



National Guideline

For supporting the learning, participation,
and wellbeing of autistic children and
their families in Australia

DECEMBER 2022



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Cover art by Jed, age 6, and mum, Leanne.

Publication Approval



Australian Government

National Health and Medical Research Council

The guideline recommendations on pages 58-117 of this document were approved by the Chief Executive Officer of the National Health and Medical Research Council (NHMRC) on 6 December 2022 under section 14A of the *National Health and Medical Research Council Act 1992*. In approving the guideline recommendations, NHMRC considers that they meet the NHMRC standard for clinical practice guidelines. This approval is valid for a period of five years.

NHMRC is satisfied that the guideline recommendations are systematically derived, based on the identification and synthesis of the best available scientific evidence, and developed for health professionals practising in an Australian health care setting.

This publication reflects the views of the authors and not necessarily the views of the Australian Government.

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Reference Group

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Executive summary

Autistic children deserve a childhood full of love, family, fun, learning, and personal discovery. They should be safe, have their rights respected, and be supported. Many autistic children experience challenges to their learning, participation, and wellbeing. These challenges begin with the environment and belong to society, but are often most effectively addressed through a combination of supporting children's development of functional and personally meaningful skills; supporting families and those around them to nurture their growth; and creating safe, accessible, and enjoyable spaces.

This Guideline has been developed to help ensure that practitioners who provide supports to autistic children and their families do so in ways that are safe, effective, and desirable to children and their families. The Guideline focuses on practitioners delivering supports in community and clinical settings. It concentrates on non-pharmacological supports (i.e., not primarily based on medication) that aim to support children's learning, participation, and wellbeing. These supports often go by other names such as *interventions and therapies*. The Guideline focused on children aged 0-12 years but has a lifespan perspective, recognising that early supports should lay the foundation for a positive future. Pharmacological supports and supports specifically designed to be delivered by teachers and educators were beyond the scope of the Guideline.

A Guideline Development Group led the development of this Guideline, and comprised people with diverse knowledge, skills, experience, and perspectives, including members from both the autistic (autistic adults) and autism (e.g., family members, practitioners, researchers) communities. The Guideline was developed within an evidence-based practice framework, combining the best available research evidence, with evidence from clinical practice and the lived experience of autistic people and their families, and the preferences and unique context of each child and family. The Guideline Development Group undertook a range of research and community consultation activities, including systematic reviews of the research evidence, focus groups with members of the autistic and autism communities, and community and practitioner surveys. The information collected through these activities was systematically collated, analysed, and structured into a series of Recommendations to guide practice using an internationally accepted framework.

The Guideline has 84 Consensus-Based Recommendations that span the support pathway, including guiding principles, goal setting, selecting and planning supports, delivering supports, and the monitoring and safeguarding of supports. Recommendations are key elements of practice that must be followed for a practitioner to deliver evidence-based support. Recommendations are accompanied by Good Practice Points that provide critical context to each Recommendation, such as how a Recommendation should be implemented in clinical practice, or how it is applied to a specific population or under specific circumstances. Supporting evidence collected through the research and community consultations activities is presented for each Recommendation, and an Administration and Technical Report provides detailed information on the Guideline development process.

This is the first national Guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia. The Recommendations provide a framework through which evidence-based practice can be implemented across Australia. The next step will be for professional associations and individual practitioners to endorse and implement the Guideline; a process Autism CRC will support through a range of activities. It is recommended that this Guideline be updated within 5 years of publication.



Plain language **summary**



Plain language summary

This Guideline explains to practitioners how to work with autistic children and their families in ways that are safe, effective, and desirable. This is a summary of the key messages.

Section 1: Guiding Principles

Practitioners should work in partnership with children and families, individualise supports, and respect the children's human rights. Practitioners should be ethical, have appropriate qualifications, and use evidence to guide decisions. They should help children and families be confident in themselves, and to access the supports they need when they need them.

Section 2: Goal Setting

Practitioners should help children and families select goals that are helpful and meaningful to them. Goals should also consider each child's family, and where the child and family live, learn, and play. Goals should be written down and understood by everyone.

Section 3: Selecting and planning supports

Practitioners should help children and families choose supports that are safe, effective, and desirable. Supports can help children develop new skills, help people around the child develop new skills, and help create more accessible and enjoyable environments. Practitioners who plan supports should be properly qualified and have relevant knowledge, skills, supervision, and experience. If a practitioner does not have these things, they should refer the child and family to other people who do.

Section 4: Delivering supports

Practitioners should help children and families make decisions about how supports are delivered. This includes choosing who will be involved, how and where they are delivered, and how much support is appropriate. Where another person helps deliver supports, they should be appropriate and supervised. Supports should be coordinated, to maximise benefits and minimise burden for children and families.

Section 5: Outcomes, quality, and safeguarding

Practitioners should work in ways that maximise benefits and minimise risks for children and their families. They should have a plan and processes in place to make sure the supports they provide are safe, of high quality, and desirable to children and families. Practitioners should monitor progress, and work with the child and family to make adjustments and stop when support is no longer needed and/or desired. They should respect each child and family for who they are, what they want, and what they need to uphold their human rights.



List of Recommendations



List of Recommendations

This is a complete list of Consensus-based Recommendations included in the Guideline, and is provided here as a quick reference guide only. It is critical that the Recommendations are read in the context of the accompanying Good Practice Points that are presented in the body of this Guideline.

All Recommendations are equally important and should be implemented. However, to help readers be aware of issues to consider when implementing the Recommendations (e.g., resources required, feasibility), each Recommendation includes a 'Grade of Recommendation.' Where a recommendation is 'conditional', it simply indicates that there are factors to consider during implementation. This approach to providing grades is consistent with the Grading of Recommendations, Assessment, Development and Evaluation (GRADE) Evidence to Decision framework (Alonso-Coello, Oxman et al., 2016; Alonso-Coello, Schünemann, et al., 2016). Further information about this approach is provided in the Administration and Technical Report.

Section 1: Guiding Principles

What guiding principles should be followed when providing supports to autistic children and their families?

Recommendation 1

Child and family-centred: Supports should be child and family-centred, where individual goals, preferences, and circumstances are respected, valued, and supported through shared decision making.

- ▶ Grade of Recommendation: Strong
-

Recommendation 2

Individualised: Supports should be individualised for each child and family.

- ▶ Grade of Recommendation: Strong
-

Recommendation 3

Strengths-focused: Supports should build on each child's and family's strengths and interests.

- ▶ Grade of Recommendation: Strong
-

Recommendation 4

Holistic: Supports should be holistic in terms of the goals that are targeted and the way they are achieved, considering all aspects of the child, family, and their community.

- ▶ Grade of Recommendation: Strong
-

Recommendation 5

Honour childhood: Supports should honour the goals and activities of childhood including play, relationships, and personal discovery.

- ▶ Grade of Recommendation: Strong
-

Recommendation 6

Foundation for the future: Supports should lay the foundation for a positive future, including optimum health, choice, learning, self-identity, participation, and wellbeing.

- ▶ Grade of Recommendation: Strong

Recommendation 7

Ethical: Supports should be ethical to protect the rights of the child and family.

- ▶ Grade of Recommendation: Strong
-

Recommendation 8

Culturally safe: Practitioners should acknowledge and respect the values, knowledge, preferences, and cultural perspectives of the child and family, and reflect on their own cultural knowledge and competency in delivering services.

- ▶ Grade of Recommendation: Strong
-

Recommendation 9

Respecting Australia's First Nations Peoples: Supports should be culturally safe for Aboriginal and Torres Strait Islander Peoples, built on an acknowledgment of the barriers to accessing supports that they may experience; an understanding of current and historical truths and their enduring impact; and respect for deep connection to Country, language, customs, and traditions.

- ▶ Grade of Recommendation: A rating is not provided as this Recommendation was developed through direct consultation with First Nations Peoples and received unanimous endorsement of the Guideline Development Group.
-

Recommendation 10

Evidence-based: Supports should reflect the best available research evidence, integrated with evidence from clinical practice and the lived experience of autistic people and their families, and the preferences and unique context of each child and family.

- ▶ Grade of Recommendation: Strong
-

Recommendation 11

Assent (children): Each child has the right to say no to supports and their assent (expression of approval) should be sought and respected, whether they communicate using words or in other ways.

- ▶ Grade of Recommendation: Strong
-

Recommendation 12

Informed consent (parents): Parents should have the information they need to make informed choices about supports and provide consent for any supports received.

- ▶ Grade of Recommendation: Strong

Recommendation 13

Qualified practitioners: Practitioners should have relevant qualifications, be regulated, work within their scope of practice with appropriate supervision, and engage in continuing professional development.

- ▶ Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Recommendation 14

Neurodiversity-affirming: Supports should be neurodiversity-affirming, embracing each child's unique understanding of other people and the world around them, without seeking to 'cure' autism.

- ▶ Grade of Recommendation: Strong
-

Recommendation 15

Parent and family affirming: Supports should uphold the parents' autonomy in raising their child, and ensure the natural roles of children, parents, siblings, and other family members are affirmed and preserved.

- ▶ Grade of Recommendation: Strong
-

Recommendation 16

Timely and accessible: Each child and family should be able to access the supports they need, when they need them, and in ways they desire, regardless of who they are, where they live, or how much money they have.

- ▶ Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Recommendation 17

Coordinated: Practitioners should engage in open and regular communication with other practitioners, the child's educators, and other service providers, with appropriate consent, to ensure supports are coordinated.

- ▶ Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Section 2: Goal Setting

What are appropriate goals for supporting children and families?

Recommendation 18

Practitioners should work in partnership with the child and family to consider goals that help the child acquire skills that promote their learning, participation, and wellbeing.

- ▶ Grade of Recommendation: Strong
-

Recommendation 19

Practitioners should work in partnership with the family to consider goals that empower the family to support and advocate for the child, and promote the child's learning, participation, and wellbeing.

- ▶ Grade of Recommendation: Strong
-

Recommendation 20

Practitioners should work in partnership with the child and family to consider goals that create safe and accessible environments that support the child's learning, participation, and wellbeing.

- ▶ Grade of Recommendation: Strong
-

Recommendation 21

Goals should be neurodiversity-affirming.

- ▶ Grade of Recommendation: Strong
-

How should goals be selected?

Recommendation 22

Goal setting should be led by the child and family, with support from practitioners, and involvement of other people when relevant.

- ▶ Grade of Recommendation: Strong

Recommendation 23

In working in partnership with the child and family to set goals, practitioners should consider the unique aspects of the child and the contexts in which they live.

- ▶ Grade of Recommendation: Strong
-

Recommendation 24

In working in partnership with the child and family to set goals, practitioners should consider the unique aspects of the family and the contexts in which they live.

- ▶ Grade of Recommendation: Strong
-

Recommendation 25

Practitioners should have a strong rationale for why a goal is recommended, which considers the potential benefits and risks for the child and family.

- ▶ Grade of Recommendation: Strong
-

Recommendation 26

Practitioners should ensure that the agreed goals are discussed and documented in a way that is informative, understandable, and meaningful to the child and the family.

- ▶ Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Section 3: Selecting and planning supports

What types of supports might be relevant to children and their families?

Recommendation 27

Supports should help the child communicate with a variety of people in everyday contexts, for a variety of reasons, and in ways that they desire.

- ▶ Grade of Recommendation: Strong
-

Recommendation 28

Supports should meet the child’s sensory needs across activities, interactions, and settings.

- ▶ Grade of Recommendation: Strong
-

Recommendation 29

Supports should help the child develop their cognitive skills as the foundation for learning about themselves, other people, and the world around them.

- ▶ Grade of Recommendation: Strong
-

Recommendation 30

Supports should help the child develop social-emotional skills, supporting them to understand, express, and regulate their emotions as a foundational skill for learning, participation, and wellbeing.

- ▶ Grade of Recommendation: Strong
-

Recommendation 31

Supports should help the child develop motor skills and functional movement that is meaningful, assists with daily activities, and enhances participation in activities of their choice.

- ▶ Grade of Recommendation: Strong

Recommendation 32

Supports should help the child to acquire academic skills that optimise their learning and participation in educational settings.

- ▶ Grade of Recommendation: Strong
-

Recommendation 33

Supports should help the child to acquire skills that are relevant to their participation in meaningful daily activities.

- ▶ Grade of Recommendation: Strong
-

Recommendation 34

Supports should empower families in raising the child and promote the wellbeing of the child and family.

- ▶ Grade of Recommendation: Strong
-

Recommendation 35

Supports should lead to the creation of accessible environments that support the child's learning, participation, and wellbeing.

- ▶ Grade of Recommendation: Strong
-

How should supports be selected?

Recommendation 36

The practitioner should work in partnership with the child and family in selecting supports, as well as with other people when relevant.

- ▶ Grade of Recommendation: Strong
-

Recommendation 37

In considering possible supports, practitioners should draw on multiple sources of information about the potential benefits and risks for the child and family.

- ▶ Grade of Recommendation: Strong

Recommendation 38

In considering possible supports, practitioners should be aware of the best available research evidence and discuss this with the child and family.

- ▶ Grade of Recommendation: Strong
-

Recommendation 39

Practitioners should recommend supports that offer a plausible, practical, desirable, and defensible pathway to helping the child and family achieve personally meaningful and valued outcomes.

- ▶ Grade of Recommendation: Strong
-

Recommendation 40

Practitioners should ensure the child and family understand the rationale for recommended supports, along with potential benefits, costs, and alternative options.

- ▶ Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

What knowledge and skills are required to select and plan supports?

Recommendation 41

Practitioners involved in selecting and planning supports should have relevant qualifications and work within their scope of practice.

- ▶ Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Recommendation 42

Practitioners involved in selecting and planning supports should have professional experience that matches their responsibilities.

- ▶ Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Recommendation 43

Practitioners involved in selecting and planning supports should be eligible for membership with the relevant professional association and regulated.

► **Grade of Recommendation: Conditional**

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Recommendation 44

Practitioners involved in selecting and planning supports should have knowledge and practical skills that are directly relevant to working with autistic children and their families.

► **Grade of Recommendation: Conditional**

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Recommendation 45

Practitioners involved in selecting and planning supports should provide the child and family with an accurate, complete, and timely plan of proposed supports.

► **Grade of Recommendation: Strong**

Recommendation 46

Where a practitioner does not have the qualifications; professional experience; professional regulation; relevant knowledge and skills; personal capacity; and/or professional capacity to select, plan and/or deliver a particular support, they should refer the child and family to a practitioner who does.

► **Grade of Recommendation: Conditional**

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Section 4: Delivering supports

Who should deliver supports?

Recommendation 47

Supports should be delivered by the people (e.g., parents, practitioners) who are likely to lead to the most meaningful and sustained increase in the child's learning, participation, and wellbeing.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

What knowledge and skills are required to deliver supports?

Recommendation 48

Practitioners who deliver supports should have relevant qualifications and work within their scope of practice.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Recommendation 49

Practitioners who deliver supports should have professional experience that matches their responsibilities.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Recommendation 50

Practitioners who deliver supports should be eligible for membership with the relevant professional association and regulated.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Recommendation 51

Where another person assists a practitioner in the delivery of supports, that person should have appropriate knowledge, skills, experience, training, and regulation; and be adequately supervised and supported by the practitioner who has overall responsibility for the delivery of supports.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Who should receive the support?

Recommendation 52

Practitioners should work in partnership with the child and family to determine which people and/or environments will be the focus of supports and likely lead to the most meaningful and sustained increase in the child's learning, participation, and wellbeing.

► Grade of Recommendation: Strong

In what settings should supports be delivered?

Recommendation 53

Practitioners should work in partnership with the child and family to determine the setting(s) in which the delivery of supports is likely to lead to the most meaningful and sustained increase in the child's learning, participation, and wellbeing.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

In what formats and modes should supports be delivered?

Recommendation 54

Practitioners should work in partnership with the child and family to determine the delivery format(s) (one-on-one, in a group) that will likely lead to the most meaningful and sustained increase in the child's learning, participation, and wellbeing.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Recommendation 55

Practitioners should work in partnership with the child and family to determine the delivery mode(s) (e.g., in person, telepractice) that will likely lead to the most meaningful and sustained increase in the child’s learning, participation, and wellbeing.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The ‘conditional’ rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

In what amount and duration should supports be delivered?

Recommendation 56

Practitioners should work in partnership with the child and family to determine the delivery amount and duration that will likely lead to the most meaningful and sustained increase in the child’s learning, participation, and wellbeing.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The ‘conditional’ rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

How should practitioners engage with other service providers and service systems?

Recommendation 57

Practitioners should coordinate the supports they deliver with other relevant service providers and service systems.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The ‘conditional’ rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Section 5: Outcomes, quality, and safeguarding

How should the effects of supports be monitored and reviewed?

Recommendation 58

Monitoring and reviewing of supports should be conducted by the practitioner in partnership with the child and family, with support from other people when relevant.

- ▶ Grade of Recommendation: Strong
-

Recommendation 59

Practitioners, in partnership with the child and family, should monitor the extent to which the supports were delivered as planned.

- ▶ Grade of Recommendation: Strong
-

Recommendation 60

Practitioners, in partnership with the child and family, should monitor progress towards the child's and family's goals.

- ▶ Grade of Recommendation: Strong
-

Recommendation 61

Practitioners, in partnership with the child and family, should monitor the child's and family's generalisation and maintenance of skills across people, settings, and activities, and over time.

- ▶ Grade of Recommendation: Strong
-

Recommendation 62

Practitioners, in partnership with the child and family, should monitor the costs and benefits to the child and family of receiving the supports.

- ▶ Grade of Recommendation: Strong

Recommendation 63

Practitioners, in partnership with the child and family, should monitor for unplanned outcomes associated with the supports they deliver.

- ▶ Grade of Recommendation: Strong
-

Recommendation 64

Practitioners should monitor progress by directly asking and listening to the child and family.

- ▶ Grade of Recommendation: Strong
-

Recommendation 65

Practitioners, in partnership with the child and family, should monitor progress through child observations.

- ▶ Grade of Recommendation: Strong
-

Recommendation 66

Practitioners, in partnership with the child and family, should monitor progress through reports from others.

- ▶ Grade of Recommendation: Strong
-

Recommendation 67

Practitioners, in partnership with the child and family, should monitor progress through the collection and evaluation of outcome data.

- ▶ Grade of Recommendation: Strong
-

Recommendation 68

Practitioners, in partnership with the child and family, should review goals, experiences, and outcomes at regular intervals based on the needs and preferences of each child and family.

- ▶ Grade of Recommendation: Strong
-

Recommendation 69

Practitioners should ensure that information they collect during monitoring is shared with the child and family, and when relevant and appropriate, shared with other people.

- ▶ Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Recommendation 70

Practitioners should share information related to monitoring and reviews in a way that is informative, understandable, and meaningful to the child and family.

- ▶ Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Recommendation 71

Practitioners should empower and support the child and family to make decisions about whether to continue, change, or stop accessing supports.

- ▶ Grade of Recommendation: Strong
-

Recommendation 72

Practitioners should communicate to the child and family when there is indication that their services are no longer required or recommended.

- ▶ Grade of Recommendation: Strong
-

How can the risk of adverse effects be reduced?

Recommendation 73

Practitioners should ensure that the delivery of supports takes place in a safe environment.

- ▶ Grade of Recommendation: Strong
-

Recommendation 74

Practitioners should have up-to-date knowledge of research evidence for the effectiveness, acceptability, feasibility, and risks of the supports they recommend and deliver.

- ▶ Grade of Recommendation: Strong
-

Recommendation 75

Practitioners should have up-to-date knowledge of the views and preferences of autistic people regarding different supports and their delivery.

- ▶ Grade of Recommendation: Strong

Recommendation 76

Practitioners should engage in continuing professional development.

- ▶ Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Recommendation 77

Practitioners should access clinical supervision that matches their knowledge, skills, and professional experience.

- ▶ Grade of Recommendation: Strong
-

Recommendation 78

Practitioners should inform the child and family about how they can provide feedback and make complaints about the supports they receive.

- ▶ Grade of Recommendation: Strong
-

Recommendation 79

Practitioners should inform the child and family of any potential or actual conflicts of interest they have in providing supports or making referrals.

- ▶ Grade of Recommendation: Strong
-

Recommendation 80

Practitioners should follow relevant international conventions, national and state/territory legislative requirements, and other associated principles, frameworks, and regulations.

- ▶ Grade of Recommendation: Strong
-

Recommendation 81

Practitioners should ensure clear, appropriate, and accurate information is shared with the child, family, and other relevant people.

- ▶ Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

How should adverse effects be managed?

Recommendation 82

Practitioners should have a documented procedure for the monitoring of adverse effects of supports.

- ▶ Grade of Recommendation: Strong
-

How should the rights of children and families be protected?

Recommendation 83

Practitioners should be familiar with, and respect, the individual language and terminology preferences of the child and family.

- ▶ Grade of Recommendation: Strong
-

Recommendation 84

Practitioners should respect each child and family member for who they are; respect their goals, values, and preferences; and work in ways that promote and protect their human rights.

- ▶ Grade of Recommendation: Strong



Introduction



Introduction

Background

All children deserve a healthy and happy start to life, surrounded by people who love, value, and support them, within environments that are conducive to their learning, participation, and wellbeing. Children have rights (United Nations, 1989; 2006): to learn in ways that fully develop their personalities, talents, and abilities; to have their culture, dignity and safety respected and preserved; and to have their views and voices heard, no matter how they communicate. Inherent in these rights is the requirement that adults and organisations responsible for children should do what is best for each child, and that governments should ensure these rights are upheld at all times.

This Guideline is about the rights of autistic children and their families to access safe, effective, and desirable supports during childhood. Autism affects the way a person understands and interacts with other people and the world around them. From a diagnostic perspective, the term Autism Spectrum Disorder (herein referred to as autism) is the collective term for a group of neurodevelopmental conditions characterised primarily by differences in social-communication skills, and the presence of repetitive behaviours, intense or focussed interests and/or sensory differences (American Psychiatric Association, 2013). The behavioural features of autism are often present before 3 years of age, but may not become apparent until the school years or later in life, as social and cognitive demands increase. Many autistic people experience co-occurring conditions such as language and learning difficulties, and a range of medical conditions.

Many autistic people view autism as intrinsic to their identity and sense of being (Cooper et al., 2017). However, there is broad acknowledgment from autistic people, family members, and the wider community that autistic people can face substantial barriers to their learning, participation, and wellbeing. These barriers arise from a combination of developmental differences inherent to autism, and societal factors such as a lack of accessible environments. The provision of supports during childhood can help autistic children acquire skills, increase child and family wellbeing, minimise environmental barriers, and maximise each child's participation in individually meaningful life activities. These supports are typically non-pharmacological (i.e., not primarily based on medication) and are often known by a variety of names, including interventions, therapies, programs, and services.

