



Supporting Children National Guideline

Draft Guideline: Organisation Feedback Form

INSTRUCTIONS

Thank you for telling us what you think about the Draft National Practice Guideline for supporting autistic children and their families. Please follow these steps to share feedback on behalf of your organisation.

1. Read and complete the Participant Information Statement and Consent Form (attached in this document and in the online form).
2. Consult with relevant people within your organisation. It is expected that each person who contributes will read the Participant Information Statement (attached in this document), so that they understand the context for this feedback survey, as well as their individual rights, including the right not to contribute feedback.
3. Read and respond to the questions in the survey to your satisfaction.
4. Ensure that your form is approved by the relevant officer/authorising person.
5. Lodge the form via the survey link – you will have been provided with a personal return code to the survey when you exited the online form. If you are unable to locate the link, you can access the survey again here using the original link from the Autism CRC webpage. (Note: if you access the survey again via the original survey link, you will be required to provide informed consent once again, prior to uploading the form).

If you have any questions about the process for providing feedback, please contact the Guideline Development Group at supportingchildren@griffith.edu.au.

Information Statement for the Research Project:

Development of a National Practice Guideline for Supporting Autistic Children and their Families: Community Feedback on the Draft Guideline (GU ref no:2021/843)

Part 1: Participation Information

What is this project about?

The Autism CRC is leading the development of a National Practice Guideline for supporting autistic children and their families in Australia. A draft version of the Guideline has been developed based on both research and consultation with the community. The draft Guideline includes a set of Recommendations and Good Practice Points for practitioners that are intended to guide the delivery of support services for autistic children and their families.

Why are you being invited to participate?

We want to hear feedback from all community members on the draft Guideline. We are inviting you to participate, by providing your feedback on the draft Guideline via an online form. Your feedback may be used to inform revisions to the Guideline, to make it better.

Who can participate in the research?

We would like to receive feedback on the draft Guideline from the following community members/groups:

- Autistic people.
- Parents, caregivers, and family members of autistic people.
- Individuals who provide supports to autistic children and their families.
- Members of organisations/bodies/groups that provide supports and services to autistic children and their families.
- Organisations/bodies/groups that provide supports and services to autistic children and their families.
- Other members of the autism community (e.g., researchers).

What would I need to do?

If you agree to provide feedback on the draft Guideline, it would involve:

1. *Accessing the draft Guideline:*

You can access the draft Guideline via the Autism CRC webpage.

2. *Reading the draft Guideline*

The draft Guideline includes:

- An introduction about the purpose and scope of the Guideline, who the Guideline is intended for (i.e., target users), and information about how the draft Guideline was developed.
- A set of Recommendations and Good Practice Points relating to the following aspects of practice:
 - Guiding Principles
 - Goal Setting
 - Selecting and Planning Supports
 - Delivering Supports
 - Outcomes, Quality and Safeguarding

3. *Providing feedback about the draft Guideline*

Individual members of the community: We will ask you questions in an online survey. You can choose if you would like to provide feedback on any/all of the five sections of the draft Guideline and/or specific Recommendations within each section.

Organisations: If you are submitting feedback on behalf of an organisation/peak body/group (i.e., not as an individual member of an organisation), there is a separate form available to you in the online survey to download and input your feedback. This form requests information about your organisation and will require a signatory. Once the downloaded form is completed, you can submit your feedback via a 'file upload' option in the online form.

If you agree to provide feedback, the link to the feedback survey will appear on your screen after you provide informed consent.

Do I have to participate?

Participation in this research is entirely your choice. Only information collected from those who give consent will be included in this phase of the project. If you decide not to participate, this decision will not disadvantage you or impact your relationship with Griffith University or any other institutions affiliated with this research.

What happens if I change my mind?

If you begin the feedback form and decide that you would like to withdraw consent, there is a button at the end of the form you can select to indicate that you no longer want the information you provided to be used. If you decide to withdraw consent after submitting the form, your individual responses will not be able to be identified, due to the anonymous nature of data collection. If you change your mind after submitting feedback, the Guideline Development Group will endeavour to, but cannot guarantee that it will be able to, withdraw the feedback from consideration or publication.

What are the benefits of participating?

We hope that it will be a positive experience for you, in helping to inform the Guideline. While you may not receive any direct benefits from participating in this research, the benefits of the research more broadly include an opportunity to improve a National Practice Guideline for supporting autistic children and their families.

Are there any potential risks?

We do not believe there are any direct risks associated with participation in this research.

Who are the researchers?

