (the occupational therapist)

3. What could make it better?.... [please use the name of the therapy/support that will make the most sense to the person]

For example, you might ask, "What could make going to occupational therapy better?" Alternatively, you could say the name of the person they see, such as "What could make seeing Jessica (the occupational therapist) better?"

Would you like to enter another response

1. What was/is your most favourite thing about.... [please use the name of the therapy/support that will make the most sense to the person]

For example, you might ask "What is your most favourite thing about going to occupational therapy?" Alternatively, you could say the name of the person they see, such as "What is your most favourite thing about seeing Jessica?" (the occupational therapist)

2. What was/is your least favourite thing about.... [please use the name of the therapy/support that will make the most sense to the person]

For example, you might ask, "What is your least favourite thing about going to occupational therapy?" Alternatively, you could say the name of the person they see, such as "What is your least favourite thing about seeing Jessica?" (the occupational therapist) ○ Yes



3. What could make it better? [please use the name of the therapy/support that will make the most sense to the person]	
For example, you might ask, "What could make going to occupational therapy better?" Alternatively, you could say the name of the person they see, such as "What could make seeing Jessica (the occupational therapist) better?"	
Questions for you, the parent/caregiver:	
What type of therapies/supports was your child, young person, or adult person talking about? (if different to above)	
Which do you think they are reflecting on?	
The whole time they accessed these therapies and supports Just part of the time they accessed these therapies and supports (e.g., at the start, more recently, at one point in time)	
Final questions for you, the parent/caregiver:	
1. How was the survey completed?	<ul> <li>By the autistic child, young person, or adult person on the autism spectrum</li> <li>With the help of a parent/caregiver</li> </ul>
2. Is there anything else you would like to share to help us understand their responses?	
We would like to ask you again, now that you have provided information: Are you happy for us to use the information you provided?	○ Yes ○ No
Please note: all information collected through the survey will be completely confidential.	
If you have any final comments, please feel welcome to share them here.	



#### A note from the research team

Thank you very much for answering the questions. The information that you and others provide will directly inform the recommendations in the guideline.

The next step for the research team will be to analyse all of the information provided. The Guideline Development Group will then formulate recommendations.

If you have not already done so, please register with Autism CRC to receive updates about the guideline. You can do so here.

Before we finish, we want to take a moment to acknowledge the time it takes to complete surveys like this. While we are not able to send a personal response to each person who completes it, please know that we genuinely value the information you have provided and will be reading every word.

We also acknowledge that if you are an autistic person, a parent, or other family members of a child on the autism spectrum, you will have shared in the survey insights from your own life, your experience, and your expertise. It is likely that you will have been asked to do this many times before, and we warmly thank you for being willing to do so again here, to help make the guideline the best it can be. We simply could not do this piece of important work, without your insights. Thank you.

We look forward to sharing updates, and the guideline in due course, via Autism CRC's website.

Sincerely,

Rhylee, Kandice, Hannah, Sarah, David, and Andrew, on behalf of the Guideline Development Group.



National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia

 Appendix 11.1
 Parent Reflection Survey





## Supporting Children National Guideline





Development of a National Practice Guideline for Supporting Children on the Autism Spectrum and their Families: Sharing Experiences through Observation and Reflection

(GU ref no:2021/843)

Part 1: Participation Information

#### What is this project about?

The Autism CRC is leading the development of a National Practice Guideline for supporting children on the autism spectrum and their families in Australia. The Guideline will be developed based on both research and consultation with the community. The result will be a set of recommendations to guide the delivery of therapy and support services for children on the autism spectrum and their families.

#### Why are you being invited to participate?

We want to hear the voices of all community members with an interest in the Guideline, including those of children and young people, as well as those of adults who communicate mainly in ways other than speech. We are inviting you to reflect on your child's experiences of accessing therapies and supports when they are/were between the ages of 0-12 years, based on your observation.

Who can participate in the research?

#### This activity caters for:

Parents of children who communicate/d mostly in ways other than speech during the ages 0-12 years, as they access/ed therapies and supports. The children and young people, whose experiences will be reflected on. What is it?

We would ask parents to share their observations of their child or young person accessing therapies and supports. These may be current experiences, or reflections on the past. We want to learn from your observations of their emotions and actions, that can give insights into how they may have been feeling, what they may have been thinking, and what they may have been experiencing. We understand that many children, young people, and adults communicate mainly in ways other than speech, and that all emotions and actions are communication. Our goal here is to try to gain an understanding of their experiences, based on the insights of people who know them best.