There is a strong need to develop a nationally consistent approach to supporting autistic children and their families in Australia (Whitehouse et al., 2020). First, a large number of supports are offered to children and families, and there is considerable variability in their theoretical premise, delivery characteristics (e.g., by whom, in what settings, in what amount), and evidence for safety and effectiveness. Second, while it is recognised that supports should be individualised to meet the strengths, preferences, and support needs of each child and their family, there is little guidance for practitioners as to how this should occur. Third, community understanding of autism and views about the nature and delivery of support are evolving, driven in large part by the self-advocacy of autistic people and advocacy by parents and significant others. It is imperative that this evolving understanding is reflected in the selecting, planning, delivery, monitoring, and safeguarding of supports provided to children and their families.

In 2021, the Autism CRC commissioned the development of Australia's first Guideline for supporting the development and participation of autistic children and their families (the 'Guideline'). Andrew Whitehouse and David Trembath were requested to chair this process, in collaboration with a Guideline Development Group comprising Gary Allen, Katharine Annear, Valsamma Eapen, Jessica Feary, Emma Goodall, Sarah Pillar, Teresa Pilbeam, Felicity Rose, Nancy Sadka, Natalie Silove, Rhylee Sulek, Kandice Varcin, and Hannah Waddington.

The Recommendations in the Guideline were developed within an evidence-based practice framework, combining the best available research evidence; with evidence from clinical practice; and evidence relating to the experiences, preferences, and priorities of children and their families (Sackett, Richardson, Rosenberg, & Haynes, 2000). The Guideline was developed according to the National Health and Medical Research Council (NHMRC, 2016) *Guidelines for Guidelines* manual, and used the internationally recognised Grading of Recommendations, Assessment, Development and Evaluation (GRADE) method (Schünemann et al., 2013) for moving from questions, to evidence, and then recommendations. Each Recommendation in this Guideline reflects multiple converging sources of evidence from the autistic and autism communities, gathered through systematic reviews of the literature and extensive community consultation. A glossary of key terms used in this Guideline is provided as Appendix A.

A Guideline for the provision of supports in Australia must ensure that recommendations are directly underpinned by evidence for safety and effectiveness, while also being flexible enough to account for the unique aspects of the child and family, and the settings and contexts in which they live. Autistic children vary widely in their strengths, behavioural characteristics, support needs, and preferences, and it is recognised that there is no one way to support all aspects of learning, participation, and wellbeing for all children. There is also considerable variability in the settings and contexts through which supports can be provided. By drawing on the synthesis evidence from systematic reviews, extensive community consultation, and consensus agreement amongst practitioners regarding good practice, the Recommendations provide guidance to practitioners that is appropriate, relevant, and meaningful in the Australian context.

Purpose and objectives

This Guideline was developed to provide practitioners with an evidence-based practice framework that facilitates the safe and effective provision of non-pharmacological supports to autistic children aged 12 years or younger and their families in Australia. 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 skills, intellectual capacity, cultural or language background, socio-economic status, 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.

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 1.

Table 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 these criteria.
Supports and services	Non-pharmacological supports.	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 medical, early childhood, primary, and secondary education settings.
Outcomes targeted by supports	Learning, participation, and wellbeing.	Outcomes related to conditions that co-occur with autism (e.g., attention deficit hyperactivity disorder, sleep, gastrointestinal function, mental health).

This Guideline focuses on practitioners working within community and clinical settings. These practitioners are typically engaged by children and families through publicly-funded (e.g., National Disability Insurance Scheme, Medicare) or privately-funded (e.g., health insurance, self-funding) means.

Early childhood, primary, and secondary education plays a critical role in the learning, participation and wellbeing of autistic children and their families. The Recommendations and Good Practice Points within this Guideline emphasise the importance of linking supports and other connections between clinical, community and educational settings. However, it was beyond the scope of the current Guideline to develop Recommendations specifically for teachers and other educators (e.g., early childhood educators) whose role is to care for children and/or support their education as employees within early childhood, primary, and secondary education services (e.g., childcare, school). The rationale for limiting the scope was to acknowledge that additional considerations may be required in developing (e.g., ensuring appropriate consultation) and implementing (e.g., ensuring alignment with standards, regulations, frameworks, and pedagogy) a set of Recommendations that are directly relevant to teachers and other educators working in education settings.

It is acknowledged that delineating between people (e.g., practitioners, teachers, and other educators) and settings (e.g., education versus other community settings) is often imprecise, given that organisations may serve multiple functions (e.g., provide early childhood education as well as therapies and supports) and people often have multiple qualifications, roles, and workplaces. It is also acknowledged that teachers and other educators may find the Recommendations relevant to their practice. The scope of this Guideline does not prohibit teachers and other educators from adopting the Recommendations presented in this Guideline: it simply ensures that readers are fully aware of the scope and methodology used to arrive at the Recommendations.

Target users

The primary target users of this Guideline are practitioners working in Australia who are involved in the selecting, planning, delivery, and/or monitoring of supports for autistic children and their families. These include, but are not limited to, allied health and medical practitioners.

Secondary target users of this Guideline include the following groups:

- Autistic children and their families can use this Guideline to understand an evidence-based practice framework for accessing and receiving supports.
- Service providers can use this Guideline to align resource allocation within an evidence-based practice framework.
- Early childhood, primary school, and secondary school educators can use this Guideline to set expectations regarding how practitioners who provide supports in education settings should operate.
- Australian training providers, including peak bodies and tertiary education institutions, can use this Guideline to tailor clinical training resources, courses, and qualifications to ensure practitioners achieve the learning outcomes required for the selecting, planning, 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.



Guideline development process



Guideline development process

The Guideline development process adhered to the approach described in the *Guidelines for Guidelines* handbook (2016), published by the National Health and Medical Research Council (NHMRC). The Grading of Recommendations, Assessment, Development and Evaluation (GRADE) method was used to move from questions, to evidence, and then recommendations (Schünemann, 2013). A detailed account of each aspect of the Guideline development process is provided in the Administration and Technical Report that accompanies the Guideline.

Step 1: Establishing the Guideline Development Group

The first step was to establish a Guideline Development Group (GDG) to lead the research and community consultation process. To commence this process, 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. 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 co-designed research, systematic reviews, community consultation, and Guideline development. Following this, 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 GDG members are listed in Table 2. Among the 15-member group were autistic adults; parents and other family members of autistic children, including children and young adults with complex needs; people with expertise in working alongside Aboriginal and Torres Strait Islander Peoples and Communities; people with expertise in ethics and research integrity; clinicians with experience in government and non-government sectors; and researchers with expertise in the guideline development process, including community consultation. Processes were put in place to declare and manage any potential conflicts of interest, consistent with the NHMRC and GRADE methodologies.

Table 2. Members of the Guideline Development Group.



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 the 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.



Dr Kandice Varcin

Dr Kandice Varcin is a Research Fellow at the Menzies Health Institute Queensland, Griffith University and Honorary Research Associate at CliniKids, Telethon Kids Institute. 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 Integrity at Griffith University. Gary has worked in the human research ethics area since 1997, working with a number of research institutions, state and federal departments, private companies and research ethics committees internationally. He also has a degree in education and a professional doctorate in social sciences. Gary brings extensive experience in regards to the national and international governance of ethical conduct in research.



Mx Katharine Annear

Mx Katharine Annear is a founding member of the Autistic Self Advocacy Network of Australia and New Zealand, a registered Developmental Educator, and Casual Academic at Flinders University. They bring lived experience as an Autistic person who also has numerous Autistic family members, and are a passionate advocate for co-design in research and public policy and the translation of research and policy into meaningful 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 Feary

Jess Feary is the Victoria and Tasmania Coordinator for Positive Partnerships. She has a background in occupational therapy and public health and brings over 15 years' experience working with neurodiverse people and their families in clinical, research, policy 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 National Disability Insurance Scheme (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

Dr 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.

To support its work in community consultation, the GDG formed a Reference Group, comprising 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 communities; or that were from the key Government agency, the National Disability Insurance Agency. Members of the Reference Group, and the national peak bodies they represented, are listed in Table 3.

Table 3. Members of the Reference Group.

Stakeholder group	National peak body	Representative	Position
Autistic people	Autistic Self Advocacy Network – Australia and New Zealand	Lisa Smith (first two meetings)	Member
Family members of autistic people	Autism Awareness Australia	Nicole Rogerson	Founding Chief Executive Officer
First Nations peoples	National Aboriginal Community Controlled Health Organisation	Jess Styles	Director, Programs
Culturally and linguistically diverse communities	Federation of Ethnic Communities’ Council of Australia	Daniel Coase	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 and mental health	Australian Psychological Society	Tamara Cavenett	President
Focusing on children’s sensory development and occupations of childhood	Occupational Therapy Australia	Karen Brown	Division Manager (ACT, NSW)

Stakeholder group	National peak body	Representative	Position
Representing service providers (peak body)	Australian Autism Alliance	Frances Scodellaro	Member
Representing services (early childhood)	Relmagine Australia (formerly Early Childhood Intervention Australia)	Trish Hanna	Board Chair
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

Step 2: Defining Guideline questions

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. These questions are presented in Table 4. The GRADE framework typically recommends the formulation of questions structured in a PICO format (Patient, Intervention, Comparison, Outcome). However, because of the purpose and objectives of the current Guideline, the relevance of PICO questions to the aspects of practice considered, and the nature and availability of research evidence that would inform the answers to the questions, the questions for this Guideline were structured around aspects of professional practice that impact on the experiences and outcomes for children and families in accessing supports. For this same reason, the Recommendations included in the Guideline are considered Consensus-Based Recommendations, drawing on evidence from the research literature, combined with evidence collected through extensive community consultation.

Table 4. Questions that provided the foundation for the research activities and community consultation underpinning the Guideline.

Section	Question
Overarching principles	What guiding principles should be followed when providing supports to autistic children and their families?
Goal setting	What are appropriate goals for supporting children and families?
	How should goals be selected?
Selecting and planning supports	What types of supports might be relevant to children and families?
	How should supports be selected?
	What knowledge and skills are required to plan supports?
Delivering supports	Who should deliver supports?
	What knowledge and skills are required to deliver supports?
	Who should receive supports?
	In what settings should supports be delivered?
	In what formats and modes should supports be delivered?
	In what amount and duration should supports be delivered?
	How should practitioners engage with other service providers and service systems?
Outcomes, quality and safeguarding	How should the effects of supports be monitored and reviewed?
	How can the risk of adverse effects be reduced?
	How should adverse effects be managed?
	How should the rights of children and families be protected?

Step 3: Gathering evidence

Evidence can take many forms. For this Guideline, there was a concerted effort to gather evidence through systematic reviews of the research evidence alongside extensive community consultation. Evidence was gathered over a 9-month period (October 2021 to June 2022) using a structured research process. Ethical approval for the community consultation activities was procured through the Griffith University Human Research Ethics Committee (2021/843). The day-to-day work in 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 literature reviews and community consultation activities are described in detail in the Administration and Technical Report. In brief, these activities comprised the following:

Literature reviews

Three systematic literature reviews were undertaken to synthesise current research evidence in three areas. First, a systematic scoping review was conducted to explore and map the breadth of principles and recommendations made within existing clinical guidelines for autism. There were 14 English-language guidelines that were included within this scoping review. Second, a systematic review was undertaken to identify and explore research relating to the experiences of autistic individuals and their family members accessing supports during childhood in Australia. There were 12 research articles that met inclusion criteria and were reviewed. Third, an umbrella review (a systematic review of systematic reviews) was conducted to synthesise data regarding the effects of different supports on a range of child and family outcomes. There were 48 systematic reviews that met study inclusion criteria and were reviewed.

Community consultation activities

A series of community consultation activities were conducted. These activities provided a range of opportunities for community members in Australia to give input into the Guideline development process in a way that suited their needs and preferences. The community consultation activities were advertised through the Autism CRC mailing list and traditional and social media networks. The community consultation activities are described in further detail in Appendix B. In brief, these activities were:

1. An online survey designed to understand the experiences of members of the autistic and autism communities in accessing supports, and their views on good practice.
2. A brief online survey designed to understand the views of autistic children in accessing supports.
3. A brief online survey designed to ask parents to reflect on their view of their autistic children's experience accessing supports.
4. A consultation activity involving the creation of art, which was designed to engage autistic children and adults who may communicate, or prefer to communicate, through ways other than spoken language.
5. A practitioner survey designed to understand areas of consensus for various aspects of clinical practice in supporting autistic children and their families. This followed a Delphi format, with two survey rounds.
6. A series of focus groups designed to provide opportunity for further detailed discussion on the experiences of members of the autistic and autism communities in accessing supports, and their views on good practice.

Step 4: Moving from evidence to recommendations

An iterative process, built around an Evidence to Decision 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. A detailed explanation is provided in the Administration and Technical Report.

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 systematic 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., Australian Institute of Aboriginal and Torres Strait Islander Studies [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 Scheme- Practice Standards 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.

Iteration 3: Grade 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 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 across populations; 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 accompanying this Guideline.

The grade of Recommendations do not reflect whether a Recommendation should be implemented or prioritised. All Recommendations within the Guideline represent good practice and should be implemented. Rather, the grade of Recommendations (strong, conditional) is intended to support users in considering a range of factors when implementing a given Recommendation, such as the benefits and harms, resources needed, and the acceptability to children, families, and practitioners. A grading of a Recommendation as 'conditional' reflects a judgment that there are key factors to consider during implementation. Further information on the grading of each Recommendation 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, as well as an Easy Read summary of the Guiding Principles Recommendations. The Easy Read summary was drafted by Katharine Annear, with review by the DRWG and formatting provided by Autism CRC. 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: Public consultation on Draft Guideline

The GDG prepared the Draft Guideline and supporting documents (Summary of Evidence, Administration and Technical Report, and Easy Read summary) for public consultation, which opened on 18th July 2022 and closed on 29th August 2022 (a 6-week period).

Ahead of public consultation

The public consultation on the Draft Guideline complied with *Section 74A of the Commonwealth National Health and Medical Research Council Act 1992* and accompanying regulations. The following activities were undertaken ahead of the public consultation period:

- Autism CRC updated its webpage devoted to the Guideline development to reflect the upcoming consultation period and invitation to participate.
- Autism CRC 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. Key professional and consumer organisations were identified through the Reference Group and were invited to provide feedback. Further announcements were made via Autism CRC 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 GDG 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 11th July 2022. These offices were then directly emailed the Draft Guideline on the 18th July 2022.

During public consultation

During public consultation, Autism CRC:

- Updated its website to include:
 - › A video explaining the public consultation process, and how people could participate.
 - › Direct links to the Draft Guideline, Summary of Evidence, Administration and Technical Report, and Easy Read summary.
 - › A link to participate in an online feedback survey.
- Announced the opening and closing of the public consultation period via email and social media.
- Sent reminders inviting participation throughout the public consultation period.

Feedback survey

Public consultation feedback was collected via a custom online survey developed by the GDG and delivered via REDCap (hosted by Griffith University). The survey comprised three sections, commencing with a Participant Information Statement and Consent Form, 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. Furthermore, participants were able to choose whether to provide feedback as an individual, or on behalf of an organisation. Where feedback was provided on behalf of an organisation, a copy of the survey was available for download to assist those completing the survey to compile feedback within their organisation.

The feedback survey was accessed 333 times during the consultation period. Of those who provided a response, 105 participants indicated they were providing feedback as an individual, and 58 participants indicated they were providing feedback on behalf of an organisation. Of the 105 responses provided by individuals, 55 (52%) individuals provided responses beyond participant demographics and were therefore considered by the GDG. Of the 58 responses provided on behalf of an organisation, 35 (60%) included demographic information about the organisation and so were considered by the GDG. Further information about the feedback survey is provided in the Administration and Technical Report.

Independent review: AGREE-II

As per NHMRC Guidelines for Guidelines, the GDG arranged for the Draft Guideline to 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).

Independent Review: NHMRC

The NHMRC organised independent review of the Guideline:

- Two reviewers with methodological expertise in guideline development reviewed the methodology and provided feedback using a standard form supplied by NHMRC. These reviewers focused on the extent to which the Draft Guideline complied with the NHMRC Standards for Guidelines.
- Two reviewers with content expertise reviewed the Guideline using a standard form supplied by NHMRC. These reviewers focused on the extent to which the Draft Guideline aligned with the scope and clinical questions posed by the Guideline, whether the Guideline Recommendations adequately consider the risks and potential harms of clinical practice, and whether there are relevant international guidelines on the same topic that conflict with the Recommendations of this Guideline.

Health Department Review

The Office of the Director General, Chief Executive or Secretary of each state, territory, and Commonwealth Health Department were invited to provide feedback on the Draft Guideline, in a form of their choosing (e.g., letter).

Step 6: Analysing Feedback and Revisions

All feedback received through public consultation and independent review was considered and used to inform revisions to the Guideline where relevant, in a systematic manner.

Feedback survey

The GDG reviewed and responded to each piece received through the online feedback portal through a structured process.

- Both Co-chairs reviewed all feedback received.
- Feedback was then grouped into the relevant Guideline sections, and was allocated to one of six members of the DRWG for more detailed review. Where feedback referred directly to a member of the DRWG by name or affiliation (e.g., the DRWG member's employer), that member excluded themselves from review of that feedback.
- The DRWG members first categorised feedback as either requiring no changes to the Draft Guideline or possible changes to the Draft Guideline. A second member of the GDG then reviewed the proposed response, and the two members made a consensus decision as to whether or not a change should be made. Any disagreements were taken to the broader DRWG.
- Any proposed changes to the Draft Guideline were also brought to the six-member DRWG, where a broader consensus decision was made.
- Where changes were agreed to, a member of the DRWG drafted the change in the Guideline document, and all corresponding points in the Administration and Technical Report, Evidence Summaries, and Easy Read summary of the Guiding Principles.
- A second reviewer within the DRWG reviewed the proposed change and either endorsed or resolved any differences in views on how to approach the change via consensus. Every change was reviewed by all six members of the DRWG.
- The DRWG members compiled feedback tables in which they provided a response to each comment

received through the online feedback portal including, where relevant, an explanation of why a change to the Guideline was or was not made, as well as the nature of the change where that had occurred. Each response in the feedback tables was reviewed by a second member of the DRWG and either endorsed or revised via consensus. The Co-chairs reviewed the complete set of feedback and DRWG responses. The feedback tables are provided in the Public Consultation Summary, published with the Guideline.

Independent review: AGREE-II

All feedback was considered by members of the DRWG and changes made where relevant (e.g., suggestions for further elaboration on aspects of the methodology).

Independent Review: NHMRC

All feedback was considered by members of the GDG and changes made where relevant. A copy of the reviewer feedback and the GDG's response is provided in the Public Consultation Summary document that accompanies the Guideline.

Health Department Review

All feedback was considered by members of the DRWG and changes made where relevant. A copy of feedback received and the GDG's response is provided in the Public Consultation Summary document that accompanies the Guideline.

Guideline Development Group review of feedback and changes

All GDG members were provided with a penultimate draft of the Guideline with all changes highlighted and accompanying comments that explained the changes made. The GDG members were also provided with the complete set of feedback from the feedback survey, with feedback that had resulted in changes to the Guideline highlighted. GDG members were invited to provide feedback, including raising any issues for further discussion, via email, in text-suggested edits and comments, or via discussion at the monthly meeting (September, 2022) of the GDG.

The feedback from the independent content reviewers, commissioned by NHMRC, was provided to the GDG on 16/09/22, which was following the GDG meeting (09/09/22). Accordingly, the DRWG reviewed and responded to this feedback using the same method outlined above. The GDG were provided with a summary of the final changes and a copy of all Guideline documents on 21/09/22. Once satisfied, each member of the GDG confirmed their endorsement of the documents via email to the GDG Co-chairs.



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



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 includes proper consideration of issues relating 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 activities.
 - › Established with the National Aboriginal Community Controlled Health Organisation (NACCHO) an understanding that the Autism CRC seeks to enter into a long-term partnership with the Aboriginal and Torres Strait Islander community, 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 autistic Aboriginal and Torres Strait Islander children.
 - › Reviewed key documents to inform the development of the Guideline, including the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) Code of Ethics for Aboriginal and Torres Strait Islander Research (2020).



Reading the Guideline



Reading the Guideline

This Guideline was developed to ensure that autistic children and their families in Australia receive safe, effective, and desirable supports. The Guideline reflects the current knowledge in the area, weighs the benefits and harms identified, and provides Recommendations based on this information. These Recommendations are designed to provide practitioners who have the appropriate qualifications, experience, knowledge, and skills with an evidence-based framework through which they can support the learning, participation, and wellbeing of autistic children and their families.

Recommendations and Good Practice Points

The Guideline is structured into a set of 84 Consensus-Based Recommendations with associated Good Practice Points:

- Consensus-Based Recommendations are key elements of practice that must be followed for a practitioner to deliver evidence-based supports.
- Good Practice Points are linked to specific Recommendations, and are 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.

The Recommendations and Good Practice Points may include examples for illustrative purposes. These examples are provided to further contextualise the information, and should not be interpreted as a complete list.

Talking about autism

The language used to talk about autism is important. During the Guideline development process, the GDG took a proactive approach to understanding community views on different language choices, and prioritising the use of language that is the most acceptable to the widest range of the community. Through an open consultation process embedded within the online community survey, it was determined that the use of identity-first language (e.g., 'autistic children') is preferred by the autistic community and acceptable to the broader community in the context of this Guideline. Based on this consultation, identity-first language is used in this Guideline. However, the Guideline also respects that no one term is preferred by all people. In this regard, the Guideline recommends that practitioners be familiar with, and respect, the individual language and terminology preferences of each individual child and family. The process undertaken to guide language use in this Guideline is described in the Administration and Technical Report.

Talking about parents, carers, and families

The Guideline recognises that families come in many forms, and a family unit may include one or more parents, siblings, and/or biologically related and unrelated children and adults. The Guideline recognises that conceptions of parents and families are culturally bound and equally valid. For clarity of writing, the Guideline refers to ‘parents’ when referring to people who have parenting responsibilities for a child, including guardian, kinship and foster carers. Recommendations that refer to ‘parents’ refers to these individuals specifically, whereas Recommendations and Good Practice Points referring to ‘family’ or ‘families’ refers to parents and also other people within a child’s family, including siblings, grandparents, aunts, uncles, cousins, and other people the child and parents themselves consider to be family.

Involving children in decision making

Consistent with a human rights framework, the Guideline recommends that autistic children are involved in decisions regarding the supports they receive. How this occurs will be different for different children and take into consideration factors such as how old they are, their cognitive and communication skills, and the nature of the decision being made. These are the same considerations that are given to involving children in decision making in other health and education contexts. Practitioners are expected to draw on their clinical training, adhere to the ethical and professional practice requirements of their professional organisations, and abide by the laws and regulations governing their practice in upholding their professional obligations and duty of care to children and their families.

Seeking the child’s assent, and obtaining parental consent, are critical and complementary processes that help ensure the rights of the child and family are protected. This protection extends to circumstances in which the child is unable to comprehend the decision being made due to their age, cognitive skills, and/or communication needs. In circumstances where the child cannot not reasonably be expected to take on the full burden of decision making, parents and other legal guardians fulfil an essential role in weighing up the potential benefits and risks of a particular course of action and acting in the child’s best interests.