Professor Andrew Whitehouse, Bennett Chair of Autism & Director, CliniKids, Telethon Kids Institute
A/Professor David Trembath, Menzies Health Institute Queensland, Griffith University & CliniKids, Telethon Kids Institute.

Dr Kandice Varcin, Research Fellow, Menzies Health Institute Queensland, Griffith University

Dr Rhylee Sulek, Research Fellow, School of Health Sciences and Social Work, Griffith University

Dr Hannah Waddington, Lecturer, School of Education, Victoria University of Wellington

Ms Sarah Pillar, Integration Project Manager, CliniKids, Telethon Kids Institute

Who can I contact for further information?

You might be unsure if you are able to participate or unsure about how the research process works. We encourage you to contact the research team (supportingchildren@griffith.edu.au) to discuss this and anything else you might wish to talk about in relation to the project.

How can I receive information about the research results?

Regular updates regarding the progress and publishing of the Guideline will be provided on the Autism CRC website. All community members will be able to access a copy of the final Guideline, once published. If you would like to discuss this further with the research team, you can do so via email (supportingchildren@griffith.edu.au).

How can I trust this research is safe for me?

This research is being conducted by skilled research staff and supported by a Guideline Development Group that includes people with a range of knowledge and experience, including autistic adults and parents raising autistic children. The team has drafted the Guideline based on international and national research and community

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consultation activities undertaken in Australia in 2022. The team has also made available different options for you to share your feedback on the draft Guideline. Only anonymous feedback will be used and reported.

Part 2: Ethical Information we must provide you.

What will be done with the information you provide?

- 1. We will use it to revise the Guideline:** Feedback on each section and each Recommendation will be considered alongside all of the evidence collected through the Guideline development process for that particular section/Recommendation. We will read all written responses you provide using the designated online survey. To ensure that everyone providing feedback has the same opportunity, and to ensure that the GDG considers all feedback equally, we will only consider feedback provided via the survey and we make no undertaking to review (and will not respond to) any further information referred to via links (e.g., weblinks, resources).
- 2. We will provide a de-identified copy of all responses to the National Health and Medical Research Council.** This is a requirement for the development of clinical guidelines in Australia. All feedback collected from the community through this process will be submitted anonymously to the NHMRC. The NHMRC uses this information to evaluate how the Public Consultation occurred and how the information gathered was used, when they decide whether or not to endorse the Guideline.
- 3. If you provide an individual response and agree, we will publish a copy of your de-identified feedback, and our response, when the Guideline is released.** This is optional. If you agree for your feedback to be published, we will publish it verbatim, but reserve the right to redact any potentially personally identifying or defamatory information.
- 4. If an organisation provides a response, we will publish your organisation's name, a copy of your de-identified feedback, and our response, when the Guideline is released.** This is not optional. By making a submission you agree to the use of the information in this way. We will publish your responses verbatim, but reserve the right to redact any potentially personally identifying or defamatory information.

What type of feedback will you receive?

If you agree for your feedback to be published when the Guideline is released, you will see a brief response from the Guideline Development Group to your feedback. The Guideline Development Group will only provide feedback in this form and will not enter into additional correspondence regarding the feedback. By submitting feedback, you are acknowledging that this is the limit of feedback that will be provided.

How will privacy be protected?

The conduct of this research involves the collection, access, storage and/or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. Your anonymity will at all times be safeguarded. For further information consult the University's Privacy Plan at <http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan> or telephone (07) 3735 4375.

To further explain how your privacy will be protected, all of the data that is collected through the survey will be completely confidential. All data will be stored securely on an encrypted and password protected storage drive that will be accessible only by the members of the research team. This data will be stored securely for five years.

The ethical conduct of this research

Griffith University conducts research in accordance with the National Statement on Ethical Conduct in Human Research. Please feel free to contact the researchers if you have any questions (supportingchildren@griffith.edu.au).

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If you have any additional questions or concerns about ethical issues, please contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee (research-ethics@griffith.edu.au; 07 3735 4375).