#### Who is it designed for?

We have designed this activity with children and young people who communicate mainly in ways other than speech in mind. We are focusing on therapies and supports received when they were 0-12 years of age, but the reflections can be current or from the past.

How long will it take?

We anticipate that sharing this will take between 5-15 minutes, depending on how much you would like to tell us.

#### What will you need to do?

We will give you some instructions about what to reflect on, and a set of questions we would like you to answer.

07/08/2022 2:53pm

#### Can you have a look first?

Yes, you can click on the pdf link below to see a copy of the instructions and questions you will be asked.

#### Do you have to participate?

Participation is voluntary. If you decide not to participate, this decision will not disadvantage you or impact your relationship with Griffith University or any other institutions affiliated with this research.

#### What happens if you/they have a change of mind?

If you and your child/young person/adult person begin participating but then change your mind, there is a button at the end of the questionnaire that you/your child can select to indicate that you no longer want the information you provided to be used in the project. If you decide to withdraw consent after submitting the survey, your individual responses will not be able to identified, due to the anonymous nature of data collection. If you are unsure you can contact the research team at supportingchildren@griffith.edu.au

#### What are the benefits of participating?

We hope that it will be a positive experience for you and your child in helping to inform the Guideline. While you may not receive any direct benefits from participating in this research, the benefits of the research more broadly include an increase in knowledge and understanding regarding the most important factors relevant to the delivery of therapies and supports for young children on the autism spectrum.

#### Are there any potential risks?

We do not believe there are any direct risks associated with participation in this research. However, we understand that for some people thinking and talking about their experiences, can lead to a mixture of emotions, including sadness. If you or anyone close to you, participates in this research and experiences any distress, we ask that you contact Lifeline on 13 11 14.

Who are the researchers?

A/Professor David Trembath, Menzies Health Institute Queensland, Griffith University

Professor Andrew Whitehouse, Bennett Chair of Autism & Director, CliniKids, Telethon Kids Institute

Dr Kandice Varcin, Research Fellow, Menzies Health Institute Queensland, Griffith University

Dr Rhylee Sulek, Research Fellow, School of Health Sciences and Social Work, Griffith University

Dr Hannah Waddington, Lecturer, School of Education, Victoria University of Wellington

Ms Sarah Pillar, Integration Project Manager, CliniKids, Telethon Kids Institute

Who can you contact for further information?

You might be unsure if you are able to participate or unsure about how the research process works. We encourage you to contact A/Prof David Trembath at supportingchildren@griffith.edu.au

to discuss this and anything else you might wish to talk about in relation to the project.

How can you receive information about the research results?

Regular updates regarding the progress of the Guideline including a summary of the outcomes of this set of consultation activities, will be provided on the National Practice Guideline Community Hub website. Participants will be able to access a copy of the Guideline, once published. If you would like to discuss this further with the research team, you can do so via email.

#### How can you trust this research is safe for me?

This research is being conducted by skilled research staff and supported by a Guideline Development Group that includes people with a range of knowledge and experience, including autistic adults and parents raising children on the autism spectrum. The team has carefully designed the activities to include only questions that are relevant and to ensure that different activities can cater for all children. Only anonymous, summarised and combined information will be used and reported.

Part 2: Ethical Information we must provide you.

What will be done with the information collected?

We will use the information you and others provide to help develop a set of draft recommendations for supporting children and their families, and then share these with the community for feedback. The information will be published and presented in public, including through the Guideline document but also potentially in presentations, academic journals, online newspapers and newsletters, and social media.

#### When we share our findings, we will:

Present a summary of de-identified information about who participated (e.g., the children's ages, their communication skills). Present the themes that emerge from the information you and other parents share, and use direct quotes to help explain what the themes are about. Any quotes will be presented anonymously, not using your child's real name. It is possible that if you read the findings or see them presented at a workshop or seminar that you might recognise your own quotes/artwork, but we will never attach real names to these quotes or drawings. How will privacy be protected?

The conduct of this research involves the collection, access, storage and/or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. Your anonymity will at all times be safeguarded. For further information consult the University's Privacy Plan at http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan or telephone (07) 3735 4375.

To further explain how your privacy will be protected, all of the data that is collected through the survey will be completely confidential. All data will be stored securely on an encrypted and password protected storage drive that will be accessible only by the members of the research team. This data will be stored securely for five years.