There may be circumstances in which the preferences of a child and parent are in conflict. Such conflicts should be resolved through a principled approach, given that the issues to consider will be unique to the particular circumstance. A key consideration is the balancing of principles honouring, respecting, and supporting the autonomy and self-determination of the child, while also maintaining duty of care. The child’s right to have their views sought, heard, and respected is enshrined in laws and conventions in Australia and internationally. Accordingly, the child’s views should be prioritised, provided doing so maintains the practitioner’s duty of care within the ethical, professional, legal, and regulatory context in which they are operating.

The Guideline is purposefully non-prescriptive in relation to addressing who should be involved in seeking the child’s assent, when this should occur, how much information should be provided to the child, what type of information should be provided, and how practitioners should respond when clear assent is not forthcoming or withdrawn. Again, a principled approach is required, within the ethical, professional, legal, and regulatory context in which the practitioner is operating. Of particular consideration here is the understanding that all children have the capacity to assent and that they may communicate their wishes using a range of communication modes. The modes children may use to express assent, or lack thereof, include but are not limited to movements, physical actions, facial expressions, expression of emotions, gestures, manual signs, vocalisations, words, drawing, writing, and use of augmentative and alternative communication modes.

Children may also express their assent, or lack thereof, by acting on the environment in ways that convey their assent, or lack thereof, such as actively retrieving preferred toys or materials to indicate willingness to participate in an activity; or rejecting, hiding, or destroying objects and materials to express a lack of assent. Furthermore, children may communicate in idiosyncratic ways (i.e., unique to them) or indicate their feelings about a particular interaction, activity, or environment through fluctuations and changes in their interest, engagement, or need for other interests and activities (e.g., an increase in sensory behaviours in response to increasing anxiety).

Practitioners should assume that assent may not be given and that even when provided, it may change or be withdrawn. For example, an activity a child finds enjoyable on one day may be distressing on another, due to a child's fluctuating sensory or other needs. Practitioners should continually ask themselves: "What evidence do I have that the child is assenting to the supports I am providing?" Where the evidence for a clear answer to this question is lacking, changing, or ambiguous, practitioners should respond by ceasing or adjusting the support, at the same time consulting the child, to the extent possible, and parents regarding appropriate next steps, at all times maintaining their duty of care. Furthermore, practitioners should consider supporting children to have input into decisions about their own lives as a priority when working together. Supporting children to develop their capacity to make informed decisions about their own lives; to express these effectively and with confidence; to ensure those around them are listening and acting on their wishes; and to counter learned helplessness, compliance, and acquiescence, are essential goals of childhood for all children, and of paramount concern for autistic children who are the focus of this Guideline.

Making use of the Guideline and all supporting documents

To make the best use of the Guideline, it is essential that practitioners familiarise themselves with its entire content by reading all sections. The Recommendations relate to the entire clinical process, from overarching principles, through to goal setting, selecting and planning of supports, delivery of supports, monitoring and review of outcomes, and safeguarding of the wellbeing and rights of children and their families. Thus, it is strongly advised that the Recommendations are taken as a whole, rather than in isolation.

Updating the Guideline

Guidelines should be regularly updated to incorporate new research and clinical evidence, as well as the changing understandings and preferences of the autistic and autism communities. A review of the Guideline should take place within five years of the publication of this original version.



Acknowledging and respecting **Aboriginal and Torres Strait Islander Peoples**



Acknowledging and respecting Aboriginal and Torres Strait Islander Peoples

The Guideline Development Group offers respect to the Traditional Owners and Custodians across the country now known as Australia. We acknowledge the journey of Elders past, and we recognise historical truths and the enduring impact for First Nations Australians.

We recognise and value the knowledge and wisdom of Elders present, as well as those emerging leaders who share a continuing connection with Aboriginal and Torres Strait Islander Peoples and Country. We are strengthened together through upholding the continuation of the First Peoples lore of cultural and spiritual ways that help to grow children and families strong.

We recognise inequalities and commit our efforts to work alongside Aboriginal and Torres Strait Islander Peoples to better understand their lived experience. We support engaging two-worlds to progress deep knowledge of culturally safe, responsive, and timely supports and services.

The Guideline Development Group have strengthened existing relationships and initiated new networks to support *proper way* collaboration and consultation. Our intention is to continue the journey of walking alongside First Nations Peoples through deep listening and upholding shared knowledge. We acknowledge the valuable contribution of Aboriginal and Torres Strait Islander Peoples to this Guideline and recognise the perspectives, preferences, and priorities of First Peoples as key to guiding good practice across Australia.



Section 1: Guiding Principles



Section 1: Guiding Principles

Guiding principles provide practitioners with a starting point for approaching all aspects of their work with children, families, and those who seek to support them. Guiding principles can also be helpful to children, families, all members of the autistic and autism community, and policy makers when making decisions about services and supports in the best interests of children.

What guiding principles should be followed when providing supports to autistic children and their families?

Practitioners should be guided by principles that inform their approach to working with children: child and family-centred, individualised, strengths-focused, and holistic. Their approach should honour the experiences and activities of childhood, and lay the foundation for a positive future. Practitioners should work in ways that respect Aboriginal and Torres Strait Islander Peoples, and that are culturally safe and appropriate for all people. The supports practitioners provide should be evidence-based. They should be ethical, seek children's assent, and always obtain parents' consent. Practitioners should be qualified, have relevant knowledge, skills, experience, and supervision, and operate within a professional regulation framework that helps to ensure high quality and safe services. They should work in ways that are neurodiversity-, parent-, and family-affirming, and that honour the rights and role of each person. Practitioners should work in ways that contribute to children and families having access to timely, accessible, and coordinated supports.

Recommendation 1

Consensus-Based Recommendation

Child and family-centred: Supports should be child and family-centred, where individual goals, preferences, and circumstances are respected, valued, and supported through shared decision making.

- ▶ Grade of Recommendation: Strong

Recommendation 2

Consensus-Based Recommendation

Individualised: Supports should be individualised for each child and family.

- ▶ Grade of Recommendation: Strong

Recommendation 3

Consensus-Based Recommendation

Strengths-focused: Supports should build on each child's and family's strengths and interests.

- ▶ Grade of Recommendation: Strong

Recommendation 4

Consensus-Based Recommendation

Holistic: Supports should be holistic in terms of the goals that are targeted and the way they are achieved, considering all aspects of the child, family, and their community.

- ▶ Grade of Recommendation: Strong

Recommendation 5

Consensus-Based Recommendation

Honour childhood: Supports should honour the goals and activities of childhood including play, relationships, and personal discovery.

- ▶ Grade of Recommendation: Strong

Recommendation 6

Consensus-Based Recommendation

Foundation for the future: Supports should lay the foundation for a positive future, including optimum health, choice, learning, self-identity, participation, and wellbeing.

- ▶ Grade of Recommendation: Strong

Recommendation 7

Consensus-Based Recommendation

Ethical: Supports should be ethical to protect the rights of the child and family.

- ▶ Grade of Recommendation: Strong

Recommendation 8

Consensus-Based Recommendation

Culturally safe: Practitioners should acknowledge and respect the values, knowledge, preferences, and cultural perspectives of the child and family, and reflect on their own cultural knowledge and competency in delivering services.

- ▶ Grade of Recommendation: Strong

Recommendation 9

Consensus-Based Recommendation

Respecting Australia's First Nations Peoples: Supports should be culturally safe for Aboriginal and Torres Strait Islander Peoples, built on an acknowledgment of the barriers to accessing supports that they may experience; an understanding of current and historical truths and their enduring impact; and respect for deep connection to Country, language, customs, and traditions.

- ▶ **Grade of Recommendation:** A rating is not provided as this Recommendation was developed through direct consultation with First Nations Peoples and received unanimous endorsement of the Guideline Development Group.

Recommendation 10

Consensus-Based Recommendation

Evidence-based: Supports should reflect the best available research evidence, integrated with evidence from clinical practice and the lived experience of autistic people and their families, and the preferences and unique context of each child and family.

- ▶ **Grade of Recommendation:** Strong

Recommendation 11

Consensus-Based Recommendation

Assent (children): Each child has the right to say no to supports and their assent (expression of approval) should be sought and respected, whether they communicate using words or in other ways.

- ▶ **Grade of Recommendation:** Strong

Recommendation 12

Consensus-Based Recommendation

Informed consent (parents): Parents should have the information they need to make informed choices about supports and provide consent for any supports received.

- ▶ **Grade of Recommendation:** Strong

Recommendation 13

Consensus-Based Recommendation

Qualified practitioners: Practitioners should have relevant qualifications, be regulated, work within their scope of practice with appropriate supervision, and engage in continuing professional development.

- ▶ **Grade of Recommendation:** Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Recommendation 14

Consensus-Based Recommendation

Neurodiversity-affirming: Supports should be neurodiversity-affirming, embracing each child's unique understanding of other people and the world around them, without seeking to 'cure' autism.

- ▶ Grade of Recommendation: Strong

Recommendation 15

Consensus-Based Recommendation

Parent and family affirming: Supports should uphold the parents' autonomy in raising their child, and ensure the natural roles of children, parents, siblings, and other family members are affirmed and preserved.

- ▶ Grade of Recommendation: Strong

Recommendation 16

Consensus-Based Recommendation

Timely and accessible: Each child and family should be able to access the supports they need, when they need them, and in ways they desire, regardless of who they are, where they live, or how much money they have.

- ▶ Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Recommendation 17

Consensus-Based Recommendation

Coordinated: Practitioners should engage in open and regular communication with other practitioners, the child's educators, and other service providers, with appropriate consent, to ensure supports are coordinated.

- ▶ Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.



Section 2: Goal Setting



Section 2: Goal Setting

Selecting appropriate, meaningful, and feasible goals provides the foundation for safe and effective supports that are desired by children and families. Goal setting should be led by the child and family, with support from practitioners and other people where relevant. Different children and families will have different goals, reflecting their individuality as people, their individual contexts, and their individual views regarding the relevance of supports in their lives.

What are appropriate goals for supporting children and families?

Goals should focus on supporting the child to acquire and maintain skills, empowering their parents and families, and/or creating accessible environments, as the basis for supporting learning, participation, and wellbeing. All goals should be neurodiversity-affirming.

Recommendation 18

Consensus-Based Recommendation

Practitioners should work in partnership with the child and family to consider goals that help the child acquire skills that promote their learning, participation, and wellbeing.

► Grade of Recommendation: Strong

Good Practice Points

18.1 Goals may include helping a child:

- Acquire communication, cognitive, social-emotional, motor, and academic skills, meet their sensory needs, participate in daily activities, and build and maintain their quality of life.
- Acquire skills across developmental domains that are personally meaningful, and developmentally and culturally relevant.
- Acquire and apply skills within play, daily routines, and other childhood activities.
- Acquire skills that enable them to express their views, interests, personality, preferences, and needs.
- Acquire skills that support their emerging autonomy, independence, self-identity (including gender identity), and capacity for self-advocacy.
- Acquire an understanding of their own sexual development and associated protective behaviours.
- Acquire skills that replace the need for behaviours that cause harm to themselves, others, and/or property.
- Acquire skills that support them to consider their own future goals, aspirations, and preferences including in terms of life, work, relationships.

- Consolidate and generalise skills previously acquired.
 - Build and maintain nurturing and positive relationships with parents, siblings, other family members, peers, and others in the community.
 - Gain experience interacting with a range of people in a range of different places, in ways that build their confidence, keep them safe, and enable them to develop interests, connections, and their individual identities.
- 18.2 Practitioners should be aware of existing frameworks that can provide further guidance for goal setting, such as the International Classification of Functioning, Disability and Health (World Health Organisation, 2001).

Recommendation 19

Consensus-Based Recommendation

Practitioners should work in partnership with the family to consider goals that empower the family to support and advocate for the child, and promote the child's learning, participation, and wellbeing.

► Grade of Recommendation: Strong

Good Practice Points

- 19.1 Goals focusing on helping parents and family members gain knowledge may include:
- Understanding autism from a neurodiversity perspective, including via the lived expertise of autistic children, young people, and adults.
 - Understanding the characteristics of autism, including common strengths of autistic children, as well as commonly experienced challenges.
 - Understanding the aims, attributes, and evidence (research, clinical, lived experience) for a range of supports.
 - Understanding the roles, qualifications, and regulation of those who provide supports.
 - Understanding the ways to access broader community support including through education and health service systems.
 - Understanding what disability-specific support may be available, including planning and funding through the National Disability Insurance Scheme (NDIS).
- 19.2 Goals focusing on helping parents and family members to acquire skills may include:
- Understanding their child's unique strengths and needs, including behaviours and ways of communicating.
 - Acquiring knowledge and skills to support the child's learning, participation, and wellbeing.
 - Learning techniques to monitor the child's experiences and outcomes as they access supports, as the basis for informed decision-making.
 - Learning skills that support them in advocating for the child as they access supports including advocating for the child's enjoyment, learning outcomes, safety, quality of life, and wellbeing.
 - Acquiring knowledge and skills that will support and sustain family wellbeing.
- 19.3 Practitioners should be aware that goals aimed at helping parents and family members to acquire knowledge and skills may create a burden for them and/or detract from their natural role, and be adjusted accordingly.
- 19.4 Goals focusing on helping parents and family members to create and maintain networks of support may include:
- Connecting with family (e.g., siblings, grandparents) and family-like people in the community in

ways that support them in raising the child, and support their personal and family wellbeing.

- Connecting with other parents and family members who have lived expertise of raising autistic children.
- Connecting with autistic adults.
- Connecting with appropriately qualified disability-specific and mainstream (e.g., health, education) service providers to access appropriate supports, including respite and advocacy services.

19.5 Practitioners who recommend goals focusing on supporting parents or other family members to acquire knowledge and/or skills should clearly explain the rationale for these goals, and ensure they represent an opportunity to further enhance the intrinsic expertise parents and other family members bring to raising children, not to imply or address a lack of effort or ability.

Recommendation 20

Consensus-Based Recommendation

Practitioners should work in partnership with the child and family to consider goals that create safe and accessible environments that support the child's learning, participation, and wellbeing.

► Grade of Recommendation: Strong

Good Practice Points

20.1 Goals focused on the physical environment may include:

- Ensuring spaces are safe (e.g., childproof fencing near roads, locked cabinets for medicines).
- Ensuring spaces are accessible and as inclusive as possible (e.g., consideration of sensory needs, physical access for a child with co-occurring physical disability; communication access for children who communicate mainly in ways other than speech; and provision of information in Easy Read formats for children with literacy needs).
- Ensuring spaces are appropriate (e.g., compliance with standards regarding restrictive practices in the physical environment).

20.2 Goals focused on working in collaboration with other people to gain knowledge that will help them to support the learning, participation, and wellbeing of a child may include:

- Understanding autism from a neurodiversity perspective, including via the lived expertise of autistic children, young people, and adults.
- Understanding the characteristics of autism, including strengths and challenges commonly experienced by autistic children.
- Understanding the child's individual strengths, needs, interests, and preferences.
- Understanding the aims, characteristics, and evidence (research, clinical, lived experience) for a range of supports.
- Raising awareness and empowering other people to identify and address individual and systemic discrimination experienced by autistic children and their families.

20.3 Goals focused on working in collaboration with other people to gain skills that will help them to support the learning, participation, and wellbeing of a child include:

- Acquiring knowledge and skills to support the child's learning, participation, and wellbeing.
- Acquiring knowledge and skills to monitor the child's experiences and outcomes as they access supports, as the basis for informed decision-making.

Recommendation 21

Consensus-Based Recommendation

Goals should be neurodiversity-affirming.

► Grade of Recommendation: Strong

Good Practice Points

- 21.1 Practitioners should be aware of neurodiversity principles, where brain-based and behavioural differences observed in autistic children are regarded as natural human variation.
- 21.2 Practitioners should be aware that many autistic people consider autism to be intrinsic to their identity, which is in turn inherent to their sense of self and wellbeing.
- 21.3 Practitioners should be aware that goals that focus on helping children acquire neurotypical social-communication skills (e.g., making eye contact during conversations) and/or support changes in their experience of the world or behaviour (e.g., supports to transition away from engaging with a passionate interest) may be interpreted as seeking to reduce or 'cure' autism, because these goals relate to core characteristics of autism.
- 21.4 Where practitioners recommend goals related to characteristics of autism, practitioners should:
 - Discuss the goal openly with the child and family.
 - Explain how the goal aligns with a neurodiversity-affirming approach to practice.
 - Document the rationale for the goal in relation to reducing barriers to the children's activities, participation and associated wellbeing and quality of life.
 - Consider the impacts of the goal on the child's developing identity.
 - Develop and document ways of safeguarding to ensure the supports do not impinge on the right of the child to develop and preserve their own identity.

How should goals be selected?

Goal setting should focus on helping children and families set their own individually meaningful goals, with support from practitioners and involvement of other people when relevant and desirable to the child and family. The process should include consideration of the unique aspects of the child, their family, and the broader context of their lives. Goals, including rationales, should be discussed and recorded. Agreed goals should be supported by multiple sources of evidence, and contain all the information that the child, their family, and those who support them require to ensure they can work together with clarity and purpose.

People involved

Recommendation 22

Consensus-Based Recommendation

Goal setting should be led by the child and family, with support from practitioners, and involvement of other people when relevant.

► Grade of Recommendation: Strong

Good Practice Points

- 22.1 Goal setting should always involve the child and parents.

- 22.2 Where relevant and agreed to by the child and family, the following people may also be involved in setting goals:
- Family (e.g., siblings, grandparents) and family-like people (e.g., family friends, peers).
 - Suitably qualified and experienced practitioners (e.g., allied health professionals, medical doctors, educators).
 - People who can support the child's participation in community activities (e.g., sports coaches; community and faith leaders; art teachers; and community members the child interacts with regularly including in retail environments, community groups, and cultural activities).
 - Staff in agencies that support the provision and/or access to supports (e.g., NDIS planners, child safety officers).

Understanding the child, family, and context

Recommendation 23

Consensus-Based Recommendation

In working in partnership with the child and family to set goals, practitioners should consider the unique aspects of the child and the contexts in which they live.

► Grade of Recommendation: Strong

Good Practice Points

- 23.1 In working with the child and family to set goals, practitioners should consider the following aspects of the child:
- The child's view of their own strengths, challenges, wellbeing, and quality of life.
 - The child's preferences regarding accessing supports.
 - The child's expectations for the outcomes of receiving supports.
 - The child's health – including physical health, mental health, co-occurring diagnoses, and health history.
 - The child's developmental skills – including strengths and difficulties in motor, social-emotional, cognitive, communication, and academic skills.
 - The child's autism characteristics – including the functional impact of differences in social-communication skills, behaviours, interests, and sensory experiences. The functional impact includes both the strengths and challenges arising from these differences.
 - The child's activities and participation – including enablers and barriers to participation in the home, educational, and community settings.
 - The child's activity-related strengths, preferences, and needs – including activities that bring the child joy and/or that they have expertise in.
 - The child's behaviours that may harm themselves, others, and/or property – including full consideration and addressing of factors that may cause or contribute to these behaviours including the child's health and aspects of the environment.
 - Other aspects related to the safety of the child – including water safety skills, road safety awareness, and risk of wandering (also known as 'absconding').
 - The child's access to early childhood and primary school education – including the provider's educational philosophy, the child's learning goals, supports provided, and the knowledge and skills of staff.
 - The current and previous supports received by the child – including the type of supports received,

their delivery mode (e.g., in person, telepractice), format (e.g., one-on-one, in a group), setting (e.g., home, community, clinic, school), agent (e.g., practitioner, family member), amount and duration, and their experiences and the effects of those supports (e.g., outcomes, adverse effects, views and preferences expressed by the child and family).

- The child's culture and spiritual beliefs.
- The child's gender identity and developing sexuality.

Recommendation 24

Consensus-Based Recommendation

In working in partnership with the child and family to set goals, practitioners should consider the unique aspects of the family and the contexts in which they live.

► Grade of Recommendation: Strong

Good Practice Points

- 24.1 In working with the child and family to set goals, practitioners should consider the following aspects of the family:
- The family's physical and mental health – including the presence of any conditions that may impact upon family members' capacity to participate, or need to be considered, in the setting of goals.
 - The family's social-emotional resources and supports – including the positive and challenging factors associated with the child's support needs, resilience factors and the capacity to deal with stressful situations, and the availability of social and emotional support via extended family, friends, and support groups.
 - The family's experience of autism and co-occurring conditions – including whether the parents, siblings, and/or other family members of the child are autistic.
 - The family's financial resources and supports – including funding to pay for supports to achieve the goal, capacity to purchase unfunded supports, travel costs to access the supports, and capacity to take time away from paid work to access supports.
 - The family's views, perspectives, and preferences – including views about their child's, strengths, challenges, learning, participation, and wellbeing now and in the future; views on disability, child-rearing, and child development; the perceived relevance of the goals to the child; cultural and spiritual beliefs relevant to the goals; the motivation of the family to receive supports; the language that is preferred by the family; preferences for goals; and expectations for outcomes.
 - The family's dynamics – including the nature and strength of relationships between family members, the wellbeing and quality of life of siblings, the nature and distribution of roles and responsibilities (including guardianship arrangements and related decision-making authority), stability of care, and living/care arrangements.
 - The family's activities – including work, social, cultural, sport and recreational, and educational activities that may act as enablers or barriers to a particular goal.
 - The family's location – including access to supports and networks in their local community.
- 24.2 Practitioners should be aware of and acknowledge the emotional impact that children, parents, and families may experience through sharing information about their lives with multiple people on multiple occasions and take steps, where possible, to reduce the burden (e.g., reading prior reports shared by the family).

Ensuring goals are relevant, safe, desired, and feasible

Recommendation 25

Consensus-Based Recommendation

Practitioners should have a strong rationale for why a goal is recommended, which considers the potential benefits and risks for the child and family.

► Grade of Recommendation: Strong

Good Practice Points

- 25.1 Goals should be developed through a process of shared decision making.
- 25.2 Practitioners should ensure that goals are:
 - Specific.
 - Measurable.
 - Achievable.
 - Relevant and meaningful to the child, family, and their context.
 - Set with a clear timeframe.
 - Understood by the family and relevant stakeholders.
 - Documented.
- 25.3 Practitioners should ensure that each goal is supported by multiple converging sources of evidence including:
 - Information gathered about the child and family that is relevant to the goal, including assessment information.
 - A theoretical rationale for why the goal is likely to lead to an increase in the child's learning, participation, and/or wellbeing.
 - The best available research evidence that the goal is likely to lead to an increase in the child's learning, participation, and/or wellbeing, along with consideration of any evidence regarding adverse effects.
 - Evidence gathered through clinical practice that the goal is likely to lead to an increase in the child's learning, participation, and/or wellbeing, along with consideration of any evidence regarding adverse effects, including evidence drawn from the experiences and outcomes of other children and families the practitioner has supported.
 - Perspectives expressed by autistic people regarding goals of this nature.
 - Consideration of how multiple goals may be coordinated, such as how goals may enhance and impede progress towards other goals.
- 25.4 Consideration of how the goal may align with education frameworks (e.g., National Early Years Learning Framework, the Australian Curriculum)
- 25.5 Goals should be selected with a view towards how the outcome of this goal may support the child's learning, participation, and wellbeing over:
 - The short-term (i.e., <12 months).
 - The medium-term (i.e., 12 months to 2 years).
 - The long-term (i.e., >2 years).