Consent Form for the Research Project:
Development of a National Practice Guideline for Supporting Autistic Children and their Families: Community
Feedback on the Draft Guideline
(GU ref no:2021/843)

Community Feedback on the Draft Guideline

By selecting the check box below, I confirm that I have read and understood the information sheet and I have noted that:

- I understand that my participation in this research will include:
 - Reviewing the draft Guideline
 - Providing feedback on the draft Guideline via an online form
- I understand that the feedback I provide in the online form will be used to inform the development of the final version of the Guideline.
- If I am submitting an individual response, I understand that:
 - An anonymous copy of my feedback will be provided to the National Health and Medical Research Council
 - I can choose whether an anonymous copy of feedback is published with the Guideline when it is released
 - I will receive feedback from the Guideline Development Group if I agree to have my feedback published with the Guideline when it is released. The feedback I receive will be limited to a brief response from the Guideline Development Group
 - I will not receive feedback from the Guideline Development Group if I do not agree to have my feedback published with the Guideline when it is released
- If I am submitting a response by an organisation, I understand that:
 - An identified copy of my feedback, including the name of the organisation and person who authorised the submission, will be provided to the National Health and Medical Research Council
 - A copy of my feedback, including the name of the organisation (but not the name of the person who authorised the submission), will be published with the Guideline when it is released
 - The Guideline Development Group may contact the person submitting the feedback, to verify the submission
 - I will receive feedback when the Guideline is published, limited to a brief response from the Guideline Development Group
- I understand that a summary of demographic information (de-identified) will be published when the Guideline is released (e.g., how many parents provided feedback).
- I have read the Information Statement, or someone has read it to me in a language that I understand.
- I understand why this research is being conducted and how I can participate.
- I understand any risks as described above.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I understand that I am free to withdraw from this research by not submitting feedback. Once the feedback is received, the Guideline Development Group will endeavour to, but cannot guarantee that it will be able to, withdraw the feedback from consideration or publication.
- I understand that I can contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee if I have any concerns about the ethical conduct of this project.
- I agree to participate in the research.

PLEASE NOTE: This consent form is accessible online through the secure survey link (in REDCap). The person submitting the form on behalf of the organisation will be asked to also provide contact details and indicate their consent via a checkbox in the online form.

***REQUIRED INFORMATION**

Participant First and Last Name: Tim Moore
Organisation Name: Professionals and Researchers in Early Childhood Intervention (PRECI)
Position within the organisation: Member of Board of Management
Contact email: tim.moore@mcri.edu.au

SECTION 1: Feedback on key sections within the Draft Guideline

The draft Guideline contains five key sections:

- Guiding Principles
- Goal setting
- Selecting and planning supports
- Delivering supports
- Outcomes, quality, and safeguarding

This set of items gives you the option to provide feedback on these overarching sections of the Guideline.

The next set of items (Section 2 of this form) gives you the option to provide feedback on specific Recommendations/Good Practice Points within each of the sections.

PLEASE NOTE: To ensure that everyone providing feedback has the same opportunity, and to ensure that the Guideline Development Group considers all feedback equally, we will only consider feedback provided via this form and we make no undertaking to review (and will not respond to) any further information referred to via links (e.g., weblinks, resources).

Feedback on Key Section: Guiding Principles

Please provide your feedback (up to 150 words) on the 'Guiding Principles' section of the Draft Guideline. You can tell us what you like/support about this section or what could be improved.

Maximum word limit: 150 words (to ensure equal opportunity, the Guideline Development Group will not read beyond 150 words).

This is a strong set of principles that PRECi endorses, but with three caveats.

First, there is no detail provided in the Draft Guideline of what these guiding principles look like in practice. All the later recommendations include Good Practice Points, but none are provided for the guiding principles. These principles have no real force or value unless there is some description of what they look like in practice. We recommend that Good Practice Points be provided for all the guiding principles.

Second, the principles are not reflected in the remainder of the recommendations. In many, the Good Practice Points do not describe practices that are truly family-centred, strength-based etc. We recommend that all recommendations be reviewed with the key principles in mind.

Third, there is not enough emphasis in the proposed Guideline on promoting parents' capabilities to meet their children's needs. This should really be an additional guiding principle..

Feedback on Key Section: Goal-setting

Please provide your feedback (up to 150 words) on the 'Goal-setting' section of the Draft Guideline. You can tell us what you like/support about this section or what could be improved.

Maximum word limit: 150 words (to ensure equal opportunity, the Guideline Development Group will not read beyond 150 words).

Many of these recommendations depict the goal-setting process as one in which the professionals play the dominant role, rather than one in which the professionals play a facilitating role in helping parents set goals and partnering with them in deciding how best to meet them. This is an example of the problem highlighted in our comments on the Guiding Principles – that the recommendations and good practice points do not always reflect the guiding principles.

There is not enough recognition of the importance of goals focused on the needs of the parents and the family, and of the importance of parental and family well-being.