#### The ethical conduct of this research

Griffith University conducts research in accordance with the National Statement on Ethical Conduct in Human Research. Please feel free to contact the researchers if you have any questions (A/Prof David Trembath, supportingchildren@griffith.edu.au). If you have any additional questions or concerns about ethical issues, please contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee (research-ethics@griffith.edu.au; 07 3735 4375).

#### THIS SURVEY WILL CLOSE AT 11:59 PM ON 30TH APRIL, 2022.

[Attachment: "Child Parent Observation and Reflection\_Participant Information statement.docx"]

Please click on the pdf attachment if you would like to view a copy of the survey before deciding to participate.

[Attachment: "Parent Observation and Reflection\_activity & questions.pdf"]

Consent Form for the Research Project:

Development of a National Practice Guideline for Supporting Children on the Autism Spectrum and their Families: Sharing Experiences through Observation and Reflection

(GU ref no:2021/843)

By selecting the check box below, I confirm that I have read and understood the information sheet and I have noted that:

I understand that my/my child's participation in this research will involve me sharing observations about my child's experiences accessing therapies and supports when they are/were between the ages of 0-12 years. I understand that I will be responsible for providing informed consent, and then sharing/facilitating my child's access to or completion of the task. I understand that the information collected will be used to inform the development of a National Practice Guideline for supporting children on the autism spectrum and their families in Australia. I understand that written responses I provide in this activity may be reproduced in the Guideline and related research activities (e.g., community presentations, research articles, online news and newsletters, social media), provided they contain no personally identifying information. I have read the Information Statement, or someone has read it to me in a language that I understand. I understand why this research is being conducted and how I and my child can participate I understand any risks as described above. I have had an opportunity to ask questions and I am satisfied with the answers I have received. I understand that I am free, and my child is free, to withdraw at any time during the project without comment or consequence. I understand that I can contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee if I have any concerns about the ethical conduct of this project. I agree to participate in the research.

Your child's first and last name:		
(Note: this information is only collected to obtain consent and is not used in the research)		
Your first and last name:		
(Note: this information is only collected to obtain consent and is not used in the research)		
Contact email:		
(Note: this information is only collected to obtain consent and is not used in the research)		
I agree to participate in this research project and for my child to participate in this research project.	○ No ○ Yes	

Thank you again for your interest in this research.

As a reminder, you will have the opportunity to save your responses and return at a later time to complete this survey. To assist us in our data collection, we ask that you please finalise your responses within one week of starting the survey. We will not analyse any additional answers provided after this time.



# Parent/child demographic survey - Parents Please answer the following questions so that we can describe, in general terms, children and adults who participated in this aspect of the study. All questions are optional, but it is very helpful to us if you complete them as this helps us interpret the information provided.

About you:	○ Yes ○ No
Are you the parent/primary caregiver/legal guardian of a child on the autism spectrum?	
About your child:	
What is their age? (in years)	
With what gender does you child identify?	<ul> <li>Female</li> <li>Male</li> <li>Non-binary</li> <li>Prefer not to say</li> <li>Other</li> </ul>
Please specify if other	
Are they of Aboriginal and/or Torres Strait Islander origin?	<ul> <li>No</li> <li>Yes, Aboriginal</li> <li>Yes, Torres Strait Islander</li> <li>Yes, both Aboriginal and Torres Strait Islander</li> </ul>
Were they born in Australia?	○ No ○ Yes
Are they living in home where a language other than English is spoken?	○ No ○ Yes
Has your child received a formal diagnosis of autism (or a related condition e.g., Asperger's, Pervasive Developmental Disorder)?	○ No ○ Yes
At what age was your child diagnosed (please round to the nearest year)?	
Did you access therapies and/or supports for your child at some stage between the ages of 0-6 years?	○ No ○ Yes
Did you access therapies and/or supports for your child at some stage between the ages of 7-12 years?	○ No ○ Yes

Page 6

The below table outlines the three levels of support required within the autism spectrum as described in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5).

Level

Social communication

Restricted, repetitive behaviors

#### Level 3 "Requiring very substantial support"

Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches

Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.

#### Level 2 "Requiring substantial support"

Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.

Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.

#### Level 1 "Requiring support"

Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.

Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

If your child was diagnosed under the DSM-5, please indicate which support level is associated with their diagnosis.	<ul> <li>Level 1 - Requires support</li> <li>Level 2 - Requires substantial support</li> <li>Level 3 - Required very substantial support</li> <li>I am unsure</li> <li>I would prefer not to say</li> </ul>
If your child has not yet received a formal diagnosis or was not diagnosed as a child under the DSM-5, please indicate which level you feel would have best represented their support needs as a child.	<ul> <li>Level 1 - Requires support</li> <li>Level 2 - Requires substantial support</li> <li>Level 3 - Required very substantial support</li> <li>I am unsure</li> </ul>



#### Sharing Experiences through Observation and Reflection

- Task Instructions/Survey

Development of a National Practice Guideline for Supporting Children on the Autism Spectrum and their Families: Sharing Experiences through Observation and Reflection

#### Instructions

Please explain this activity to your child, young person, or adult person in a way that matches their understanding and gives you confidence that they are comfortable to be involved.

Reflect on your experiences observing your child or young person as they access/ed therapies and supports. This can be before, during, and/or after they access/ed them. If your child or young person is 0-12 years of age, please reflect on their experiences of therapies and supports they are currently accessing. Alternatively, you can reflect on the experiences of your young person or adult person accessing services in the past, when they were 0-12 years of age.

Please share your reflections by answering the questions below

Questions for you, the parent/caregiver:		
<ol> <li>What types of therapies and supports are you reflecting on?</li> </ol>		
2. Over what period of time are you reflecting (e.g., a particular day, a number of weeks, a number of months, a number of years)?		
You can answer the following questions based on what is hap	opening now or happened in the past:	
1. What do you think they currently like (or did like if in the past) about accessing these therapies and supports? How do/did they show you through their emotions and actions?		
2. What do you think they do not like (or did not like if in the past) about accessing these therapies and supports? How do/did they show you through their emotions and actions?		
3. What do you think they would like to change about accessing these therapies and supports? How do/did they show you through their emotions and actions?		
<ol> <li>Is there anything else you would like to share to help us understand their experiences of accessing therapies and supports.</li> </ol>		



We would like to ask you again, now that you have provided information: Are you happy for us to use the information you provided? ⊖ Yes ⊖ No

Please note: all information collected through the survey will be completely confidential.

A note from the research team

Thank you very much for completing the activity. The information that you and others provide will directly inform the recommendations in the guideline.

The next step for the research team will be to analyse all of the information provided. The Guideline Development Group will then formulate recommendations.

If you have not already done so, please register with Autism CRC to receive updates about the guideline. You can do so here.

Before we finish, we want to take a moment to acknowledge the time it takes to participate in research projects like this. While we are not able to send a personal response to each person who completes it, please know that we genuinely value the information you have provided and will be reading every word.

We simply could not do this piece of important work without your insights. Thank you. We look forward to sharing updates, and the guideline in due course, via Autism CRC's website

Sincerely, David, Rhylee, Kandice, Hannah, Sarah, and Andrew, on behalf of the Guideline Development Group.



National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia

Appendix 12.1Expression through art – Young people





## Supporting Children National Guideline

[Attachment: "Expressing through Art Video Script.docx"]

[Attachment: "Voice-to-text instructions.doc"]

Development of a National Practice Guideline for Supporting Children on the Autism Spectrum and their Families:

Expression through Art

Instructions for Completing with Consent and Support of Parent

#### Instructions

Please explain this activity to your child, young person, or adult person in way that matches their understanding and gives you confidence that they are comfortable to be involved.

Invite them to produce a piece of art (e.g., do a drawing, painting or other artwork) about their experiences and/or feelings of accessing therapies and supports.

If your child or young person is 0-12 years of age, please ask them to think about therapies and supports they are currently accessing.

If the young person or adult person is older than 12 years, please ask them to think about what it was like accessing therapies and supports when they were under 12 years of age.

Take a photo/scan the artwork and upload it via the link provided.

Answer three brief questions about the artwork to help us understand it.