Recommendation 26

Consensus-Based Recommendation

Practitioners should ensure that the agreed goals are discussed and documented in a way that is informative, understandable, and meaningful to the child and the family.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Good Practice Points

- 26.1 Practitioners should ensure that all key considerations about the recommended goals are shared with the child and family, including the anticipated time frame to achieve goals and plans to monitor progress.
- 26.2 Practitioners should ensure that information is shared in a way that is aligned with the cultural, language, and communication preferences (such as preference for written, visual or verbal information) of the child and family.
- 26.3 Practitioners should ensure that goals are documented in a way that is informative and practical, so as to foster timely and coordinated collaboration between practitioners supporting the child and family, where parental consent to collaborate has been provided.
- 26.4 Practitioners should provide the child and the family sufficient time to consider all information and provide the opportunity for further discussion and questions.



Section 3: Selecting and planning supports



Section 3: Selecting and planning supports

The goal setting process may identify that the child, parent, and/or family need further supports to promote child learning, participation, and wellbeing. These supports should align with child and family goals, as well as their strengths, needs, preferences, and contextual considerations.

What types of supports might be relevant to children and families?

A range of supports may be relevant to autistic children and their families. Supports may focus on helping children acquire meaningful skills, helping the people around the child better support the child, and/or creating environments that are accessible and conducive to the child's learning, participation, and wellbeing. Supports are intended to have a positive effect in relation to one or more child and family outcomes that are valued by the child and family.

Focusing on the child's communication

Recommendation 27

Consensus-Based Recommendation

Supports should help the child communicate with a variety of people in everyday contexts, for a variety of reasons, and in ways that they desire.

► Grade of Recommendation: Strong

Good Practice Points

27.1 Supports focusing on the child's *comprehension* (understanding) should:

- Help the child develop functional skills in understanding and interpreting other people's spoken, non-verbal, written, and visually presented communication.
- Help communication partners to be aware of, and support, the child's strengths and preferences in relation to comprehension, including with regard to spoken, written, and visually presented information.
- Help create accessible environments, where the child's strengths and preferences in relation to comprehension are supported, including with regard to spoken, written, and visually presented information.

27.2 Supports focusing on the child's *comprehension* (understanding) should not:

- Make assumptions regarding the child's strengths and preferences in relation to comprehension,

including with regard to spoken, written, and visually presented information.

- Deny the child access to multiple and preferred modes of support for their comprehension.
- Focus on the child, without considering support for other people and potential adjustments in the environment.

27.3 Supports focusing on *how* the child communicates (i.e., modes) should:

- Help the child explore and acquire a combination of communication modes that are most effective for and desirable to them, including, and not limited to movements, physical actions (including on other people, objects, and the environment), facial expressions, expression of emotions, gestures, manual signs, vocalisations, words, drawing, writing, and use of augmentative and alternative communication modes.
- Help communication partners be effective in supporting the child's preferred modes of communication (e.g., family members learning how to create and support the use of visual supports).
- Help create environments that are conducive to supporting the child's preferred modes of communication (e.g., ensuring visual supports are available at home and in the community, accessible hearing environments).
- Account for cultural differences in communication (e.g., cultures in which non-verbal language is embedded in ways of being).
- Account for co-occurring conditions that may influence the child's most effective and preferred modes of communication (e.g., co-occurring motor speech impairment), and complement any other supports currently being implemented.

27.4 Supports focusing on *how* the child communicates (i.e., modes) should not:

- Force the child to communicate using one or more modes that are not of their choosing, or which may cause harm. Practitioners should be aware of evidence from the autistic community that forcing children to make eye contact during communication can be distressing for some children.
- Have a communication partner use a child's augmentative communication system (e.g., pictures, typing), or physically guide the child's use of the communication system, to convey a message on the child's behalf.
- Focus on the child, without considering support for other people and potential adjustments in the environment.

27.5 Supports focusing on *why* the child communicates (i.e., communicative functions) should:

- Help the child express their wants, needs, preferences, feelings, and desires.
- Help the child share their ideas, interests, and aspects of their own experience and personality.
- Help the child make choices and advocate for what is right for them.
- Help the child form and engage in relationships that are meaningful to and desired by them.
- Help the child to express refusal, opposition, and dissent.
- Help communication partners be effective in supporting the child to communicate for a range of reasons that are meaningful to them (e.g., ensuring communication partners are aware of the different reasons the child communicates and create opportunities for them to do so).
- Help create environments that are conducive to supporting the child to communicate for a variety of reasons that are meaningful to them (e.g., ensuring that the child can make choices about play activities at preschool and have opportunities to share joy and create meaning).

27.6 Supports focusing on *why* the child communicates (i.e., communicative functions) should not:

- Force the child to engage in communicative behaviours that serve no functional purpose (e.g., learning and reciting lists of words without practical application).

- Force the child to interact with others in ways that are common in neurotypical children but may be non-preferred, challenging, and potentially harmful for the child. This may include teaching neurotypical ‘social skills,’ if doing so will impinge on their right for freedom of identity and expression. Practitioners should also consider that attempting to modify the child’s social-communication to reflect a neurotypical profile may lead to ‘masking’ – the suppressing of certain natural behaviours – which can have significant implications for the child’s wellbeing.
 - Focus on the child, without considering support for other people and potential adjustments in the environment.
- 27.7 Practitioners should be aware that goals that focus on helping the child acquire neurotypical social-communication skills (e.g., making eye contact during conversations) and/or support changes in their experience of the world or behaviour (e.g., reducing sensory-seeking behaviours) may be interpreted as seeking to reduce or ‘cure’ autism, because these goals relate to core characteristics of autism.
- 27.8 Where practitioners recommend goals related to social-communication, practitioners should:
- Discuss the goal openly with the child and parents.
 - Explain how the goal fits with a neurodiversity affirming approach to practice.
 - Document the rationale for the goal in relation to reducing barriers to the child’s activities, participation and associated wellbeing and quality of life.
 - Consider the impacts of the goal on the child’s developing identity.
 - Develop and document ways of safeguarding to ensure the supports do not impinge on the right of the child to preserve their identity.

Focusing on the child’s sensory experiences

Recommendation 28

Consensus-Based Recommendation

Supports should meet the child’s sensory needs across activities, interactions, and settings.

► Grade of Recommendation: Strong

Good Practice Points

28.1 Supports for sensory needs should:

- Help the child to develop an understanding and awareness of their own internal physical and emotional states (interoceptive awareness) to aid in understanding their sensory needs.
- Help the child to identify, express, and address their own sensory needs, sensitivities, and preferences, including through access to sensory tools, experiences, and modification of environments.
- Help the people around the child to be effective in meeting the child’s sensory needs.
- In cases where sensory responses may compromise safety (e.g., self-injurious behaviour), support the child to meet their sensory needs in an alternative and safe manner.
- Help create environments that are conducive to meeting sensory needs.
- Help the child feel as comfortable as possible in all life situations as well as confident and supported in meeting their sensory needs and preferences.
- Help the child to regulate sensory experiences.
- Account for co-occurring conditions that may influence the child’s sensory needs (e.g., skin conditions), and complement any other supports currently being implemented.

28.2 Support for sensory needs should not:

- Attempt to modify the child's sensory seeking or avoiding behaviours, where they serve a functional purpose in meeting their needs or are individually meaningful.
- Focus on the child, without considering support for other people and potential adjustments in the environment.

Focusing on the child's cognitive development

Recommendation 29

Consensus-Based Recommendation

Supports should help the child develop their cognitive skills as the foundation for learning about themselves, other people, and the world around them.

► Grade of Recommendation: Strong

Good Practice Points

29.1 Supports for cognition should:

- Help the child to develop their skills including executive functioning, in the context of meaningful and relevant childhood activities.
- Help the people around the child to be effective in supporting their cognitive development.
- Help the child develop skills that support transitions between activities and settings.
- Help create environments that are conducive to developing the child's cognitive skills, and support their cognitive strengths, needs, and preferences.
- Help the child feel respected and valued in the way they understand other people and the world around them, including preferences for learning and passionate interests.
- Account for co-occurring conditions that may influence the child's cognitive development (e.g., intellectual disability, specific learning disorders), and complement any other supports currently being implemented.

29.2 Supports for cognition should not:

- Work within a framework that views a neurotypical profile of cognitive skills as being superior to that of an autistic child.
- Attempt to modify a child's cognitive skills to reflect a neurotypical profile.
- Attempt to reduce or eliminate a child's passionate interest(s).
- Focus on the child, without considering support for other people and potential adjustments in the environment.

Focusing on the child's social-emotional development and wellbeing

Recommendation 30

Consensus-Based Recommendation

Supports should help the child develop social-emotional skills, supporting them to understand, express, and regulate their emotions as a foundational skill for learning, participation, and wellbeing.

► Grade of Recommendation: Strong

Good Practice Points

30.1 Supports for social-emotional development and wellbeing should:

- Help the child to develop an understanding and awareness of their own internal physical and emotional states (interoceptive awareness) to aid in developing social-emotional skills.
- Help the child to develop social-emotional skills that are both functional and individually meaningful in helping them understand and interact with others.
- Help the child to identify, express, and address their own social-emotional needs and preferences, including through self-regulation and co-regulation.
- Help the child to form and foster healthy relationships that they want, and in ways that they value.
- Help the child to feel safe and secure in trusting relationships.
- Help the child to enjoy playful interactions in ways that they value.
- Provide opportunities for the child and those around the child to develop shared understanding and meaning through cooperative, co-regulated interactions.
- Help the child to navigate unavoidable challenges (e.g., changes in routine and surprises).
- Help the people around the child to be effective in supporting the child's development of social-emotional skills and expression of their needs and preferences. This includes these people working in ways that help the child identify and express their full range of emotions, including in the context of giving or refusing assent.
- Support the child to develop skills that help regulate their emotions during daily activities, as a way of promoting the child's wellbeing and increase their opportunities to learn and participate.
- Help create environments that are conducive to the child's social-emotional development and wellbeing.
- Scaffold ways to express anger and frustration as well as give, refuse, or withdraw assent in ways that other people can understand.
- Account for co-occurring conditions that may influence the child's social-emotional development and wellbeing (e.g., anxiety, depression), and complement any other supports currently being implemented.

30.2 Support for social-emotional development and wellbeing should not:

- Attempt to modify the child's social-emotional development, skills, and preferences to reflect a neurotypical profile. Doing so may lead to 'masking' – the suppressing of certain natural behaviours – which can have significant negative implications for the child's current and future wellbeing.
- Focus on the child, without considering support for other people and potential adjustments in the environment.
- Deny the child the right or ability to express difficult emotions.

- 30.3 Supports for social-emotional development may include addressing behaviours that result in the child harming themselves, others, and/or property. Such supports should:
- Be based on a comprehensive, holistic assessment in order to (a) understand the nature and functions of behaviour, (b) identify the individual and environmental factors that influence and maintain the behaviour, and (c) identify changes to the environment and support for the child that reduce or replace the need for the behaviour. The comprehensive assessment should include consideration of possible medical conditions that may cause and/or contribute to the behaviour (e.g., a child hitting their head due to earache, unrecognised constipation).
 - Focus on understanding the meaning and purpose of the behaviour from the child's viewpoint.
 - Find safe and appropriate alternatives to the behaviour that are most helpful and desirable to the child and family.
 - Be discussed with the child and parents explicitly, to ensure they are aware of the intended effect, that they are valued, and that they agree to them.
- 30.4 Practitioners should be aware that the following restrictive practices can present human rights infringements, and should only be used as a last resort and in compliance with relevant State and Territory requirements and regulatory frameworks, such as the National Disability Insurance Scheme (NDIS; Restrictive Practices and Behaviour Support Rules) 2018:
- Seclusion – sole confinement of a person with disability in a room or a physical space at any hour of the day or night where voluntary exit is prevented, or not facilitated, or it is implied that voluntary exit is not permitted.
 - Chemical restraint – the use of medication or chemical substance for the primary purpose of influencing a person's behaviour (not including the use of medication prescribed by a medical practitioner for the treatment of, or to enable treatment of, a diagnosed mental disorder, a physical illness, or a physical condition).
 - Mechanical restraint – the use of a device to prevent, restrict, or subdue a person's movement for the primary purpose of influencing a person's behaviour but does not include the use of devices for therapeutic or non-behavioural purposes.
 - Physical restraint – the use or action of physical force to prevent, restrict or subdue movement of a person's body, or part of their body, for the primary purpose of influencing their behaviour (not including the use of a hands-on technique in a reflexive way to guide or redirect a person away from potential harm/injury).
 - Environmental restraint – a restraint restricts a person's free access to all parts of their environment, including items or activities.

Focusing on the child's motor development

Recommendation 31

Consensus-Based Recommendation

Supports should help the child develop motor skills and functional movement that is meaningful, assists with daily activities, and enhances participation in activities of their choice.

► Grade of Recommendation: Strong

Good Practice Points

31.1 Supports for motor development should:

- Help the child to develop gross motor and fine motor skills that are functional and individually

meaningful in helping them engage in everyday childhood activities.

- Help the people around the child to be effective in supporting their motor development.
- Help create environments and contexts that are conducive to the child developing motor skills (e.g., through using preferred activities and the child's interests).
- Account for co-occurring conditions that may influence the child's motor development and functional skills (e.g., cerebral palsy, dyspraxia/developmental coordination disorder), and complement any other supports currently being implemented.

31.2 Supports for motor development should not:

- Focus on the child, without considering support for other people and potential adjustments in the environment.

Focusing on the child's academic skills

Recommendation 32

Consensus-Based Recommendation

Supports should help the child to acquire academic skills that optimise their learning and participation in educational settings.

► Grade of Recommendation: Strong

Good Practice Points

32.1 Supports for academic skills delivered by practitioners should:

- Help the child to develop skills that are foundational to, and a reflection of, learning within the education curriculum.
- Help the people around the child to be effective in supporting their development of academic skills, including identifying passionate interests the child may have (e.g., interest in a particular topic).
- Help create environments that are conducive to the child developing academic skills, including harnessing passionate interests.
- Account for co-occurring conditions that may influence the child's development of academic skills (e.g., specific learning disorders), and complement any other supports currently being implemented.
- Be planned and delivered in coordination with educators who support the child.

32.2 Supports for academic skills, delivered by practitioners, should not:

- Focus on the systematic acquisition of non-applied knowledge or skills (e.g., memorisation of items) without clear application, and evidence for use in everyday settings.
- Attempt to reduce or eliminate a child's passionate interests (e.g., interest in a particular topic).
- Focus on the child, without considering support for other people and potential adjustments in the environment.

Focusing on the child's daily activities and participation

Recommendation 33

Consensus-Based Recommendation

Supports should help the child to acquire skills that are relevant to their participation in meaningful daily activities.

► Grade of Recommendation: Strong

Good Practice Points

33.1 Supports for the child in their daily activities should:

- Help the child optimise their participation in meaningful daily activities.
- Help the people around the child to be effective in supporting their participation in daily activities.
- Help create environments that are conducive to the child developing skills for participation in daily activities, at a level and with independence that matches their chronological age. This includes increasing accessibility and reducing any barriers.
- Account for co-occurring conditions that may influence the child's participation in daily activities (e.g., physical and/or intellectual disability, health conditions), and complement any other supports currently being accessed.
- Help the child develop confidence and take measured risks as part of childhood development.

33.2 Supports for the child in their daily activities should not:

- Focus on the child, without considering support for other people and potential adjustments in the environment.

Focusing on family wellbeing

Recommendation 34

Consensus-Based Recommendation

Supports should empower families in raising the child and promote the wellbeing of the child and family.

► Grade of Recommendation: Strong

Good Practice Points

34.1 Supports to empower families should:

- Respect and value the parent and family's autonomy, authority, strengths and support needs, and agency in raising the child.
- Support parents in raising their child, including helping them identify and build on their own strengths, build and utilise skills and resources, address any needs, and advocate for their child.
- Aim to enhance family quality of life as an important facilitator of the quality of life for their child.
- Value and respect the contribution that siblings make in the lives of autistic children, across the lifespan. Consider the impacts, both positive and challenging, that arise for siblings of autistic children, across the lifespan, with the view to supporting their development of skills, knowledge, and social-emotional wellbeing.
- Acknowledge and accommodate, to the extent possible, different family member's ideas, expectations, and preferences regarding the supports they would like to, and are able to, accept.

- Acknowledge the power imbalances that may exist when families and practitioners work together and take steps to identify and address these imbalances.
- Recognise that some parents and family members may be autistic, which may influence their views, needs, and preferences for raising their child and working with practitioners.
- Recognise the unique characteristics, context, and experiences of each parent and family including possible health and education needs that may be relevant, such as parents experiencing high levels of stress or needing support with learning and literacy.
-

34.2 Supports to empower families should not:

- Impose the practitioner's or other people's experiences and views upon the family, as they should feel supported in finding their own path to raising their child.
- Make family members feel they should take the role of a practitioner or ignore their own wellbeing in supporting the child.

Focusing on accessible environments

Recommendation 35

Consensus-Based Recommendation

Supports should lead to the creation of accessible environments that support the child's learning, participation, and wellbeing.

► Grade of Recommendation: Strong

Good Practice Points

35.1 Supports aimed at creating accessible environments should:

- Help other people in the child's environment to gain knowledge and skills that will help them to maximise the child's learning, participation, and wellbeing.
- Consider the physical environment (e.g., physical access, lighting, materials, textures, acoustics, and availability of assistive technology).
- Consider the social environment (e.g., disabling attitudes and language, knowledge barriers, and skills barriers created by others).
- Be informed by and respect the views, experiences, needs, and preferences of the child and family.
- Consider the views, experiences, needs, and preferences reported by autistic children, young people, and adults.
- Be implemented collaboratively with all relevant stakeholders, using a co-design process wherever possible.
- Focus on creating the most inclusive, least restrictive environments possible, which seek to maximise outcomes and minimise stress and distress for the child and family.
- Focus on addressing social (e.g., discriminatory attitudes and systems), policy (e.g., discriminatory laws), and environmental (e.g., lack of accessibility) sources of discrimination experienced by autistic children and their families.
- Reflect universal design principles.
- Be consistent with all relevant building, design, health, and safety standards.

35.2 Supports aimed at creating accessible environments should not:

- Be imposed on the child, family, or other stakeholders without their full understanding of the rationale, the potential benefits, and potential costs.
- Focus on the environment, without considering other support the child or family may also benefit from.

How should supports be selected?

Selecting appropriate supports requires the involvement of the child and family, as well as other people when relevant, and should take into consideration the unique aspects of the child and family, and the broader context of their lives. When recommending supports, practitioners should combine the best available research evidence with evidence from clinical practice and the preferences and priorities of the child and family. The supports that are agreed to should be clearly explained to the child and family, including the benefits, costs, and risks of the supports, and alternative options that may be available to achieve the same goal.

People involved

Recommendation 36

Consensus-Based Recommendation

The practitioner should work in partnership with the child and family in selecting supports, as well as with other people when relevant.

► Grade of Recommendation: Strong

Good Practice Points

- 36.1 Selecting supports should always involve the child and parents.
- 36.2 Where relevant and agreed to by the child and family, the following people may also be involved in selecting supports:
 - Family (e.g., siblings, grandparents) and family-like people (e.g., family friends, peers).
 - Suitably qualified and experienced practitioners (e.g., allied health professionals, medical doctors, educators).
 - People who can support the child's participation in community activities (e.g., sports coaches; community and faith leaders; art teachers; and community members the child interacts with regularly including in retail environments, community groups, and cultural activities).
 - Staff in agencies that support the provision and/or access to supports (e.g., NDIS planners, child safety officers).
- 36.3 Supports should be selected through an equitable process of shared decision making between the practitioner and the child and family.

Sources of information

Recommendation 37

Consensus-Based Recommendation

In considering possible supports, practitioners should draw on multiple sources of information about the potential benefits and risks for the child and family.

► Grade of Recommendation: Strong

Good Practice Points

37.1 Practitioners should consider the following sources of information when considering possible supports:

- A theoretical rationale for why a support is likely to lead to achievement of a stated goal.
- Research evidence (from published, peer-reviewed research) that a support is likely to lead to achievement of a stated goal.
- Evidence gathered through clinical practice that a support is likely to lead to achievement of a stated goal, including evidence drawn from the experiences and outcomes of other children, families, and practitioners.
- Information gathered through an assessment of the child and family across appropriate contexts that is relevant to the delivery or receipt of a particular support.
- Perspectives expressed by autistic people regarding a particular support.
- Consideration of whether the child and family have the time, social and emotional support (i.e., family members willing to assist), and financial resources required to access and make use of the support.
- Consideration of whether the support is consistent with the child and family's cultural background and their preferences for the language in which support is delivered; the family's views on disability (i.e., whether to focus on the child versus environment); and the parents' views on child-rearing and child development.
- Consideration of the availability and accessibility of the support to the child and family.
- Consideration of whether the child and family desires the support.
- Consideration of the potential benefits and risks associated with the support.
- Consideration of the alternative options to this support.
- Consideration of how particular support(s) may enhance and/or impede progress towards other goals.
- Consideration of the relevance of the possible support to the child and family, currently and in the future.

37.2 Sources of information should be considered through an equitable process of shared decision making.

Using research evidence to inform the selection of supports

Recommendation 38

Consensus-Based Recommendation

In considering possible supports, practitioners should be aware of the best available research evidence and discuss this with the child and family.

► Grade of Recommendation: Strong

Good Practice Points

- 38.1 Practitioners should be aware that evidence taken from high-quality meta-analyses indicates that different supports have different effects on child and family outcomes. Appendix C presents evidence from meta-analyses regarding the effects of different supports on different child and family outcomes.
- 38.2 Practitioners should be aware that evidence taken from high-quality meta-analyses indicates that no one type of support leads to better outcomes than another type of support for all children.
- 38.3 Practitioners should be aware that evidence taken from high-quality meta-analyses does not support the concept that a child's age, cognitive skills, or adaptive behaviour determines how much they will benefit from a particular type of support, or from a particular way it is delivered (e.g., a particular amount, particular setting, a particular person who delivers it).
- 38.4 Practitioners should be aware that the research evidence relating to supports is complex for a variety of reasons, including a lack of consistent terminology used to describe supports, the variable quality of studies used to generate the evidence, and the relevance of findings to individual children and families.
- 38.5 Practitioners should consider the relevance of research evidence to the individual child and family and the broader context of their lives. This includes:
 - The quantity, quality, and consistency of research evidence for the specific support. Practitioners should always critically appraise sources of evidence for risk of bias (e.g., poor research design, poor interpretation of data, the publication of positive results only).
 - The extent to which the evidence from research is relevant to the proposed model of support delivery (e.g., who will deliver it, in what setting, in what mode, in what amount?)
 - The extent to which the evidence from research is relevant to the individual child, family, and their circumstances.
 - The extent to which potential or actual adverse effects have been measured and reported.
 - The extent to which the long-term effects of the specific support have been measured and reported.
- 38.6 Where a specific type of support, a specific outcome, or a combination of these was not examined in the meta-analyses summarised in Appendix C (e.g., practitioner proposes to combine approaches, the support was not examined, only single case experimental design studies were available), practitioners should consider the best available research evidence.
- 38.7 Practitioners should consider evidence from clinical practice when considering possible supports. In doing so, they should consider:
 - Knowledge of the child, family, and the context.
 - Evidence for the effects of the possible supports, gathered in clinical practice by themselves and/or colleagues.
 - Evidence for the effects of the possible supports, gathered from reports of autistic people, parents, and other family members.
- 38.8 Practitioners should consider the preferences and priorities of the child and family when considering possible supports. This includes full consideration of contextual factors that may influence the safety, effectiveness, and desirability of the outcomes.