There is also no reference to aspirational long-term goals, capturing the family's hopes for their child.

Suggest changing the order of these recommendations so that those dealing with *how* goals are selected (Recs 22-24) and put before those that deal with *what* goals are selected (Recs 18-21).

Feedback on Key Section: Selecting and Planning Supports

Please provide your feedback (up to 150 words) on the 'Selecting and Planning Supports' section of the Draft Guideline. You can tell us what you like/support about this section or what could be improved.

Maximum word limit: 150 words (to ensure equal opportunity, the Guideline Development Group will not read beyond 150 words).

As with the goal-setting recommendations, many of these recommendations describe the process of selecting and planning supports as one in which the professionals play the dominant role, rather than one in which the professionals partner with parents in planning how to meet the goals they have selected. Again, this is an example of failing to embed key guiding principles throughout the Practice Guideline.

There is no coverage of key worker role or of transdisciplinary teamwork

There's also no coverage of embedding learning and participation strategies in regular daily routines, considered best practice in early childhood intervention services.

Feedback on Key Section: Delivering Supports

Please provide your feedback (up to 150 words) on the 'Delivering Supports' section of the Draft Guideline. You can tell us what you like/support about this section or what could be improved.

Maximum word limit: 150 words (to ensure equal opportunity, the Guideline Development Group will not read beyond 150 words).

Several of these recommendations describe three different service options as if they were equally valid approaches. The provision of direct services (ie. clinically-based therapy services) to young children is not supported by evidence or best practice recommendations. This needs to be acknowledged.

Feedback on Key Section: Outcomes, Quality, and Safeguarding

Please provide your feedback (up to 150 words) on the 'Outcomes, Quality, and Safeguarding' section of the Draft Guideline. You can tell us what you like/support about this section or what could be improved.

Maximum word limit: 150 words (to ensure equal opportunity, the Guideline Development Group will not read beyond 150 words).

SECTION 2: Feedback on Recommendations/Good Practice Points within the Draft Guideline

The draft Guideline contains 84 Recommendations. Many of these Recommendations also contain a set of Good Practice Points.

This set of items gives you the option to provide feedback on specific Recommendations (and associated Good Practice Points) within the draft Guideline. For the purposes of this form, we have included the Recommendation number and text. Please refer to the draft Guideline itself, for the associated Good Practice Points.

You can tell us (in up to 100 words) what you like/support about particular Recommendations, or what could be improved.

PLEASE NOTE: To ensure that everyone providing feedback has the same opportunity, and to ensure that the Guideline Development Group considers all feedback equally, we will only consider feedback provided via the survey and we make no undertaking to review (and will not respond to) any further information referred to via links (e.g., weblinks, resources).

Maximum word limit: 100 words (to ensure equal opportunity, the Guideline Development Group will not read beyond 100 words).

Guiding Principles: Feedback on Recommendations

Recommendation 1

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

This needs strengthening Family-centred practice involves a partnership between parents and professionals, and is not just a matter of professionals respecting and supporting family goals etc.

(Word limit: 100 words)

Recommendation 2

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

Endorse

(Word limit: 100 words)

Recommendation 3

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

Endorse

[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.

Endorse

(Word limit: 100 words)

[Recommendation 5](#)

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

Endorse

(Word limit: 100 words)

[Recommendation 6](#)

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

Endorse

[Recommendation 7](#)

Ethical: Supports must be ethical to protect the rights of children and families.

Endorse

(Word limit: 100 words)

[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.

Endorse

(Word limit: 100 words)

[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.

Endorse

(Word limit: 100 words)

[Recommendation 10](#)

Evidence-based: Supports should reflect the best available evidence from research, evidence from clinical practice, and the preferences and unique context of each child and family.

The term 'evidence-informed' is preferable, with the term 'evidence-based' referring only to research evidence.

(Word limit: 100 words)

[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.

Endorse – but note that this is a simpler principle to apply with older child, and is trickier with young children. We recommend adding something about “involving children to the greatest extent possible”.

[Recommendation 12](#)

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

Endorse

(Word limit: 100 words)

[Recommendation 13](#)

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

Endorse – but why is the strength of the recommendation only conditional? Surely having a properly qualified and regulated workforce is essential.

[Recommendation 14](#)

Neurodiversity-affirming: Supports should be neurodiversity-affirming, embracing each child's unique understanding of other people and the world around them, and not seek to 'cure' autism.

Endorse

(Word limit: 100 words)

[Recommendation 15](#)

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

Endorse

(Word limit: 100 words)

[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.