Please upload your artwork here.	
If you have any issues uploading your artwork via this link, please email supportingchildren@griffith.edu.au for assistance.	
Questions for your child, young person, or adult person.	
If they are able to answer, please ask them:	
What is the artwork about? You can ask further questions to help such as: Who is in the picture? What are they doing? How are they feeling? What is good? What is bad? What would make it better?	
Please write down exactly what they say, in their own words, even if there are mistakes or you disagree.	
2. Is there anything else they would like to share to help us understand their artwork?	
3. How were the answers to these questions entered?	<ul> <li>By the autistic child, young person, or adult person on the autism spectrum</li> <li>With the help of a parent/caregiver</li> </ul>
Questions for you, the parent/caregiver:	
1. Please share your own thoughts about the artwork. What do you think it tells us about their experiences and/or feelings about accessing therapies and supports?	
2. What type of therapies/supports do you think are being represented in the artwork? If you are not sure, please say so.	
3. Have they accessed any other therapies and supports in addition to these?	○ Yes ○ No
4. Which do you think they are reflecting on?	<ul> <li>The whole time they accessed these therapies and supports</li> <li>Just part of the time they accessed these therapies and supports (e.g., at the start, more recently, one point in time)</li> </ul>
5. Is there anything else you would like to share to	

help us understand their artwork?



We would like to ask you again, now that you have provided information: Are you happy for us to use the information you provided? ⊖ Yes ⊖ No

Please note: all information collected through the survey will be completely confidential.

If you have any final comments, please feel welcome to share them here.

A note from the research team

Thank you very much for completing the activity. The information that you and others provide will directly inform the recommendations in the guideline.

The next step for the research team will be to analyse all of the information provided. The Guideline Development Group will then formulate recommendations.

If you have not already done so, please register with Autism CRC to receive updates about the guideline. You can do so here: https://www.autismcrc.com.au/supporting-children

Before we finish, we want to take a moment to acknowledge the time it takes to participate in research projects like this. While we are not able to send a personal response to each person who completes it, please know that we genuinely value the information you have provided and will be reading every word.

We simply could not do this piece of important work without your insights. Thank you. We look forward to sharing updates, and the guideline in due course, via Autism CRC's website.

Sincerely, David, Rhylee, Kandice, Hannah, Sarah, and Andrew, on behalf of the Guideline Development Group.



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National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia

Appendix 12.2Expression through art - Adults





## Supporting Children National Guideline

[Attachment: "Expressing through Art Video Script.docx"]

[Attachment: "Voice-to-text instructions.doc"]

Development of a National Practice Guideline for Supporting Children on the Autism Spectrum and their Families:

Expression through Art

Instructions for People who are Self-Completing

Instructions

Please produce a piece of art (e.g., do a drawing, painting or other artwork) about your experience and/or feelings of accessing therapies and supports when you were a child, aged 0-12 years.

Take a photo/scan the artwork and upload it via the link provided.

Answer the following questions about the artwork to help us understand it.



Please upload your artwork here.	
If you have any issues uploading your artwork via this link, please email supportingchildren@griffith.edu.au for assistance.	
Questions for you.	
What does the artwork tell us about your experience of accessing therapies and supports as a child (0-12 years)?	
2. What type of therapies/supports are represented in the artwork?	
3. Did you access any other therapies and supports in addition to these when you were between the ages of 0-12 years?	○ Yes ○ No
4. Does the artwork reflect on:	<ul> <li>The whole time you accessed these therapies and supports</li> <li>Just part of the time you accessed these therapies and supports (e.g., at the start, more recently, one point in time)</li> </ul>
5. Is there anything else you would like to share to help us understand your artwork?	
We would like to ask you again, now that you have provided information: Are you happy for us to use the information you provided?	○ Yes ○ No
Please note: all information collected through the survey will be completely confidential.	
If you have any final comments, please feel welcome to share them here.	
A note from the research team	

Thank you very much for completing the activity. The information that you and others provide will directly inform the recommendations in the guideline.

The next step for the research team will be to analyse all of the information provided. The Guideline Development Group will then formulate recommendations.

If you have not already done so, please register with Autism CRC to receive updates about the guideline. You can do so here.

Before we finish, we want to take a moment to acknowledge the time it takes to participate in research projects like this. While we are not able to send a personal response to each person who completes it, please know that we genuinely value the information you have provided and will be reading every word.

07/08/2022 3:01pm



We simply could not do this piece of important work without your insights. Thank you. We look forward to sharing updates, and the guideline in due course, via Autism CRC's website.

Sincerely, David, Rhylee, Kandice, Hannah, Sarah, and Andrew, on behalf of the Guideline Development Group.



#### Autism CRC

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@autismcrc

### **Our values**



#### Inclusion

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



#### Innovation

New solutions for long term challenges



#### Evidence

Guided by evidence-based research and peer review



#### Independence

Maintaining autonomy and integrity



#### Cooperation

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