- 38.9 Practitioners should discuss the research evidence they are using to inform support recommendations with children and families, including its strengths and limitations.

Making recommendations

Recommendation 39

Consensus-Based Recommendation

Practitioners should recommend supports that offer a plausible, practical, desirable, and defensible pathway to helping the child and family achieve personally meaningful and valued outcomes.

► Grade of Recommendation: Strong

Good Practice Points

- 39.1 Practitioners may recommend a single support, or combine elements of multiple supports in an eclectic manner.
- 39.2 Recommended supports should be clearly linked to achieving the goals mutually agreed by the child, family, and practitioner.
- 39.3 Practitioners should recommend supports for the child and family based on a decision-making framework that considers:
- Plausibility– there is a plausible reason for why a particular support is likely to lead to the achievement of a goal, and evidence to support this reason, as well as its safety.
 - Practicality – it is practical to receive the support within the child and family’s time schedule and financial resources, and the support is able to be accessed without placing excessive stress on the child and family.
 - Desirability – it is desirable to the child and family to receive the support when considering the child and family’s culture and customs, the parents’ views on child-rearing and child development, and the priority of receiving the support within a hierarchy of their needs.
 - Defensibility – there is a clear rationale for why the recommended support is preferred over alternative options.
- 39.4 Practitioners should ensure that the child and family do not feel pressured or coerced into receiving supports that they do not need or desire.
- 39.5 Practitioners should ensure that recommended supports are safe and appropriate for the assessed needs of the child and family, and are not excessive or unnecessary.

Recommendation 40

Consensus-Based Recommendation

Practitioners should ensure the child and family understand the rationale for recommended supports, along with potential benefits, costs, and alternative options.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The ‘conditional’ rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Good Practice Points

- 40.1 Practitioners should ensure that the child and family are fully informed about:

- The rationale for the support – providing an explanation of how a particular support may help achieve the goal in the context of the child and family, why a particular support may be more effective than others, and the evidence supporting this rationale.
- The potential benefits of the support – providing an explanation of the desired effects of the support in the context of the stated goal, including a timeframe for when those effects may be observed.
- The potential costs of the support – including any financial and opportunity costs, and providing an explanation of any adverse effects that may be associated with the support.

40.2 Practitioners should inform the child and family that:

- There are a variety of supports that may support children’s development, their learning, participation, and wellbeing.
- There is no one support that is equally effective in supporting all autistic children and families.
- There is no one support that has been shown to be effective in supporting all child and family outcomes.

40.3 Practitioners should share and discuss the supports recommended in a way that is accessible, informative, understandable, and meaningful to the child and the family.

40.4 The way in which information about recommended supports is shared should be personalised to the circumstances and preferences of the child and family, and may include:

- A face-to-face discussion.
- A written report.
- A telephone conversation.
- A videoconference conversation.
- A video recording (e.g., of a support being delivered, with appropriate consent).
- Other digital means (e.g., emails, shared online documents).
- Other ways that may be meaningful to the child and family (e.g., graphical mode such as drawing).
- A combination of these modes.

40.5 Practitioners should develop a plan with other practitioners who are delivering supports to the child and family to ensure that clear, appropriate, and accurate information is communicated between all practitioners.

What knowledge and skills are required to select and plan supports?

Practitioners who select and plan supports should ensure that they have the appropriate qualifications, knowledge and skills, professional experience matching their level of responsibility, supervision, and regulation, or should refer to an appropriate practitioner if they do not. An accurate and complete plan of the proposed supports should be provided to the child and the family in a timely manner.

Relevant qualifications

Recommendation 41

Consensus-Based Recommendation

Practitioners involved in selecting and planning supports should have relevant qualifications and work within their scope of practice.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Good Practice Points

- 41.1 Recommendations related to supporting a child's health should come from practitioners with medical qualifications.
- 41.2 Recommendations related to supporting a child's development of functional skills in one or more developmental domains should come from practitioners with allied health and/or education qualifications that correspond with those domains (e.g., occupational therapy for enhancing participation and engagement in occupations, physiotherapy for gross motor skills, psychology for cognition and mental health, speech pathology for communication).
- 41.3 Practitioners should only make support recommendations that are within their scope of practice.
- 41.4 Practitioners should ensure that parents are aware of their qualifications and scope of practice.
- 41.5 Practitioners working in transdisciplinary models of service delivery should ensure appropriate consultation with a practitioner who has qualifications relevant to the domain/s being supported.

Relevant professional experience

Recommendation 42

Consensus-Based Recommendation

Practitioners involved in selecting and planning supports should have professional experience that matches their responsibilities.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Good Practice Points

- 42.1 Practitioners should be aware that their level of experience influences their capacity to provide an accurate, complete, and timely plan of proposed supports.
- 42.2 Practitioners should be aware that autistic children, their families, and the broader autistic community value experience:
 - Gained through working with children and their families.
 - Gained through listening to and learning from autistic children, young people, and adults and their families.
 - Gained in multiple contexts and settings.
 - That is directly relevant to their individual circumstances.

- 42.3 Practitioners should access professional supervision and mentoring that matches their level of experience.
- 42.4 Practitioners should engage in continuing professional development that reflects an evidence-based framework including:
- Knowledge of emerging research evidence.
 - Development of new clinical skills.
 - Learning from the insights and perspectives of autistic children, their families, and the broader autistic community.
- 42.5 Practitioners should openly share the nature and level of their experience with the child and family.

Professional regulation

Recommendation 43

Consensus-Based Recommendation

Practitioners involved in selecting and planning supports should be eligible for membership with the relevant professional association and regulated.

► **Grade of Recommendation: Conditional**

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Good Practice Points

- 43.1 In Australia, the following practitioners are regulated by the Australian Health Practitioner Regulation Agency (AHPRA; www.ahpra.gov.au) and have knowledge and skills that may be relevant to autistic children and their families:
- Aboriginal and Torres Strait Islander Health Practitioners – scope of practice varies based on individual qualifications and contextual factors.
 - Medical Practitioners – supporting children's health and wellbeing.
 - Occupational Therapists – supporting children's sensory processing and fine motor development, through participation in their occupations of life, including self-care and other daily living skills, play and leisure activities.
 - Physiotherapists – supporting children's physical development of movement, functional ability, confidence, resilience, and ability in gross motor skills to encourage participation in daily life and physical activities.
 - Psychologists – supporting children's cognitive development and child and family social-emotional wellbeing including psychoeducation and supporting learning/development, adaptive behaviour, relationships, self-esteem and identity, inclusion, and social development.
- 43.2 In Australia, the following practitioners are self-regulated within the National Alliance of Self Regulating Health Professions (NASRHP; nasrhp.org.au/) and have knowledge and skills that may be relevant to autistic children and their families:
- Audiologists – supporting children's hearing as the basis for learning, participation, and wellbeing.
 - Creative Art Therapists – supporting children's development, participation, and wellbeing through creative arts.
 - Dietitians – supporting children's health and participation in relation to mealtimes.
 - Exercise Physiologists and Sports Scientists – supporting children's development, participation, and wellbeing through physical activity and sport.

- Music Therapists – supporting children’s development, participation, and wellbeing through music.
- Rehabilitation Counsellors – supporting children’s development of future work aspirations.
- Social Workers – supporting and empowering children's and families’ resilience and functioning.
- Speech Pathologists – supporting children’s speech, language, literacy, social-communication, and swallowing.

43.3 In Australia, the following practitioners are self-regulated, but not members of the National Alliance of Self Regulating Health Professions (NASRHP), and have knowledge and skills that may be relevant to autistic children and their families:

- Behaviour Practitioners – supporting children’s acquisition of skills and addressing behaviours that harm self, others, and/or property. The professional association for self-regulation and ethical practice of behaviour analysis in Australia is the Association for Behaviour Analysis Australia. The highest membership level is ‘Certified Behaviour Analyst (CBA)’ which requires professional certification from the Behavior Analysis Certification Board (BACB) international certification body or the equivalent graduate-level or doctoral-level course work and supervised field experience.
- Developmental Educators – supporting children’s and families’ holistic development, equitable participation, wellbeing, and citizenship via a disability justice approach. The professional association for developmental educators in Australia is Developmental Educators Australia Incorporated.
- Counsellors – supporting children and families’ social-emotional wellbeing. Professional associations for counsellors include the Australian Counselling Association and the Psychotherapy and Counselling Federation of Australia.

43.4 In Australia, practitioners who provide some types of supports within the National Disability Insurance Scheme must be registered with NDIS Commission. This includes NDIS-registered Behaviour Support Practitioners who are regulated by the NDIS Quality and Safeguards Commission under the Positive Behaviour Supports Capability Framework.

43.5 In Australia, the following groups of educators are regulated by authorities in State and Territory jurisdictions, and have knowledge and skills that may be relevant to autistic children and their families:

- Early Childhood Teachers – supporting children’s personal, social, physical, and academic skills during the early years of formal education.
- Primary School Teachers – supporting children’s personal, social, physical, and academic skills during the primary school years of formal education.
- Special Education Teachers – supporting children with disabilities to acquire personal, social, and academic skills in formal education settings.

Relevant knowledge and skills

Recommendation 44

Consensus-Based Recommendation

Practitioners involved in selecting and planning supports should have knowledge and practical skills that are directly relevant to working with autistic children and their families.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The ‘conditional’ rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Good Practice Points

44.1 Practitioners should have current knowledge in the following areas:

- Typical and atypical development across the age ranges of children with whom they conduct their clinical work.
- The clinical presentation of autism, including co-occurring conditions.
- The impact of other important considerations on the provision of support, such as intellectual and/or communication abilities; cultural, linguistic and socioeconomic background; regional or remote location; or complex psychosocial factors, such as the experience of trauma.
- The range of supports appropriate for autistic children, including those with co-occurring neurodevelopmental conditions, within their scope of practice.
- The theoretical principle(s) underpinning the supports that they provide (i.e., the suggested reasons why the support is likely to have the intended therapeutic effect).
- The current best available research evidence that the supports they provide result in the intended therapeutic effect.
- The circumstances when supports may and may not be appropriate for a child and family.
- The scope of practice of their own and other disciplines.
- Trauma-informed care, and the related principles of safety, trust, choice, collaboration, empowerment, and respect for diversity.
- Neurodiversity-affirming practices, which seek to affirm the child's neurodivergent identity, rather than seeking to 'cure' autism.
- Access to Government and other sources of funding to support the receipt of supports.

44.2 Practitioners should have practical skills in the following areas:

- Clinical reasoning in evaluating evidence, integrating information and decision-making.
- Clinical documentation and reporting.
- Time management and organisation.
- Self-reflection and ability to embrace feedback.
- Communicating and engaging with the child and family members in a way that:
 - Builds rapport and trust.
 - Fosters collaborative professional relationships.
 - Ensures a two-way exchange of information in a way that is accurate, meaningful, and understandable.
 - Demonstrates that the information the child and family share is listened to and valued.
 - Is non-judgmental and conveys empathy.
 - Appropriately manages expectations and concerns.
- Less experienced practitioners should be directly supervised by a practitioner who has knowledge and practical skills that are directly relevant to working with autistic children and their families.

44.3 Where practitioners also bring personal lived expertise to their work as autistic people, their insights and views should be valued by fellow practitioners in guiding ongoing efforts to improve the quality and safety of supports provided to children and families.

Planning, offering choice, and making referrals

Recommendation 45

Consensus-Based Recommendation

Practitioners involved in selecting and planning supports should provide the child and family with an accurate, complete, and timely plan of proposed supports.

► Grade of Recommendation: Strong

Good Practice Points

- 45.1 A plan for supports should include information that enables the child and family to make informed decisions in relation to:
- What supports will be provided.
 - The person/people who will provide the supports including qualifications, skills, and experience.
 - The setting/s where the supports will be provided.
 - The delivery format/s (one-on-one, in a group) and mode (e.g., in person, telepractice).
 - The amount of time the supports will take, including the frequency and length of support sessions.
 - The anticipated duration of the supports.
 - The anticipated outcomes including potential benefits and risks.
 - The roles and responsibilities of each person involved.
 - The time commitment for each person involved.
 - How the supports will be monitored.
 - The ways in which supports can be used in other contexts to facilitate generalisation of skills.
 - The ways in which the child and family can request a change in support, cease it, and/or express concern.

Recommendation 46

Consensus-Based Recommendation

Where a practitioner does not have the qualifications; professional experience; professional regulation; relevant knowledge and skills; personal capacity; and/or professional capacity to select, plan and/or deliver a particular support, they should refer the child and family to a practitioner who does.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Good Practice Points

- 46.1 Practitioners should provide the family with information about their qualifications, professional experience, professional regulations, and relevant knowledge and skills.
- 46.2 Practitioners should clearly explain what they can and cannot offer the family in terms of their qualifications, professional experience, professional regulation, and relevant knowledge and skills, so that the family can make informed decisions about the services they can provide.
- 46.3 Practitioners should clearly explain what they can offer the family regarding their personal and/or professional capacity. This includes their time, energy, resources, and interest. When a practitioner cannot provide a safe, effective, and desired service in a timely manner, the practitioner should refer to

another practitioner who can support the family.

- 46.4 Practitioners should ensure that the family are aware of how they can find and contact other service providers in the same and other related professional disciplines.



Section 4: Delivering supports



Section 4: Delivering supports

Once supports have been selected and planned, delivery requires consideration of the person/people who will provide the support (e.g., parent, practitioner), the format (one-on-one, in a group), the mode (e.g., in person, telepractice), the setting (e.g., home, clinic, community), and the amount and duration. It is imperative that decisions about how supports are delivered are made in partnership with children and families and that recommendations practitioners make align with their goals, strengths, needs, preferences, and contextual considerations.

Who should deliver supports?

The delivery of supports may involve multiple people working together to achieve the goals of the child and family. These people may include practitioners, parents and other family members, and members of the community. It is important that decisions about who is involved in the delivery of supports are made in partnership with the child and family, and that all roles and responsibilities are agreed to.

People involved

Recommendation 47

Consensus-Based Recommendation

Supports should be delivered by the people (e.g., parents, practitioners) who are likely to lead to the most meaningful and sustained increase in the child's learning, participation, and wellbeing.

► **Grade of Recommendation: Conditional**

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Good Practice Points

- 47.1 Where relevant and agreed to by the child and family, the following people may be involved in the delivery of supports:
- Parent(s).
 - Family (e.g., siblings, grandparents) and family-like people (e.g., family friends, peers).
 - Suitably qualified and experienced practitioners (e.g., allied health professionals, medical doctors, educators).
 - People who can support the child's participation in community activities (e.g., sports coaches; community and faith leaders; art teachers; and community members the child interacts with regularly including in retail environments, community groups, and cultural activities).

- 47.2 The people who deliver supports should be mutually agreed upon by the child, family, and practitioner.
- 47.3 Practitioners may deliver supports within a range of models of practice that are relevant to the context and desired by the child and family, including as sole practitioners, and within multi-disciplinary, transdisciplinary, and key worker models.
- 47.4 Parents should determine in what way and how much they are involved in the delivery of supports.
- 47.5 Practitioners should be aware that parents may perceive that their involvement in the delivery of supports detracts from their natural parental role.
- 47.6 Practitioners should be aware that there is no consistent research evidence from high-quality meta-analyses that one type of person delivering a support is likely to lead to greater improvements in children's learning, participation, and wellbeing compared to any other type of person. Within this context, it is imperative that all other Good Practice Points are followed.

What knowledge and skills are required to deliver supports?

Practitioners who deliver supports should ensure that they have appropriate qualifications, knowledge and skills, professional experience matching their level of responsibility, supervision, and regulation, or should refer to an appropriate practitioner if they do not. Those who assist in the delivery of supports should be adequately supported by a practitioner who has appropriate qualifications, knowledge and skills, and professional experience, and who maintains overall responsibility for the delivery of supports.

Recommendations relating to the knowledge and skills required to deliver supports are consistent with those provided in the 'Selecting and planning supports' section, and are repeated here for completeness in addressing the Guideline questions.

Relevant qualifications

Recommendation 48

Consensus-Based Recommendation

Practitioners who deliver supports should have relevant qualifications and work within their scope of practice.

► **Grade of Recommendation: Conditional**

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Good Practice Points

- 48.1 Delivery related to supporting a child's health should involve practitioners with medical qualifications.
- 48.2 Delivery related to supporting a child's development of functional skills in one or more developmental domains should involve practitioners with allied health and/or education qualifications that correspond with those domains (e.g., occupational therapy for enhancing participation and engagement in childhood occupations, physiotherapy for gross motor skills, psychology for cognition and mental health, speech pathology for communication).
- 48.3 Practitioners should only deliver supports that are within their scope of practice.
- 48.4 Practitioners should ensure that parents are aware of their qualifications and scope of practice.
- 48.5 Practitioners should have knowledge of trauma-informed care, and the related principles of safety, trust, choice, collaboration, empowerment, and respect for diversity.

- 48.6 Practitioners working in transdisciplinary models of service delivery should ensure appropriate consultation with a practitioner who has qualifications relevant to the domain/s being supported.

Relevant professional experience

Recommendation 49

Consensus-Based Recommendation

Practitioners who deliver supports should have professional experience that matches their responsibilities.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Good Practice Points

- 49.1 Practitioners should be aware that their level of experience influences their capacity to deliver supports safely, effectively, and in ways desired by autistic children and families.
- 49.2 Practitioners should be aware that autistic children, their families, and the broader autistic community value experience:
- Gained through working with children and their families.
 - Gained through listening to and learning from autistic children, young people, and adults and their families.
 - Gained in multiple contexts and settings.
 - That is directly relevant to their individual circumstances.
- 49.3 Practitioners should access professional supervision and mentoring that matches their level of experience.
- 49.4 Practitioners should engage in continuing professional development that reflects an evidence-based framework including:
- Knowledge of emerging research evidence.
 - Development of new clinical skills.
 - Learning from the insights and perspectives of autistic children, their families, and the broader autistic community.
- 49.5 Practitioners should openly share the nature and level of their experience with the child and family.

Professional regulation

Recommendation 50

Consensus-Based Recommendation

Practitioners who deliver supports should be eligible for membership with the relevant professional association and regulated.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Good Practice Points

- 50.1 In Australia, the following practitioners are regulated by the Australian Health Practitioner Regulation Agency (AHPRA; www.ahpra.gov.au) and have knowledge and skills that may be relevant to autistic children and their families:
- Aboriginal and Torres Strait Islander Health Practitioners – scope of practice varies based on individual qualifications and contextual factors.
 - Medical Practitioners – supporting children’s health and wellbeing.
 - Occupational Therapists – supporting children’s sensory processing and fine motor development, through participation in their occupations of life, including self-care and other daily living skills, play and leisure activities.
 - Physiotherapists – supporting children’s physical development of movement, functional ability, confidence, resilience, and ability in gross motor skills to encourage participation in daily life and physical activities.
 - Psychologists – supporting children’s cognitive development and child and family social-emotional wellbeing including psychoeducation and supporting learning/development, adaptive behaviour, relationships, self-esteem and identity, inclusion, and social development.
- 50.2 In Australia, the following practitioners are self-regulated within the National Alliance of Self Regulating Health Professions (NASRHP; <https://nasrhp.org.au/>) and have knowledge and skills that may be relevant to autistic children and their families:
- Audiologists – supporting children’s hearing as the basis for learning, participation, and wellbeing.
 - Creative Art Therapists – supporting children’s development, participation, and wellbeing through creative arts.
 - Dietitians – supporting children’s health and participation in relation to mealtimes.
 - Exercise Physiologists and Sports Scientists – supporting children’s development, participation, and wellbeing through physical activity and sport.
 - Music Therapists – supporting children’s development, participation, and wellbeing through music.
 - Rehabilitation Counsellors – supporting children’s development of future work aspirations.
 - Social Workers – supporting and empowering children’s and families’ resilience and functioning.
 - Speech Pathologists – supporting children’s speech, language, literacy, social-communication, and swallowing.
- 50.3 In Australia, the following practitioners are self-regulated, but not members of the National Alliance of Self Regulating Health Professions (NASRHP), and have knowledge and skills that may be relevant to autistic children and their families:
- Behaviour Practitioners – supporting children’s acquisition of skills and addressing behaviours that harm self, others, and/or property. The professional association for self-regulation and ethical

practice of behaviour analysis in Australia is the Association for Behaviour Analysis Australia. The highest membership level is 'Certified Behaviour Analyst (CBA)' which requires professional certification from the Behavior Analysis Certification Board (BACB) international certification body or the equivalent graduate-level or doctoral-level course work and supervised field experience.

- Developmental Educators – supporting children's and families' holistic development, equitable participation, wellbeing, and citizenship via a disability justice approach. The professional association for developmental educators in Australia is Developmental Educators Australia Incorporated.
- Counsellors – supporting children and families' social-emotional wellbeing. Professional associations for counsellors include the Australian Counselling Association and the Psychotherapy and Counselling Federation of Australia.

50.4 In Australia, practitioners who provide some types of supports within the National Disability Insurance Scheme (NDIS) must be registered with NDIS Commission. This includes NDIS-registered Behaviour Support Practitioners who are regulated by the NDIS Quality and Safeguards Commission under the Positive Behaviour Supports Capability Framework.

50.5 In Australia, the following groups of educators are regulated by authorities in State and Territory jurisdictions, and have knowledge and skills that may be relevant to autistic children and their families:

- Early Childhood Teachers – supporting children's personal, social, physical, and academic skills during the early years of formal education.
- Primary School Teachers – supporting children's personal, social, physical, and academic skills during the primary school years of formal education.
- Special Education Teachers – supporting children with disabilities to acquire personal, social, and academic skills in formal education settings.