Endorse – but why is the strength of the recommendation only conditional?

For young children, evidence supports the provision of services in “natural settings” (usually home)

For working families there needs to be more after school, evening and weekend supports offered if we are truly to engage with parents. Covid at least has made accessibility better for parents in some ways.

(Word limit: 100 words)

[Recommendation 17](#)

Coordinated: Practitioners should engage in open and regular communication with other practitioners to ensure supports are coordinated.

Endorse – but why is the strength of the recommendation only conditional?

(Word limit: 100 words)

Goal Setting: Feedback on Recommendations

Recommendation 18

Practitioners should consider goals that help the child acquire skills that promote their learning, participation and wellbeing.

Take the 'acquire skills' out of the recommendation, but keep it in the practice points. And not just acquire, but acquire, consolidate and maintain skills.

Suggested rewording: *Practitioners and parents/carers (and children as they get older) should jointly develop goals that promote learning, participation and wellbeing.*

This recommendation is appropriate for older children; for younger children, the goals should be framed in terms of building attachment, relational security, and responsive caregiving.

(Word limit: 100 words)

Recommendation 19

Practitioners should consider goals that empower parents and families to support and advocate for their child, and promote their own and their family's wellbeing.

There is so much in this recommendation that it would be better as several separate recommendations (advocacy / family wellbeing / building parental capacity).

There is not nearly enough emphasis on building parental capacity to meet child and family needs..

(Word limit: 100 words)

Recommendation 20

Practitioners should consider goals that create safe and accessible environments that support learning, participation, and wellbeing.

Some of this material (20.2 and 20.3) should be in a separate recommendation on building parental / caregiver capacity

(Word limit: 100 words)

Recommendation 21

Goals should be neurodiversity-affirming.

Endorse

(Word limit: 100 words)

Recommendation 22

The child and parents should be involved in setting goals, as well as other people, when relevant.

It is insufficient to say that parents and child should be 'involved in' setting goals; they should be the ones doing the setting. This recommendation should be changed to emphasise that services should be based on the goals that child and parents want to achieve.

(Word limit: 100 words)

Recommendation 23

In recommending goals, practitioners should consider the unique aspects of the child and the contexts in which they live.

Endorse

Consider combining this recommendation with the following one, viewing the child and family as a unit rather than separating them.

(Word limit: 100 words)

Recommendation 24

In recommending goals, practitioners should consider the unique aspects of the family and the contexts in which they live.

See comment on previous recommendation.

(Word limit: 100 words)

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.

This needs to be reframed as a process of supporting parental decision-making about goals, not a professionally-dominated process.

(Word limit: 100 words)

Recommendation 26

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

Again, this recommendation appears to be based on the assumption that the professionals are formulating the goals. There is no need for this recommendation at all if the parents and child are doing the goal-setting..

(Word limit: 100 words)

Selecting and Planning Supports: Feedback on Recommendations

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.

Endorse

(Word limit: 100 words)

Recommendation 28

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

Endorse. But note that, while we can respect sensory differences, with young children we also need to support them to become more tolerant of some of the sensory experiences they find uncomfortable.

(Word limit: 100 words)

[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.

Endorse

(Word limit: 100 words)

[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.

Subsection 30.4 should be a separate recommendation

(Word limit: 100 words)

[Recommendation 31](#)

Supports should help the child develop motor skills, maximising their ability to move in functional ways that they desire.

Endorse

(Word limit: 100 words)

[Recommendation 32](#)

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

Endorse

(Word limit: 100 words)

[Recommendation 33](#)

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

Endorse

Recommendation 34

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

Supports should do more than just empower families - there needs to be an explicit statement of the importance of actually building parental / family capacity to meet their child and family needs.

(Word limit: 100 words)

Recommendation 35

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

Endorse

(Word limit: 100 words)

Recommendation 36

The child and parents should be involved in selecting supports, as well as other people, when relevant.

Again, the idea of 'involving' the parents in selecting supports is inadequate; they should be doing the selecting..

(Word limit: 100 words)

Recommendation 37

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

The role of practitioners should be to respond to parent / child support needs and preferences with information and suggestions, not developing recommendation based on their own perspectives. This is another instance of a persistent failure in these recommendations to embody the Guiding Principles and to understand the true nature of the parent/professional partnership.

(Word limit: 100 words)

Recommendation 38

Practitioners should consider the best available research evidence when making support recommendations for the child and family.