Recommendation 51

Consensus-Based Recommendation

Where another person assists a practitioner in the delivery of supports, that person should have appropriate knowledge, skills, experience, training, and regulation; and be adequately supervised and supported by the practitioner who has overall responsibility for the delivery of supports.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Good Practice Points

51.1 Practitioners who are responsible for the delivery of supports should ensure that any person who assists in delivery, including therapy assistants and support workers:

- Is agreed to by the child and family.
- Has adequate knowledge, skills, and experience matching their role and responsibilities in the delivery.
- Has adequate supervision, mentoring, and support to fulfil their role.
- Meets any relevant regulatory requirements (e.g., has an approved working with children check).
- Is eligible to do so within requirements of the relevant professional association and/or government requirements (e.g., NDIS funding rules).
- Has the skills to communicate with children and their family members in a way that:
- Builds rapport and trust.

- Fosters collaborative professional relationships.
- Ensures a two-way exchange of information in a way that is accurate, meaningful, and understandable.
- Demonstrates that the information the child and family share is listened to and valued.
- Is non-judgmental and conveys empathy.
- Appropriately manages expectations and concerns.

Who should receive the support?

Supports may be focused on the child, the family, and/or the environment and broader community. The focus of supports should be determined in partnership with the child and family, and based on a judgment of the most appropriate and effective way to achieve their goal(s).

Recommendation 52

Consensus-Based Recommendation

Practitioners should work in partnership with the child and family to determine which people and/or environments will be the focus of supports and likely lead to the most meaningful and sustained increase in the child’s learning, participation, and wellbeing.

► Grade of Recommendation: Strong

Good Practice Points

- 52.1 When relevant to the child and family, it is appropriate for practitioners to deliver one or more of the following:
- Child-directed services: A practitioner working primarily with the child one-on-one, or in a group to directly support their learning, participation, and wellbeing.
 - Family-directed services: A practitioner working primarily to upskill parents or other family members (e.g., siblings, grandparents) to support the child’s learning, participation, and wellbeing.
 - Community-directed services: A practitioner working primarily to create more accessible environment and/or upskill other members of the community (e.g., educators) to support the child’s learning, participation, and wellbeing.
- 52.2 The amount and proportion of child-directed, family-directed, and community-directed services should be mutually agreed upon by the child, family, and practitioner.
- 52.3 When recommending child-directed, family-directed, and/or community-directed services, alone or in combination, practitioners should do so based on a decision-making framework that considers:
- Plausibility– there is a plausible reason for the child and family to receive support in this way, and evidence to support this reason, as well as its safety.
 - Practicality – it is practical for the child and family to receive the support in this way when considering the child and family’s schedule and the social and emotional wellbeing and support and financial resources available to them.
 - Desirability – it is desirable to the child and family to receive the support in this way when considering the child and family’s culture and customs, the parents’ views on child-rearing and child development; and the priority of these supports within a hierarchy of their needs.
 - Defensibility – there is a clear rationale for why receiving the support in this way is preferred over alternative options.
- 52.4 The amount and proportion of child-directed, family-directed, and community-directed services each

child receives should be individualised.

- 52.5 Practitioners should be aware that family members may be autistic themselves and/or raising more than one autistic child or have children with other needs who are receiving services. Accordingly, practitioners should discuss with families their needs in adjusting supports to minimise financial, time, energy, and other stresses on families, and consider the broader child and family context.

In what settings should supports be delivered?

Supports may be delivered in a variety of settings (e.g., home, community, clinic, school). The setting should be determined in partnership with the child and family, and based on a judgment of the most appropriate and effective way to achieve their goal(s).

Recommendation 53

Consensus-Based Recommendation

Practitioners should work in partnership with the child and family to determine the setting(s) in which the delivery of supports is likely to lead to the most meaningful and sustained increase in the child's learning, participation, and wellbeing.

► **Grade of Recommendation: Conditional**

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Good Practice Points

- 53.1 Where relevant to the child and family, it is appropriate for practitioners to deliver supports, or to support others to do so, in:
- The child's home.
 - Clinical settings.
 - Educational settings (including early childhood, and primary education settings).
 - Social settings (e.g., other people's homes, community spaces).
 - Recreational settings (e.g., sports ovals, music/art/drama studios).
 - Cultural settings (e.g., places of worship).
- 53.2 Other settings may also be appropriate for the delivery of supports, if they are relevant to the child and family.
- 53.3 The setting(s) in which supports are delivered should be mutually agreed upon by the child, family, and practitioner.
- 53.4 Where relevant, the delivery of supports should include one or more everyday (non-clinical) settings.
- 53.5 When supports are delivered in clinical settings, support goals should include use of skills in everyday settings.
- 53.6 Practitioners should be aware that skills acquired in a clinical setting may not be maintained in and/or generalise to daily activities.
- 53.7 Where possible, the child should not be separated or excluded from learning and interacting alongside their non-autistic peers.
- 53.8 When recommending delivery settings, practitioners should do so based on a decision-making framework that considers:
- **Plausibility**— there is a plausible reason for the child and family to receive the support in a given

setting, and evidence to support this reason, as well as its safety.

- Practicality – it is practical for the child and family to receive the support in a given setting when considering the child and family’s schedule, the accessibility of the setting to the child and family, and the social and emotional wellbeing of the family and the support and financial resources available to them.
- Desirability – it is desirable to the child and family to receive the support in a given setting when considering the child and family’s culture and customs, the parents’ views on child-rearing and child development; and the priority of these supports within a hierarchy of their needs.
- Defensibility – there is a clear rationale for why receiving the support in a given setting is preferred over alternative options.

53.9 Practitioners should ensure that the settings they recommend are safe, and that appropriate adjustments are made to the environment, including accommodations for sensory needs, to ensure that the child and family are comfortable, and that the delivery setting supports their learning, participation, and wellbeing.

53.10 Practitioners should be aware that there is no consistent research evidence from high quality meta-analyses that delivery in one setting is likely to lead to greater improvements in children’s learning, participation, and wellbeing compared to any other setting. Within this context, it is imperative that all other Good Practice Points are followed.

In what formats and modes should supports be delivered?

Supports may be delivered in different formats (one-on-one, in a group) or modes (e.g., face-to-face, teleconference, videoconference). The format and mode should be determined in partnership with the child and family, and based on a judgment of the most appropriate and effective way to achieve their goal(s).

Support formats

Recommendation 54

Consensus-Based Recommendation

Practitioners should work in partnership with the child and family to determine the delivery format(s) (e.g., one-on-one, in a group) that will likely lead to the most meaningful and sustained increase in the child’s learning, participation, and wellbeing.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The ‘conditional’ rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Good Practice Points

- 54.1 Where relevant to the child and family, it is appropriate for practitioners to deliver supports, or to support others to do so:
- In a one-on-one format.
 - In a group-based format.
 - In a combination of one-to-one and group-based formats.

- 54.2 The format/s in which supports are delivered should be mutually agreed upon by the child, family, and practitioner.
- 54.3 When recommending one or more delivery formats, practitioners should do so based on a decision-making framework that considers:
- Plausibility– there is a plausible reason for the child and family to receive the support in a given format, and evidence to support this reason, as well as its safety.
 - Practicality – it is practical for the child and family to receive the support in a given format when considering the child and family’s schedule, and the social and emotional wellbeing of the family and support and the financial resources available to them.
 - Desirability – it is desirable to the child and family to receive the support in a given format when considering the child and family’s culture and customs, the parents’ views on child-rearing and child development; and the priority of these supports within a hierarchy of their needs.
 - Defensibility – there is a clear rationale for why receiving the support in a given format is preferred over alternative options.
- 54.4 Practitioners should be aware that there is no consistent research evidence from high-quality meta-analyses that delivery in one format is likely to lead to greater improvements in child learning, participation, and wellbeing compared to any other format. Within this context, it is imperative that all other Good Practice Points are followed.

Support modes

Recommendation 55

Consensus-Based Recommendation

Practitioners should work in partnership with the child and family to determine the delivery mode(s) (e.g., in person, telepractice) that will likely lead to the most meaningful and sustained increase in the child’s learning, participation, and wellbeing.

► **Grade of Recommendation: Conditional**

This Recommendation is as important as any other. The ‘conditional’ rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Good Practice Points

- 55.1 Where relevant it is appropriate for practitioners to deliver supports, or to support others to do so:
- In person.
 - By telepractice.
 - By a combination of in person and telepractice.
- 55.2 The mode/s in which supports are delivered should be mutually agreed upon by the child, family, and practitioner.
- 55.3 When recommending one or more delivery modes, practitioners should do so based on a decision-making framework that considers:
- Plausibility– there is a plausible reason for the child and family to receive the support in a given mode, and evidence to support this reason.
 - Practicality – it is practical for the child and family to receive the support in a given mode when considering the child and family’s schedule, and the social and emotional wellbeing of the family and the support and financial resources available to them.
 - Desirability – it is desirable to the child and family to receive the support in a given mode when

considering the child and family's culture and customs, the parents' views on child-rearing and child development; and the priority of these supports within a hierarchy of their needs.

- Defensibility – there is a clear rationale for why receiving the support in a given mode is preferred over alternative options.

55.4 Other modes (e.g., self-directed online modules) may also be appropriate for the delivery of supports, if they are relevant to the child and family, particularly when immediate access to relevant qualified practitioners is not possible.

55.5 Practitioners should be aware that there is no consistent research evidence from high-quality meta-analyses that delivery in one mode is likely to lead to greater improvements in children's learning, participation, and wellbeing compared to any other mode. Within this context, it is imperative that all other Good Practice Points are followed.

In what amount and duration should supports be delivered?

Supports may be delivered in a variety of amounts (e.g., hours) distributed over varying time periods (e.g., days, weeks, months). 'Intensity' refers to the amount delivered in a particular period of time (e.g., hours per week). The amount and duration of support (which determine the intensity) should be decided in partnership with the child and family, and based on a judgment of the most plausible, practicable, desirable, and defensible pathway to achieving their goal(s).

Recommendation 56

Consensus-Based Recommendation

Practitioners should work in partnership with the child and family to determine the delivery amount and duration that will likely lead to the most meaningful and sustained increase in the child's learning, participation, and wellbeing.

- ▶ Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Good Practice Points

56.1 The amount and duration of support provision should be tailored to the individual needs of the child and family. This includes consideration of the frequency, length, and time of day of support sessions, and variations in support needs over time.

56.2 When recommending an amount and duration of support, practitioners should do so based on a decision-making framework that considers:

- Plausibility– there is a plausible reason for the child and family to receive the support in a given amount and duration, and evidence to support this reason, as well as its safety.
- Practicality – it is practical for the child and family to receive the support in a given amount and duration when considering the child and family's schedule, and the social and emotional wellbeing and support of the family and the financial resources available to them.
- Desirability – it is desirable to the child and family to receive the support in a given amount and duration when considering the child and family's culture and customs, the parents' views on child-rearing and child development; and the priority of these supports within a hierarchy of their needs.

- Defensibility – there is a clear rationale for why receiving the support in a given amount and duration is preferred over alternative options.
- 56.3 Practitioners should inform parents that there is no set number of hours per week of practitioner delivered child-directed supports that leads to the best outcomes for all children.
- 56.4 Practitioners should be aware that research evidence does not support the concept that supports delivered in greater amounts consistently lead to better child and family outcomes.
- 56.5 The amount and duration of support provision should take into consideration the child’s right to education; their right to relax, play and choose to join in a wide range of leisure activities, and their individual preferences for each.
- 56.6 The amount and duration of support provision should not impinge upon the natural roles of children, parents, siblings, and other family members.
- 56.7 Parents should be given options regarding the amount and duration of supports that their child/family receives.
- 56.8 Practitioners should be aware that members of the autistic and autism communities have expressed concerns and/or reported based on personal experience that supports delivered in insufficient amounts can have detrimental effects on children’s learning, participation, and wellbeing, and the wellbeing of the family in the short- and long-term.
- 56.9 Practitioners should be aware that members of the autistic and autism communities have expressed concerns and/or reported based on personal experience that supports delivered in large amounts and/or high intensities can have detrimental effects on children’s learning, participation, and wellbeing, and the wellbeing of the family in the short- and long-term.

How should practitioners engage with other service providers and service systems?

Children and families may be engaged with multiple service providers and service systems. When desired by the family, it is critical that all organisations have awareness of each other, and coordinate supports to best achieve the goals of the child and their family.

Recommendation 57

Consensus-Based Recommendation

Practitioners should coordinate the supports they deliver with other relevant service providers and service systems.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The ‘conditional’ rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Good Practice Points

- 57.1 Practitioners should have an awareness of service providers and service systems that may be involved in, or facilitate access to, the provision of supports for autistic children and their families, including:
- Education.
 - Health.
 - Disability (e.g., NDIS).
 - Social services (e.g., Services Australia).
 - Child protection.

- 57.2 Practitioners should ensure that their efforts complement – not replicate, complicate, or counteract – those of other people working to support the child’s learning, participation, and wellbeing.
- 57.3 Practitioners should consider which models of practice (e.g., sole practitioner, multi-disciplinary, transdisciplinary, key worker models) are most likely to facilitate coordination of supports for the child and family.
- 57.4 Where desired and agreed to by the child and family, practitioners should proactively engage and collaborate with relevant representatives of other service providers and service systems with which the child engages to ensure coordination of support plans through regular and transparent communication.



Section 5: Outcomes, quality, and safeguarding



Section 5: Outcomes, quality, and safeguarding

Monitoring progress and conducting periodic reviews are critical to ensuring supports are safe, effective, and desirable for children and their families. Practitioners can use monitoring and reviews to adjust supports as the circumstances, needs, and preferences of children and their families change, and to end supports when no longer needed. Monitoring and reviews also contribute to high quality practice and safeguarding. Ensuring supports are delivered in safe environments, by people with appropriate knowledge and skills, and within frameworks that help ensure ethical practice, are equally important.

How should the effects of supports be monitored and reviewed?

Monitoring and reviews should involve the child and family, as well as other people when relevant. Monitoring is a collaborative and ongoing process, focused on ensuring supports are delivered as intended, measuring progress towards goals, ensuring that any adverse effects are identified and addressed, and that the child and family can give feedback on their experiences, changes in circumstances and preferences, and outcomes. Periodic reviews provide an opportunity for the child, family, practitioner, and all key stakeholders to reflect on the goals, the information collected during monitoring, and to consider the overall experience and effect of accessing supports on the life of the child and family.

Both monitoring and reviews typically involve the gathering of multiple sources of information using a variety of methods. While monitoring is ongoing, reviews should occur at intervals that are relevant to the child and family. Information should be collected, shared, and discussed with the child and family in a way that is informative and understandable to them. Central to this is the importance of practitioners empowering the child and family to make decisions about whether to continue, change, or stop accessing a support.

People involved

Recommendation 58

Consensus-Based Recommendation

Monitoring and reviewing of supports should be conducted by the practitioner in partnership with the child and family, with support from other people when relevant.

► Grade of Recommendation: Strong

Good Practice Points

- 58.1 Where relevant and agreed to by the child and family, the following people may also be involved in decisions regarding the monitoring and review of support::
- Family (e.g., siblings, grandparents) and family-like people (e.g., family friends, peers).
 - Suitably qualified and experienced practitioners (e.g., allied health professionals, medical doctors, educators).
 - People who can support the child's participation in community activities (e.g., sports coaches; community and faith leaders; art teachers; and community members the child interacts with regularly including in retail environments, community groups, and cultural activities).
 - Staff in agencies that support the provision and/or access to services (e.g., National Disability Insurance Scheme [NDIS] planners, child safety officers).

Aspects to monitor

Recommendation 59

Consensus-Based Recommendation

Practitioners, in partnership with the child and family, should monitor the extent to which the supports were delivered as planned.

► Grade of Recommendation: Strong

Good Practice Points

- 59.1 The following aspects of supports should be monitored:
- Type – the extent to which the planned type of support was delivered.
 - People – the extent to which the intended people contributed to progress towards the goal.
 - Setting – the extent to which the support was delivered in the intended settings.
 - Format – the extent to which the support was delivered in the intended format (e.g., one-on-one, in a group).
 - Mode – the extent to which the support was delivered in the intended mode (e.g., in person, telepractice)
 - Amount and duration – the extent to which the intended amount and duration of support was delivered.

Recommendation 60

Consensus-Based Recommendation

Practitioners, in partnership with the child and family, should monitor progress towards the child's and family's goals.

► Grade of Recommendation: Strong

Good Practice Points

- 60.1 Progress monitoring should begin immediately after the commencement of supports to provide a reference point for ongoing monitoring.
- 60.2 Progress monitoring should include monitoring of:
 - The amount of progress made towards the goal.
 - The alignment between the child and family's existing goals and their current needs and preference, including any new goals arising.
 - The extent to which the child and family are satisfied with progress towards the goal.
 - The way in which people are working together to contribute to progress towards the goals.
 - The extent to which the child and family are satisfied with the services provided.
- 60.3 Progress monitoring should include monitoring of changes in:
 - The child's developmental skills.
 - The child's learning, participation, and wellbeing.
 - Family knowledge and confidence in managing the supports for their child.
 - The family's wellbeing.
 - The environments that affect learning, participation, and wellbeing.
- 60.4 Practitioners should measure the child's and family's experiences and progress towards goals in ways that are meaningful to the child and family.

Recommendation 61

Consensus-Based Recommendation

Practitioners, in partnership with the child and family, should monitor the child's and family's generalisation and maintenance of skills across people, settings, and activities, and over time.

► Grade of Recommendation: Strong

Good Practice Points

- 61.1 Practitioners should monitor:
 - Generalisation of outcome to interactions with other people.
 - Generalisation of outcome to other activities.
 - Generalisation of outcome to other settings.
- 61.2 Where practicable, practitioners should monitor the maintenance of the outcomes of supports over:
 - The short-term (i.e., <12 months).
 - The medium-term (i.e., 12 months to 2 years).
 - The long-term (i.e., >2 years).

Recommendation 62

Consensus-Based Recommendation

Practitioners, in partnership with the child and family, should monitor the costs and benefits to the child and family of receiving the supports.

► Grade of Recommendation: Strong

Good Practice Points

62.1 Cost and benefit monitoring should include:

- Benefits to the child – including gains in developmental skills, functional abilities, learning, participation, and wellbeing.
- Costs to the child – including opportunity costs of not pursuing alternative goals or supports, reduced time availability, fatigue, and other detrimental psychosocial effects.
- Benefits to the family – including an increase in their understanding of autism, neurodiversity, and how to support their autistic child; improvements in family functioning and wellbeing; and an increase in community participation.
- Costs to the family – including financial costs, reduced time availability, fatigue, stress, and other detrimental psychosocial effects.

Recommendation 63

Consensus-Based Recommendation

Practitioners, in partnership with the child and family, should monitor for unplanned outcomes associated with the supports they deliver.

► Grade of Recommendation: Strong

Good Practice Points

63.1 Unplanned outcomes monitoring should include monitoring of:

- Positive unplanned outcomes that have arisen from the delivery of supports.
- Adverse events that have arisen from the delivery of the supports and whether they may plausibly be related to the support (an adverse effect).

Methods of monitoring

Recommendation 64

Consensus-Based Recommendation

Practitioners should monitor progress by directly asking and listening to the child and family.

► Grade of Recommendation: Strong

Good Practice Points

64.1 Monitoring through child and family report should include:

- Direct report from the child about progress towards goals.
- Family report of the child's progress towards the goals.
- Child report of what they perceive to be the benefits and costs of their own experience engaging in support, including the opportunity costs of engaging with support.

- Family report of what they perceive to be the benefits and costs to the child of the support, including the opportunity costs of engaging with support.

Recommendation 65

Consensus-Based Recommendation

Practitioners, in partnership with the child and family, should monitor progress through child observations.

► Grade of Recommendation: Strong

Good Practice Points

65.1 Monitoring through child observation should include observing:

- The child's progress towards goals during the delivery of the support.
- The child's progress towards goals in contexts outside of those in which the support is being delivered (e.g., community settings).
- The child's reaction (positive, negative, mixed) to engaging in the support.

Recommendation 66

Consensus-Based Recommendation

Practitioners, in partnership with the child and family, should monitor progress through reports from others.

► Grade of Recommendation: Strong

Good Practice Points

66.1 Monitoring through reports readily obtainable from others related to the planning, selection, and delivery of supports, should include:

- Reports from people who are involved in the delivery of the support.
- Reports from people who can provide insight into the child's progress towards the goals and/or general learning, participation, and wellbeing (e.g., educators, other allied health practitioners or medical doctors who provide support for the child's health and development, other family members, sports coaches, community members the child interacts with regularly).

Recommendation 67

Consensus-Based Recommendation

Practitioners, in partnership with the child and family, should monitor progress through the collection and evaluation of outcome data.

► Grade of Recommendation: Strong

Good Practice Points

67.1 When monitoring progress through the collection and evaluation of outcome data, practitioners should consider multiple sources, including:

- Clinician collected outcome data, including:
 - Norm-referenced assessments comparing the child's skills and functioning with neurotypical children of the same age.
 - Criterion-referenced assessments comparing the child's skills and functioning with pre-

defined criteria such as developmental milestones.

– Curriculum-based assessments comparing the child's progress towards a pre-specified set of goals.

- Child collected outcome data, such as through self-report.
- Family collected outcome data.
- Outcome data collected from other stakeholders, such as a teacher.

67.2 When monitoring progress through the collection and evaluation of outcome data, practitioners should consider the relevance, reliability, and validity of the selected measures.

What and when to review

Recommendation 68

Consensus-Based Recommendation

Practitioners, in partnership with the child and family, should review goals, experiences, and outcomes at regular intervals based on the needs and preferences of each child and family.

► Grade of Recommendation: Strong

Good Practice Points

68.1 Goals and supports should be reviewed:

- When the child achieves a goal.
- When the child and family request new goals.
- When the practitioner identifies new goals relevant to the child and family.
- When there are significant changes in the life of the child and family (e.g., transition to school, parental supervision, moving house).
- At a frequency, and in a manner, that is sufficient for the practitioner delivering the support to make evidence-based recommendations.
- At a frequency, and in a manner, that is appropriate to the child and family, and the specific goal.
- At a frequency, and in a manner, that complements goal setting and, where relevant, individualised education planning at school.
- When there is a change in the family's financial capacity to access services, including changes in available funding.
- When there has been no meaningful progress made towards a particular goal across a timeframe when progress was anticipated.
- When any adverse effects occur.

68.2 At minimum, practitioners should complete a formal review of support goals and progress every three months.

68.3 The timing of reviews should meet the needs of the child and family, including where reporting will inform and/or fulfil requirements for funding and support including through NDIS planning processes and regulatory requirements (e.g., reporting of restrictive practices).

Information sharing

Recommendation 69

Consensus-Based Recommendation

Practitioners should ensure that information they collect during monitoring is shared with the child and family, and when relevant and appropriate, shared with other people.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Good Practice Points

- 69.1 Information collected during monitoring should be shared and discussed with the child and family, as it is collected, as well as at the time of review.
- 69.2 Information arising from monitoring and reviews may be shared with other people, where relevant and with appropriate consent, including:
 - Family (e.g., siblings, grandparents) and family-like people (i.e., family friends, peers).
 - Other community members (nominated by the parents) as the basis for supporting the child and family.
 - The child's school, to inform teachers and other educators of progress and/or invite consultation.
 - Other practitioners that support the child to inform them of progress and/or invite consultation.
 - Other organisations that support the child to inform them of progress and/or invite consultation.

Recommendation 70

Consensus-Based Recommendation

Practitioners should share information related to monitoring and reviews in a way that is informative, understandable, and meaningful to the child and family.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Good Practice Points

- 70.1 The way in which information is shared should be personalised to the circumstances and preferences of the child and family, and may include:
 - A face-to-face discussion.
 - A written report.
 - A telephone conversation.
 - A videoconference conversation.
 - A video recording (e.g., of a skill demonstrated by the child).
 - Other digital means (e.g., emails, shared online documents).
 - Other ways that may be meaningful to the child and family (e.g., graphical mode such as drawing, art).
 - A combination of these modes.
- 70.2 Practitioners should ensure that information is shared in a way that is aligned with the cultural and language preferences of the child and family.

- 70.3 Practitioners should provide the child and the family sufficient time to consider all information and provide the opportunity for further discussion and questions.
- 70.4 Practitioners should involve the child and the parents in any decisions about supports made in response to the information collected during monitoring and reviews.
- 70.5 Other people may be involved in decisions made in response to information collected during monitoring and reviews, where relevant and agreed to by the child and parents, including:
- Family (e.g., siblings, grandparents) and family-like people (e.g., family friends, peers).
 - Suitably qualified and experienced practitioners (e.g., allied health professionals, medical doctors, educators).
 - People who can support the child's participation in community activities (e.g., sports coaches; community and faith leaders; art teachers; and community members the child interacts with regularly including in retail environments, community groups, and cultural activities).
 - Staff in agencies that support the provision and/or access to services (e.g., NDIS planners, child safety officers).

Changing or ending supports

Recommendation 71

Consensus-Based Recommendation

Practitioners should empower and support the child and family to make decisions about whether to continue, change, or stop accessing supports.

► **Grade of Recommendation: Strong**

Good Practice Points

- 71.1 Practitioners should communicate to parents that they have a right to make decisions about the supports their child receives.
- 71.2 Practitioners should communicate to the child that they have a right to provide input into decisions about whether to continue, change, or stop accessing supports.

Recommendation 72

Consensus-Based Recommendation

Practitioners should communicate to the child and family when there is indication that their services are no longer required or recommended.

► **Grade of Recommendation: Strong**

Good Practice Points

- 72.1 Practitioners should provide clear communication to the child and family when they feel:
- The services they provide are no longer beneficial to the child and family.
 - The services they provide are no longer necessary to support the child and family.
 - Another practitioner may provide greater benefit to the child and family.
- 72.2 Practitioners should document when they feel their services are no longer required or recommended, and communicate this in a way that is informative, understandable, and meaningful to the child and the family.
- 72.3 Practitioners should ensure that information is shared in a way that is aligned with the cultural and language preferences of the child and family.

- 72.4 Practitioners should provide the child and the family sufficient time to consider all information and provide the opportunity for further discussion and questions.
- 72.5 Practitioners should invite discussion with the child and family about their views on the benefit and relevance of the service.
- 72.6 Where the service is currently, or will soon be, no longer required, or a referral needed, practitioners should provide the child and family with a clear plan for exiting the service and, where required, a plan for transitioning to another service.

How can the risk of adverse effects be reduced?

All supports have the potential to cause adverse effects, and it is critical that steps are taken prior to, and during, the provision of supports to reduce the chances that adverse effects are experienced. Practitioners have a responsibility to ensure that supports are delivered in a safe environment, and that they have current knowledge of research evidence, relevant professional knowledge and skills, and have access to clinical supervision. Practitioners should make the child and family aware of any feedback and complaints procedures, and also inform the child and family of their own potential or actual conflicts of interest in providing supports or making referrals. Central to minimising the risk of adverse effects is ensuring that accurate and complete information is shared with the child, family, and practitioners in an open and timely manner.

Safe environment

Recommendation 73

Consensus-Based Recommendation

Practitioners should ensure that the delivery of supports takes place in a safe environment.

► Grade of Recommendation: Strong

Good Practice Points

- 73.1 Practitioners should work in ways and create work spaces that are consistent with the National Principles for Child Safe Organisations.
- 73.2 Practitioners should only deliver supports in settings that meet the work health and safety requirements set out in the relevant Acts and Regulations in their State or Territory.
- 73.3 Practitioners should establish and follow a risk assessment procedure that:
- Identifies and documents organisational risks.
 - Uses data to support risk assessments.
 - Acts to reduce risks.
 - Regularly reviews and acts to improve the effectiveness of the risk management system.
 - Reports on risks to the workforce and people accessing their services.
 - Plans for, and manages, internal and external emergencies and disasters.
- 73.4 Practitioners should have awareness of any known environmental factors (e.g., loud noises, bright lights) that may cause distress to the child and take appropriate steps to manage these risks.
- 73.5 Practitioners should seek input from the parents and/or family around the suitability of recommended safety considerations, particularly in their own home.

- 73.6 Practitioners should be aware that the following restrictive practices can present human rights infringements, and should only be used as a last resort and in compliance with relevant State and Territory requirements and regulatory frameworks, such as the NDIS (Restrictive Practices and Behaviour Support Rules) 2018:
- Seclusion – sole confinement of a person with disability in a room or a physical space at any hour of the day or night where voluntary exit is prevented, or not facilitated, or it is implied that voluntary exit is not permitted.
 - Chemical restraint – the use of medication or chemical substance for the primary purpose of influencing a person’s behaviour (not including the use of medication prescribed by a medical doctor for the treatment of, or to enable treatment of, a diagnosed mental disorder, a physical illness, or a physical condition).
 - Mechanical restraint – the use of a device to prevent, restrict, or subdue a person’s movement for the primary purpose of influencing a person’s behaviour but does not include the use of devices for therapeutic or non-behavioural purposes.
 - Physical restraint – the use or action of physical force to prevent, restrict or subdue movement of a person’s body, or part of their body, for the primary purpose of influencing their behaviour (not including the use of a hands-on technique in a reflexive way to guide or redirect a person away from potential harm/injury).
 - Environmental restraint – a restraint restricts a person’s free access to all parts of their environment, including items or activities.
- 73.7 Practitioners should have an awareness of the status of health and safety screenings that are relevant to their work (e.g., Working with Children Check, Disability Worker Screening), and share these with the child and family if requested.

Current knowledge of research evidence

Recommendation 74

Consensus-Based Recommendation

Practitioners should have up-to-date knowledge of research evidence for the effectiveness, acceptability, feasibility, and risks of the supports they recommend and deliver.

► **Grade of Recommendation: Strong**

Good Practice Points

- 74.1 Practitioners should be aware of:
- Evidence regarding the effectiveness of the supports in relation to relevant child and family outcomes.
 - Evidence regarding the likely effectiveness of the supports for the individual child and family based on their characteristics, preferences, and resources.
 - Evidence regarding the acceptability of the supports among children and families.
 - Evidence regarding the feasibility of the supports for children and families, as well as practitioners.
 - Evidence for potential risks and documented adverse effects associated with the supports.
 - The quantity, quality, and consistency of evidence in relation to each of these considerations.
- 74.2 In considering the research evidence, practitioners should:
- Critically appraise the quality, consistency, and quantity of research evidence.
 - Take into account its relevance to the particular child and family.

- Have high regard for high quality studies that are autistic-led and/or co-produced with autistic people and/or family members.
- Have high regard for high quality studies that provide evidence for supports that are safe, effective, and desirable, but also practical, feasible, affordable, and achievable for the particular child and family.
- Equally value qualitative (e.g., examining personal views and experiences) and quantitative (e.g., well-designed single case experimental, cohort, and group design) studies including mixed methods, noting their different but complimentary contributions of evidence towards improving the safety, effectiveness, and desirability of supports for autistic children, including the identification of harms and other adverse effects.

Recommendation 75

Consensus-Based Recommendation

Practitioners should have up-to-date knowledge of the views and preferences of autistic people regarding different supports and their delivery.

► **Grade of Recommendation: Strong**

Good Practice Points

- 75.1 Practitioners should have an understanding of neurodiversity-affirming practices, which seek to affirm the child's neurodivergent identity, rather than seeking to 'fix' or 'cure' autism.
- 75.2 Practitioners should seek engagement with autistic people as a way of understanding the range of views and preferences regarding supports.

Current professional knowledge, skills, and access to supervision

Recommendation 76

Consensus-Based Recommendation

Practitioners should engage in continuing professional development.

► **Grade of Recommendation: Conditional**

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Good Practice Points

- 76.1 Practitioners should maintain an adequate connection with their professional discipline, and have engaged in recent practice or training, that is consistent with the recency of practice regulations
- 76.2 Practitioners should engage in continuing professional development to improve and increase their knowledge, skills, and competence.
- 76.3 Practitioners should be aware of, and able to work in ways that are consistent with Professional Codes of Conduct of professional organisations relevant to each profession.
- 76.4 Practitioners should be aware their scope of practice is determined by both:
- Profession scope of practice – the roles, functions, responsibilities, activities, and decision-making capacity that individuals within a given profession are educated, competent, and authorised to perform.

- Individual scope of practice – the roles, functions, responsibilities, activities, and decision-making capacity within a profession’s scope of practice that the practitioner (as an individual) is educated, competent, and authorised to perform.

Recommendation 77

Consensus-Based Recommendation

Practitioners should access clinical supervision that matches their knowledge, skills, and professional experience.

► **Grade of Recommendation: Strong**

Good Practice Points

- 77.1 Practitioners should receive clinical supervision to reflect on their own practice and wellbeing, and to encourage professional development in a systematic and planned manner.
- 77.2 Practitioners should receive clinical supervision and mentoring at a frequency that aligns with their professional experience working with autistic children and their families.
- 77.3 Practitioners should put in place ways to regularly monitor their own wellbeing, and have access to supports should that be necessary.

Feedback and complaints procedure

Recommendation 78

Consensus-Based Recommendation

Practitioners should inform the child and family about how they can provide feedback and make complaints about the supports they receive.

► **Grade of Recommendation: Strong**

Good Practice Points

- 78.1 Practitioners should have a feedback and complaints procedure, which is documented and shared with the child and family prior to the provision of any services.
- 78.2 When relevant, practitioners should inform the child and family of their right to make complaints to the National Disability Insurance Scheme Quality and Safeguards Commission.
- 78.3 Practitioners should share and discuss the feedback and complaints procedure in a way that is informative, understandable, and meaningful to the child and the family.
- 78.4 Complaints should be acknowledged, assessed, and resolved in a fair, efficient, and timely manner.
- 78.5 Practitioners should ensure that a complaint does not affect the provision of services to the person making the complaint (or, if different, the child) adversely.
- 78.6 If appropriate, the practitioner may need to refer the person making the complaint and/or the child to another appropriate practitioner.
- 78.7 Practitioners should ensure that the person making the complaint is:
 - Appropriately involved in the resolution of the complaint.
 - Kept informed of the progress of the complaint, including any action taken and reasons for the decisions made.

Conflicts of interest

Recommendation 79

Consensus-Based Recommendation

Practitioners should inform the child and family of any potential or actual conflicts of interest they have in providing supports or making referrals.

► Grade of Recommendation: Strong

Good Practice Points

- 79.1 Practitioners should recognise and carefully consider all actual and potential conflicts of interest they may have in the provision of services, and disclose these as appropriate to the child and family.
- 79.2 Practitioners should ensure that all services for which they receive financial or other compensation are justified and appropriate for the assessed needs of the child and family, and are not excessive, unnecessary, or not reasonably required.
- 79.3 Where a practitioner provides a referral to another practitioner or service provider, all actual and potential conflicts of interest between the referring and the receiving practitioner or service provider should be declared to the child and family.
- 79.4 Practitioners should ensure that referrals are based on objective criteria and are relevant to the needs of the child and family.
- 79.5 Practitioners should take steps to reduce conflicts of interests with referrals, including:
 - Establishing ways of monitoring referral practices.
 - Identifying or making alternative referrals when conflicts cannot be appropriately managed.

Knowledge of conventions, legislative requirements, and regulations

Recommendation 80

Consensus-Based Recommendation

Practitioners should follow relevant international conventions, national and state/territory legislative requirements, and other associated principles, frameworks, and regulations.

► Grade of Recommendation: Strong

Good Practice Points

- 80.1 Practitioners should be aware of, and work in ways that are consistent with, and not limited to:
 - The United Nations Convention on the Rights of the Child (1989).
 - The United Nations Convention on the Rights of Persons with Disabilities (2006).
 - The United Nations Universal Declaration on Human Rights (1948).
 - The Disability Discrimination Act (1992), including the Disability Standards for Education (2005).
 - The National Disability Insurance Scheme Act (2013).
 - The Child Safe Organisations: National Principles for Child Safe Organisations (Australian Human Rights Commission, 2018).
 - The Early Years Learning Framework for Australia (Commonwealth Government of Australia, 2009a).

- National Framework for Protecting Australia’s Children (Commonwealth Government of Australia, 2009b).
- Aboriginal and Torres Strait Islander Early Childhood Strategy Commonwealth Government of Australia (2021).
- The operational guidelines of the National Disability Insurance Scheme, including the Code of Conduct (2019), and Practice Standards and Quality Indicators (2021).
- The requirements for working with children, including criminal history screening, as set out in the relevant Acts and Regulations in their State or Territory.
- The work health and safety requirements set out in the relevant Acts and Regulations in their State or Territory.

Open and accurate communication

Recommendation 81

Consensus-Based Recommendation

Practitioners should ensure clear, appropriate, and accurate information is shared with the child, family, and other relevant people.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The ‘conditional’ rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

Good Practice Points

- 81.1 Practitioners should provide information in a way that is accessible and easy to understand to ensure that informed assent and consent is validly obtained from the child and family, respectively.
- 81.2 Practitioners should engage the child and family in a way that encourages open and regular communication.
- 81.3 Practitioners should have an understanding of interpreter services that the child and family may be able to access, if required.
- 81.4 Practitioners should keep clear, appropriate, and accurate records of all communication with the child and family regarding the provision of their supports.
- 81.5 Practitioners should ensure that the child and family have consented to the sharing of information with other people (e.g., practitioners, educators), including:
 - The nature of the information that will be shared.
 - The way that information will be shared.
 - The time frame in which information will be shared.
- 81.6 Practitioners should interact with each other clearly, respectfully, and promptly.
- 81.7 Practitioners should keep clear, appropriate, and accurate records of all communication with another practitioner regarding the child and family.

How should adverse effects be managed?

Practitioners should have a documented procedure for proactively identifying and managing adverse effects to help ensure the safety of the child and family throughout planning, selecting, delivering, and monitoring of supports.

Recommendation 82

Consensus-Based Recommendation

Practitioners should have a documented procedure for the monitoring of adverse effects of supports.

► **Grade of Recommendation: Strong**

Good Practice Points

- 82.1 Practitioners should have a documented procedure for monitoring adverse events and effects, which includes:
- Compliance with the relevant Acts and Regulations in their jurisdiction with which practitioners must comply.
 - Procedures for the proactive monitoring of adverse events.
 - Procedures for determining whether an adverse event is related to a support (an adverse effect).
 - Steps to be taken in response to the identification of an adverse event/effect, including:
 - Reporting of the adverse effect to the relevant authority where relevant.
 - Open and honest communication with the child and family (along with the provision of relevant documentation) as to what has occurred, and the anticipated consequences in the short and long-term.
 - Reviewing of the cause and practitioner response to the adverse effects.
 - Service improvement to reduce the risk of the adverse effect occurring again.
- 82.2 Practitioners should monitor adverse events via a range of methods, including:
- Child observations.
 - Listening to and directly asking the child and family.
 - Reports from others related to the support process.
- 82.3 Practitioners should determine whether an adverse event is caused by the support (i.e., an adverse effect) via a range of methods, including:
- Child observations.
 - Listening to and directly asking the child and family.
 - Reports from others related to the support process.
 - Awareness of adverse effects of a support previously reported through research.
 - Awareness of adverse effects of a support previously observed or reported in clinical practice.
- 82.4 If an adverse event is found to be related to a support (an adverse effect), the response of practitioners should comply with the relevant Acts and Regulations in their State or Territory.

How should the rights of children and families be protected?

Protecting the rights of children and families involves adhering to the complete list of Recommendations. Central to doing so, is recognising, valuing, and respecting the individuality of each child and family member including their language and terminology preferences.

Recommendation 83

Consensus-Based Recommendation

Practitioners should be familiar with, and respect, the individual language and terminology preferences of the child and family.

► Grade of Recommendation: Strong

Good Practice Points

- 83.1 Practitioners should be aware that different children, families, and those who support them may have different preferences regarding language and terminology, including in relation to talking about autism (e.g., identity-first, person-first), functional skills (e.g., differences, impairments), and services children and families access (e.g., therapies, supports, interventions).
- 83.2 Practitioners should ask the child and family about their preferences and adopt these during all aspects of their work together, including during interactions (e.g., with the child and family), in documentation (e.g., progress notes), and in communication about the child and family (e.g., writing reports).
- 83.3 When the child and family do not have preferences regarding language, practitioners should consider views on language and terminology from the autistic and autism community, including the information collected for this Guideline as well as other sources.

Recommendation 84

Consensus-Based Recommendation

Practitioners should respect each child and family member for who they are; respect their goals, values, and preferences; and work in ways that promote and protect their human rights.

► Grade of Recommendation: Strong

Good Practice Points

- 84.1 Practitioners should ensure that each child and family is aware of their human rights.
- 84.2 Practitioners should promote and protect individual rights, including freedom of expression, self-determination, and decision making.
- 84.3 Practitioners should respect the rights of the child and family to exercise choice and control about matters that affect them.
- 84.4 Practitioners should work in ways that makes the child feel safe, secure, and supported.
- 84.5 Practitioners should work in ways that helps the child develop their sense of self-worth and confidence in their self-identity.



Future directions



Future directions

This Guideline provides a set of Consensus-Based Recommendations for supporting the learning, participation, and wellbeing of autistic children and their families in Australia. The publication of this Guideline is an important step towards ensuring that all autistic children and their families in Australia receive safe, effective, and desirable supports. The next steps towards this goal involve the dissemination and implementation of the Guideline, its endorsement by peak clinical and consumer bodies, and a range of key clinical, research, and policy activities. These are presented here.

Dissemination and implementation of the Guideline

Following the publication of the Guideline, the Autism CRC will fund and undertake activities to support the dissemination of the Guideline and implementation of the Recommendations. It is envisaged that dissemination activities will include traditional and social media awareness campaigns, email distributions, the development of web resources, and the delivery of workshops and seminars. It is envisaged that implementation activities will include the development of quick reference guides (e.g., infographics, summary guides, videos, case studies, child-friendly version of the Guideline) and other resources (e.g., clinical training resources for students, and continuing professional development courses). It is anticipated that these activities will be conducted in close consultation with relevant professional colleges and societies and consumer representative organisations. The Dissemination and Implementation Plan is provided in further detail as a separate document to this Guideline.

The Guideline Recommendations are relevant to any jurisdiction that is involved in the funding or provision of supports and other services to autistic children aged 12 years or younger. Within the Australian context, the Recommendations have particular relevance to the National Disability Insurance Scheme (NDIS), and how this scheme can incentivise and regulate the delivery of evidence-based supports to autistic children and their families.

Endorsement of the Guideline

Following the publication of the Guideline, Autism CRC will seek endorsement of the Guideline from the peak clinical and consumer bodies represented on the Reference Group. These include the Australian Autism Alliance, Australian Association of Special Education, Australasian Society for Autism Research, Autism Awareness Australia, Autistic Self Advocacy Network – Australia and New Zealand, Australian Physiotherapy Association, Australian Psychological Society, Federation of Ethnic Communities' Council of Australia, National Aboriginal Community Controlled Health Organisation, National Rural Health Alliance, Neurodevelopmental and Behavioural Paediatrics Society of Australasia, Occupational Therapy Australia, Reimagine Australia, and Speech Pathology Australia. Autism CRC will welcome endorsement of the Guideline by other peak clinical and consumer bodies that seek to support autistic children and their families.

Future directions for research

Evaluation of Guideline

It is important that an ongoing evaluation process is in place to understand barriers and facilitators to Guideline dissemination and implementation, to monitor whether the Guideline is meeting the defined objectives, and to inform future Guideline updates.

Guideline update

The Guideline Recommendations should be reviewed and updated on a regular basis to respond to new evidence from research, clinical practice, or changes in community preferences and priorities. Recommendation 38, which is directly informed by the findings of the umbrella review (Appendix C), will be particularly affected by the publication of new high-quality systematic reviews that meet inclusion criteria. These systematic reviews will include new research, co-designed with autistic people, that will likely lead to new and improved ways of conceptualising, designing, delivering, and evaluating supports for autistic children and their families. The first update of the Guideline should take place within 5 years of publication of this original version. A suitable approach to updating the Guideline would involve reconstituting a Guideline Development Group to update the systematic reviews (restricted to evidence published since the previous systematic reviews), conduct new community consultation activities, and consider whether any of the Recommendations require amending or updating.

Evidence gaps

The research activities identified key knowledge gaps that require urgent research attention. These include:

- **Quality of life outcomes:** A shared goal of all supports is to increase a child's and family's quality of life. However, a key finding from the umbrella review was the primary focus of the extant literature on the effects of different supports on development and learning outcomes, and not on outcomes that may be more directly associated with quality of life, such as participation and wellbeing. Understanding the impact of different supports on quality of life, and whether any improvements are sustained over time, are critical areas of focus for future research.
- **Adverse effects:** The umbrella review also highlighted a lack of consideration of potentially adverse effects in clinical trials of different supports. The lack of reporting on adverse effects may reflect an assumption that non-pharmacological supports carry a negligible risk of harm. However, this is an assumption that requires constant testing in order to meet the ethical obligations of clinical research. Explicit collection and reporting of data relating to adverse effects is a critical and urgent recommendation for further research in this area.
- **Cultural diversity:** The majority of research on different supports to date has taken place in North America, Europe, and Australia, which have populations with a majority White/Caucasian background. The lack of cultural diversity in this research area is particularly salient to the provision of services to Australia's First Peoples: Aboriginal and Torres Strait Islander Peoples and their communities. A recent report highlighted the stark absence of research in this area, and the urgent need to better understand the life experiences of autistic individuals in these communities (Lilley, Sedgwick & Pellicano, 2019). A community-directed research strategy that identifies the needs, priorities, and preferences of Aboriginal and Torres Strait Islander Peoples and their communities is critical to meeting the obligation for ethical clinical practice in Australia.

- **Quality of evidence:** A common theme identified through the research and community consultation activities was the low quality of research evidence that underpins many supports accessed by autistic children and families (Whitehouse et al., 2020). This is highlighted in Appendix C, where the blank cells represent evidence that could not be obtained through the umbrella review. There is an important and urgent need for more high-quality co-designed clinical trials (adhering to the standards of the CONSolidated Standards Of Reporting Trials [CONSORT]; Begg et al., 1996) to be conducted in this area, which in turn, are summarised in high-quality meta-analyses (adhering to the standards of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses [PRISMA]; Page et al., 2021). Clinical trials that systematically examine different support characteristics, or compare responses to supports across children with different characteristics, will be particularly critical in developing a knowledge base that can inform the provision of individualised supports.
- **Co-production of supports and associated research:** Central to the Recommendations in this Guideline is the right of autistic people to have their views and voices heard, respected, and valued. This right extends to the co-design of supports with autistic people, and also the co-production of research that tests the efficacy, safety, and acceptability of these supports. Grounding research in the lived experience of the autistic community provides the greatest opportunity for research to generate outcomes that are meaningful to, and have a positive impact on, the lives of autistic children and their families. The Autism CRC Participatory and Inclusive Research Practice Guides provide important guidance in this area (den Houting, 2021).

Future directions for clinical practice

Clinical training

It is important that practitioners and other professionals undertake appropriate training to ensure they have the knowledge and skills to implement the Guideline within their service. Central to meeting this aim is having clinical training programs (through universities and other training organisations) that meet the requirements of the Recommendations enclosed in the Guideline, along with continuing professional development programs (through professional societies) that engage practitioners in life-long learning.

Communities of practice

Communities of practice connect practitioners in a similar area with the aim of deepening their collective knowledge and expertise in that area through ongoing interaction. Communities of practice help practitioners engage in reflective practice and life-long learning, and also provide connections to other practitioners who may support the clinical supervision and mentoring requirements of the Guideline Recommendations. The development of communities of practice centred around the Guideline Recommendations will be a key facilitator for the implementation of high-quality practice across Australia.

Future directions for policymakers

Incentivise and regulate Guideline adherence

The Recommendations included in this Guideline have been developed through an evidence-based practice framework, combining the best available research evidence, with insights from clinical practice, and the preferences and priorities of children and their families. Government agencies and professional societies should create and maintain frameworks that incentivise and/or regulate the adherence to the full suite of Recommendations in this Guideline as a way to ensure that all autistic children and their families receive safe, effective, and desirable supports.



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Appendices



Appendix A: Glossary

Academic skills (as a focus of supports)

The abilities, strategies, and habits that help people learn in an academic setting, such as school.

Acceptability

The extent to which the child and/or family perceives a particular support to be appropriate and meet their needs.

Adaptive behaviour

Skills that help people to function in their daily lives, this includes self-care and daily living skills, skills for communicating and relating to others in everyday settings.

Activity

The engagement in or performance of a task or action.

Adverse effect

An adverse event for which the causal relation between the support and the event is at least a reasonable possibility.

Agent

The person who is delivering the support to the child.

Amount

The quantum of support measured in units of time (e.g., minutes, hours).

Appraisal of Guidelines Research and Evaluation (AGREE-II)

AGREE II is an internationally accepted framework designed to guide the development, support the reporting, and assess the quality of practice guidelines.

Assent

The expressed approval of a person to participate in an activity, where that person is not able to give legal consent to participate. In Australia, consent for children (under 18 years of age) to receive supports is generally provided by parents.

Augmentative and alternative communication

Communication by means other than talking, to support both comprehension (understanding) and expression. 'Augmentative' means to add to someone's speech, and 'alternative' means to be used instead of speech'.

Autism Spectrum Disorder

Autism Spectrum Disorder (often referred to as autism or ASD) is the collective term for a group of neurodevelopmental conditions characterised by persistent difficulties in social-communication and interaction, and by restricted, repetitive patterns of behaviour, interests, or activities and/or sensory behaviours. The behavioural features that characterise autism are often present before 3 years of age, but may not become apparent until the school years or later in life. While these features can vary widely in nature and level between individuals, and in the same individual over time, there is evidence that autistic behaviours endure into adult life, though the impacts may change across the lifespan. A range of developmental, mental, and physical health conditions regularly co-occur with autism, including attention deficit hyperactivity disorder, intellectual disability, epilepsy, gastrointestinal issues, sleep disorders, language disorders, motor difficulties, and mental health problems. These co-occurring conditions, in conjunction with the core autism characteristics, can create significant barriers to a person's ability to function independently in his or her environment, with longer-term implications for educational and vocational attainment and wellbeing.

Autism community

The community of parents and family members of autistic people, along with practitioners and other community members who seek to support autistic people.

Autistic community

The community of autistic people.

Autism CRC

A collaborative research organisation that is focused on autism across the lifespan, and is an independent national source of evidence for best practice. The Autism CRC funded the development of this Guideline. Visit Autism CRC's website at www.autismcrc.com.au

Australian Health Practitioner Regulation Agency (AHPRA)

AHPRA is the Australian Government agency that is responsible for the implementation of the National Registration and Accreditation Scheme across Australia. AHPRA is responsible for the regulation of 16 health professions across Australia, including Aboriginal and Torres Strait Islander Health Practitioners, Medical Practitioners, Occupational Therapists, Physiotherapists and Psychologists. AHPRA's website is: www.ahpra.gov.au

Biological-based therapies

Any type of support/therapy that seeks to directly change biological processes or functions, including (but not limited to) medications, dietary supports, exercise, chiropractic, massage, acupuncture, reflexology, kinesiology, shock therapy, neurofeedback, transcranial magnetic stimulation, or hyperbaric oxygen therapy interventions.

Clinical mentoring

A reciprocal professional relationship whereby a practitioner with knowledge and experience assists with the learning and development of another. A clinical mentoring relationship is not typically related to ensuring accountability within a given place of employment.

Clinical supervision

A professional, and often contractual, relationship in which a typically more experienced supervisor

provides guidance to a practitioner on aspects of ethical and professional practice.

Cognitive development (as a focus of supports)

The process by which children acquire, organise and learn to use knowledge.

Consensus-Based Recommendation

Key elements of practice that must be followed for a practitioner to deliver evidence-based supports.

Consent

A person's agreement, based on adequate knowledge and understanding of relevant material, to participate in an activity.

Communication (as a focus of supports)

An exchange of information, ideas, and feelings between two or more people, where they create and share meaning.

Community consultation

Refers to research activities undertaken by the Guideline Development Group to gather evidence from the autistic and autism communities to inform the development of the Guideline.

Daily activities (as a focus of supports)

The activities that people undertake on a daily basis and help everyday functioning in life, such as self care (sleeping, toileting, personal grooming and eating).

Developmental skills

Skills that children gain over time, which are learnt and then combined to develop more complex tasks.

Draft Recommendations Working Group (DRWG)

The six members of the Guideline Development Group who led the analysis of the information collected through the research and community consultation activities to develop recommendations and make Evidence to Decision judgments. The group members were Sarah Pillar, Rhylee Sulek, David Trembath, Kandice Varcin, Hannah Waddington, and Andrew Whitehouse.

Duration

The length of time that a given amount of support is received, such as a given number of months.

Effectiveness

The ability of a support to lead to the desired beneficial effect.

Evidence-based supports

Supports that are based on the best available evidence from research, evidence from clinical practice, and the preferences and unique context of each child and family.

Evidence to Decision (EtD) framework

A research method that is part of the GRADE framework that guides Guideline developers to use evidence in a structured and transparent way to inform decisions in the context of Guideline Recommendations.

Family

The child's parents, siblings, and any extended family, including grandparents, aunts, uncles, and cousins.

Family-like

People who are not relatives of the child and family, but play a significant personal role in supporting the child and family.

Feasibility

The extent to which a support is able to be delivered by a practitioner in a particular context.

Format

The delivery set up in terms of the individuals receiving the support, such as delivery to an individual child (also called one-on-one delivery), or delivery to a group of children (also called group delivery).

Gender identity

An individual's perception and experience of their own gender. This may or may not correspond to their physiology or sex assigned at birth.

Generalisation

The ability to perform skills learnt in one circumstance in other settings and activities, and with other people.

Good Practice Points

Elements of practice that provide critical context to a given 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.

Grading of Recommendations Assessment, Development and Evaluation (GRADE)

GRADE is an internationally recognised research framework for assessing the certainty of evidence and strength of clinical practice recommendations.

Guideline Development Group (GDG)

The 15 member group that led the research and community consultation activities upon which this guideline is based. The group included autistic adults; parents and other family members of autistic children, including children and young adults with complex needs; people with expertise in working alongside Aboriginal and Torres Strait Islander Peoples and communities; people with expertise in ethics and research integrity; practitioners with experience in government and non-government sectors; and researchers with expertise in the guideline development process, including community consultation. The group members were: Gary Allen, Katharine Annear, Valsamma Eapen, Jessica Feary, Emma Goodall, Sarah Pillar, Teresa Pilbeam, Felicity Rose, Nancy Sadka, Natalie Silove, Rhylee Sulek, David Trembath (Co-chair), Kandice Varcin, Hannah Waddington, and Andrew Whitehouse (Co-chair).

Intensity

The amount of support (measured in units of time) provided in a particular time period (e.g., hours per week).

International Classification of Functioning, Disability and Health (ICF)

Commonly known as the ICF, this framework, published by the World Health Organisation, presents a biopsychosocial model for conceptualising, describing, and addressing disability in a way that considers individual, contextual, and environmental factors. The ICF website is:

www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health

Key worker model

A group of professionals from different disciplines who meet regularly and that nominates one member as the primary service provider or 'key worker'. The key worker acts as the primary practitioner for the child and family, and the single point of contact.

Learning

Acquiring knowledge and skills.

Meta-analysis/es

A statistical analysis that combines data from different studies focused on the same research question.

Mode

The medium through which a support is delivered, such as through in person delivery and through telepractice delivery.

Monitoring

The ongoing process of collecting information to ensure that supports are being delivered in a safe, effective, and desirable way.

Motor development (as a focus of supports)

The acquisition of skills that enable a child to move around and manipulate the environment around them. This includes gross motor skills (involving larger muscle movement, such as sitting, crawling, and walking) and fine motor skills (involving smaller muscle movement, such as grasping and drawing).

Multidisciplinary

A group of professionals from different disciplines working with a child and family, either independently or as a team.

Narrative synthesis/es

An approach to combine the results from different studies focused on the same research question, which relies primarily on words to summarise and explain the findings.

National Alliance of Self Regulating Health Professions (NASRHP)

NASRHP is a national organisation representing self-regulating health professions in Australia. NASRHP provides a quality framework for self-regulating professions, facilitating national consistency in quality and ethical practice.

National Disability Insurance Scheme (NDIS)

The NDIS is an Australian social security system that provides funding to people with disability, their families and carers. The NDIS is jointly governed by the Australian and state and territory governments.

National Health and Medical Research Council (NHMRC)

The NHMRC is the main statutory authority of the Australian Government responsible for medical research. The NHMRC provides guidelines that describes the best practice approach for developing practice guidelines in Australia (called 'Guidelines for Guidelines').

Neurodiversity

The perspective that people experience and interact with the world in different ways. Inherent in this view is that there is no one 'normal' way of thinking, learning, and behaving, and therefore differences in behaviours should not be seen as 'deficits'. In the context of autism, a neurodiversity perspective views brain-based and behavioural differences observed in autistic children as reflecting natural human variation.

Neurodiversity-affirming

Practices that seek to affirm the child's neurodivergent identity. In the context of autism, this term refers to providing supports that embrace each child's unique understanding of other people and the world around them, without seeking to 'cure' autism.

Non-pharmacological

Any type of support that is not primarily based on medication.

Parents

Any individual with parenting or caretaker responsibilities for a child, including guardian, kinship, and foster carers.

Participation

The involvement in life situations that a person desires and in a way that they agree to.

Pharmacological supports/therapies

Any type of support that uses medication.

Practitioners

People who are paid to provide support services to children and families.

Protective behaviours

Behaviours that enable a child to recognise situations in which their personal space and sense of safety may be compromised, and to express and advocate for their needs, preferences, and desires.

Public consultation

Refers to the process whereby the Guideline Development Group released the Draft Guideline, gathered feedback from the autistic and autism communities, and used this feedback to refine the Guideline.

Quality of life

An individual's perception of their own position in life, particularly in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns.

Reference Group

A group of representatives from key stakeholder organisations in Australia, who supported the community consultation process and who provided input to the guideline development process at key stages. The Reference Group comprised representatives from organisations 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 communities; as well as from the key Government agency, the National Disability Insurance Agency.

Research synthesis

A research project that combines the results from different studies focused on the same research question, and provides an overarching summary of those studies.

Restrictive practices

Any action that has the effect of restricting the rights or freedom of movement of a person with disability. In Australia, restrictive practices are subject to regulation. Restrictive practices include:

- Seclusion – sole confinement of a person with disability in a room or a physical space at any hour of the day or night where voluntary exit is prevented, or not facilitated, or it is implied that voluntary exit is not permitted.
- Chemical restraint – the use of medication or chemical substance for the primary purpose of influencing a person's behaviour (not including the use of medication prescribed by a medical practitioner for the treatment of, or to enable treatment of, a diagnosed mental disorder, a physical illness or a physical condition).
- Mechanical restraint – the use of a device to prevent, restrict, or subdue a person's movement for the primary purpose of influencing a person's behaviour but does not include the use of devices for therapeutic or non-behavioural purposes.
- Physical restraint – the use or action of physical force to prevent, restrict or subdue movement of a person's body, or part of their body, for the primary purpose of influencing their behaviour (not including the use of a hands-on technique in a reflexive way to guide or redirect a person away from potential harm/injury).
- Environmental restraint – a restraint restricts a person's free access to all parts of their environment, including items or activities.

Reviewing

A periodic assessment of all information collected during monitoring, which enables the child, family and practitioner to reflect on the overall experience of accessing supports, including whether the current goals remain relevant and meaningful, and whether the current supports are safe, effective, and desirable.

Sensory experiences (as a focus of supports)

Interpreting input from the five senses (hearing, sight, taste, touch, smell), along with other sensory information such as proprioception (the awareness of body and limbs in space) and interoceptive (the perception of sensations from inside the body).

Service

Any paid activity performed by a practitioner in the process of supporting children and families. This includes goal-setting, selecting supports, support delivery, and support monitoring.

Service provider

An organisation that provides services to autistic children and their families. These organisations may have a sole practitioner or many practitioners.

Service system

The arrangement of organisations, people, institutions, and resources that provide services to people for a shared intent (e.g., education service system, health service system, disability service system).

Sexual development

The process(es) of interacting physical, cognitive, emotional, and social changes that underlie sexual maturation.

Social-emotional development (as a focus of supports)

The child's experience, expression and management of emotions, and the ability to build healthy relationships with others.

Supports

Any paid activity performed by a practitioner that seeks to improve a person's experience of the world, either through helping the child acquire skills that promote their learning, participation and wellbeing, empowering parents to support and advocate for their child and promote their own and their family's wellbeing, and/or create safe and accessible environments that support learning, participation, and child and family wellbeing.

The term that encompasses both what are historically referred to as 'therapies' and 'supports':

Therapies – services that focus on supporting the child to acquire or enhance functional skills aimed at developing and maintaining their learning, participation, and wellbeing in the community.

Supports – services that focus on adjustments, modifications and enhancements to the environment aimed at developing and maintaining their learning, participation, and wellbeing in the community.

While supports for autistic individuals vary, they share a universal goal of minimising the impact of developmental challenges and co-occurring conditions on functional abilities, participation, and quality of life, and maximising long-term independence and autonomy.

Telepractice

The use of telecommunications (including videoconference and internet technology) to connect a practitioner with a child and family at a distance for the purpose of providing supports and/or other services.

Transdisciplinary

The delivery of a range of supports by a single practitioner, where those supports transcend professional boundaries, provided the practitioner is appropriately qualified and has the knowledge, skills, experience, and supervision to do so in ways that are safe, effective, desirable, and lawful.

Universal design

The design or composition of an environment so that it can be accessed, understood and used to the greatest extent possible by all people regardless of age, disability, and other factors.

Wellbeing

Positive and sustainable characteristics, such as being comfortable, healthy, and happy, which help an individual thrive and flourish.

Appendix B:

Community consultation activities conducted as part of the Guideline development process

Online community survey

Description

An online survey designed to understand the experiences of the autistic and autism communities in accessing supports, and their views on good practice.

Who was able to take part?

Open to all members of the community, aged 12 years or older

What was involved?

Completion of a survey, which was structured around the guideline questions, and allowed for Likert scale and/or open-ended responses. Participants were able to provide general feedback on supports for autistic children, or more detailed responses aligned to each of the guideline questions.

How was it completed?

An online survey, accessed via the Autism CRC website.

How many people took part?

665 participated in the online community survey.

Brief online survey

Description

A brief online survey designed to understand the views of autistic children in accessing supports.

Who was able to take part?

Focused on autistic children, but also open to autistic adults and designed to cater for autistic people of all ages who communicate mainly in ways other than speech.

What was involved?

Completion of a survey that requested parents ask questions of their child about their child's experience accessing supports, and write down verbatim the child's responses. Autistic adults completing the survey were asked to reflect on their childhood experiences.

How was it completed?

An online survey, accessed via the Autism CRC website.

How many people took part?

46 people participated in the brief online survey.

Parent reflections

Description

A brief online survey designed to ask parents to reflect on their view of their autistic child's experience accessing supports.

Who was able to take part?

Focused on parents of autistic children. Also open to parents of autistic adults and designed to cater for autistic people of all ages who communicate mainly in ways other than speech.

What was involved?

Completion of a survey that requested parents to reflect and report on their observations of their child as they accessed supports. Parents of autistic adults, were asked to reflect on their adult person's childhood experiences.

How was it completed?

An online survey, accessed via the Autism CRC website.

How many people took part?

25 people participated in the reflection activity.

Expression through artwork

Description

A consultation activity designed to understand the views of autistic children and adults in accessing supports. The activity design recognises that autistic individuals may communicate, or prefer to communicate, through ways other than spoken language.

Who was able to take part?

Open to autistic children and adults and designed to cater for autistic people of all ages who communicate mainly in ways other than speech.

What was involved?

Production of a piece of art (e.g., a drawing, painting, or other artwork) about their experiences and/or their feelings of accessing supports. Autistic adults completing the survey were asked to reflect on their childhood experiences.

How was it completed?

Completed remotely, and then uploaded to the Autism CRC website.

How many people took part?

The Guideline Development Group did not receive any submissions for this activity.

Delphi survey

Description

A practitioner survey designed to understand areas of consensus for various aspects of clinical practice in supporting autistic children and their families.

Who was able to take part?

A total of 100 practitioners were invited to take part; 20 practitioners were nominated by each of the five peak bodies representing clinical practitioners who have expertise in key outcomes for autistic children, specifically:

1. Health and medical needs (Neurodevelopmental and Behavioural Paediatrics Society of Australasia)
2. Communication (Speech Pathology Australia)
3. Cognition and social-emotional development (Australian Psychological Society)
4. Sensory needs (Occupational Therapy Australia)
5. Motor development (Australian Physiotherapy Association)

What was involved?

Completion of an online Delphi survey, which was structured around the guideline questions and requested responses on Likert scale. Practitioners were also able to provide additional information through open-ended questions. Two Delphi rounds were conducted.

How was it completed?

An online survey, accessed via a unique link emailed directly to invited practitioners.

How many people took part?

72 practitioners completed the first round, and 59 practitioners completed the second round.

Focus groups

Description

Focus groups designed to provide opportunity for further detailed discussion on the experiences of the autistic and autism communities in accessing supports, and their views on good practice.

Who was able to take part?

Autistic adults (four focus groups) and parents of autistic children (four focus groups).

What was involved?

Each focus group was 2 hours in length, and included dedicated time for each individual to discuss their feedback and experiences relating to the Guideline questions.

How was it completed?

Videoconference.

How many people took part?

48 people participated in the focus groups.

Appendix C:

Summary of the effect of different supports on child and family outcomes, drawn from an umbrella review of meta-analyses.

To support consideration of the best available research evidence for this Guideline, an umbrella review of 48 systematic reviews was completed. The evidence was synthesised in a way that enables practitioners to consider the evidence for the effects of nine categories of supports on a range of child and family outcomes. The nine categories each have different underlying theoretical principles for why the supports are hypothesised to support skill acquisition. These categories and a brief summary of their underlying principles, are as follows:

- **Behavioural:** Children learn new skills based primarily on the cues for, and consequences of, their behaviour (operant learning).
- **Developmental:** Children learn new skills primarily through interactions with people and environments (cognitive and social constructivist theories).
- **Naturalistic Developmental Behavioural Interventions (NDBIs):** Children learn new skills, through interactions with other people and environments (behavioural and constructivist theories).
- **Sensory-based:** Children's learning can be enhanced by addressing neurophysiological impairments in sensory processing.
- **Technology-based:** Technology use complements children's diagnostic characteristics, thus supporting learning and participation.
- **Animal-assisted:** Human-animal interactions may be particularly motivating and provide a context for learning and improved wellbeing.
- **Cognitive Behaviour Therapy:** People can learn to identify and replace unhelpful thoughts, leading to positive effects on emotions and behaviour.
- **TEACCH:** Children learn new skills most effectively when the environment is adapted to their learning characteristics.
- **Other Interventions:** Do not align directly with the features (theoretical premise, clinical application, and principles) of one of the eight specific categories identified.

Further information about these categories and umbrella review is provided in the Administration and Technical Report.

Type of support	No. of systematic reviews	Communication				Sensory	Cognitive	Social-emotional	Motor	Academic skills	School/ learning readiness	Daily activities and participation			Family wellbeing		
		Overall communication	Expressive language	Receptive language	Social-communication							Adaptive behaviour	Play	Participation	Child quality of life	Parent knowledge and skills	Parent wellbeing
Behavioural supports (variety of practices)	1	+ H			+ H		+ H	+ H	+ H			+ H					
Early intensive behavioural intervention	3	+ H	o H	+ H	+ H		+ H	o H				? H					
Developmental supports (variety of practices)	2	o H			+ H												
Naturalistic developmental behavioural interventions (variety of practices)	2	+ H	+ H	+ H	? H		+ H	o H				o H	+ H				
Early Start Denver Model	2	+ L			o L		+ L					o H					
Pivotal Response Treatment	2	o L	+ L														? L
JASPER	1	+ H	? H	? H	+ H								+ H				
Sensory-based supports (variety of practices)	1	o H															
Music therapy	2	+ H			+ H												+ H
TEACCH (variety of practices)	1				o H												
Technology based supports (variety of practices)	3				o H			o H									
Apps	3	o H	o H	o H	o H		+ H		+ H								
Animal-assisted supports (variety of practices)																	
Equine assisted therapy	2	+ L			+ L							o L					
Canine assisted therapy	1				+ L												
Cognitive behavioural therapy (variety of practices)	2				+ L			? H									
Other supports																	
Social skills training (computers + robots)	1				+ H												
UCLA PEERS	1				+ L									+ L			

+ Positive therapeutic effect ? Inconsistent therapeutic effect o Null effect L = Low quality systematic review H = High quality systematic review Blank cell indicates no evidence available

All information on effects are drawn from meta-analyses, except for the effect of Pivotal Response Treatment on the parent wellbeing, the effect of canine assisted therapy on the social-communication outcome, and the effect of JASPER on all outcomes, which have been drawn from narrative reviews

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



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