Endorse – but note that the research evidence that supports best practice in early childhood intervention is not restricted to evidence-based strategies, but also includes evidence regarding ways of working with families, including family-centred practice etc. Perhaps reword as ‘multiple converging sources of evidence’ to better reflect contemporary conceptualisations of evidence-informed practice.

(Word limit: 100 words)

Recommendation 39

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

Re 39.3, ECI practitioners would benefit from having an evidence-informed decision-making framework that ensures that consideration of interventions and supports are not introduced until there has been a true understanding of family perspective, values and circumstances, and a collaborative identification of child and family priorities and goals.

(Word limit: 100 words)

Recommendation 40

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

Once again, the framing of this recommendation emphasises the professional as expert. It needs to be reframed as a supportive role, helping the child and parents explore how the proposed support or intervention might work etc.

(Word limit: 100 words)

[Recommendation 41](#)

People who recommend supports should have relevant qualifications and work within their scope of practice.

Endorse

(Word limit: 100 words)

[Recommendation 42](#)

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

Endorse

(Word limit: 100 words)

[Recommendation 43](#)

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

Should practitioners only be eligible for membership of their professional group, or should they be actual members (and therefore required to do ongoing professional development activities)?

(Word limit: 100 words)

Recommendation 44

Practitioners who recommend supports should have knowledge and practical skills that are directly relevant to working with autistic children and their families.

Practitioners need more than knowledge; they also need relational practice skills for effective working with families and children. This should be explicitly acknowledged and recommended.

(Word limit: 100 words)

Recommendation 45

Practitioners who recommend supports should provide the child and family with an accurate, complete, and timely plan of proposed supports.

Again, this is framed as a professionally-driven process rather than a collaborative one; the family and the practitioner should be developing the plan together, so there is no need for the professional to 'provide' the family with details of the plan .

(Word limit: 100 words)

[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 plan a particular support, they should refer the child and family to a practitioner who does.

Endorse

(Word limit: 100 words)

Delivering Supports: Feedback on Recommendations

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.

This recommendation could usefully be prefaced by a note that children develop and learn in every environment in which they spend time, and that whoever is their caretaker in that environment, whether a parent or relative or professional, needs to have the understanding and skills to ensure that the environment promotes the child's inclusion and participation, and provides them with appropriate opportunities to play, socialise and learn..

There needs to be more recognition of a preference for parents and family providing supports for young children, and families being supported in that through parent coaching and peer-to-peer support.

(Word limit: 100 words)

Recommendation 48

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

This recommendation appear to be repeating points made in earlier recommendations

(Word limit: 100 words)

[Recommendation 49](#)

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

This recommendation appear to be repeating points made in earlier recommendations

(Word limit: 100 words)

[Recommendation 50](#)

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

This recommendation appear to be repeating points made in earlier recommendations

(Word limit: 100 words)

Recommendation 51

Where another person assists a practitioner in the delivery of supports, that person must 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.

Endorse

(Word limit: 100 words)

Recommendation 52

Practitioners should support the child, people around the child, and/or changes to the environment in whatever combination is likely to lead to the most meaningful and sustained increase in the child's learning, participation, and wellbeing.

This recommendation needs to be reframed as above (comment on rec. 47).

Re 52.1. There needs to be a fuller consideration of the evidence behind the three different approaches described; the evidence does not support the use of child-directed services with young children, and this should be stated.

Re 52.2. This is framed as a professionally-driven decision-making process, rather than a parent/professional partnership. Two important additional criteria are needed – whether the form of service being proposed is acceptable to families, and whether there is evidence regarding the efficacy of the form of support being proposed with young children.

(Word limit: 100 words)

Recommendation 53

Practitioners should deliver supports in the setting(s) that are likely to lead to the most meaningful and sustained increase in the child's learning, participation, and wellbeing.

As for comment on Rec 52, the inclusion of clinical settings as an option needs to be qualified by reference to the evidence regarding the efficacy or otherwise of this setting, and the appropriateness of this form of service delivery for young children. There may be some instances where clinic-based therapy is appropriate, but these are relatively rare and most likely to apply to older children. Clinic-based therapy should certainly not be the default option, and should not be first on the list of options. Change the order to put 'home' at the top, and 'clinic' at the bottom.

(Word limit: 100 words)

Recommendation 54

Practitioners should deliver supports in the format(s) (one-on-one, in a group) that are likely to lead to the most meaningful and sustained increase in the child's learning, participation, and wellbeing.

This recommendation needs to include reference to the appropriateness of these different formats according to the age of the child.

None of the three formats discussed will be appropriate for very young children..

(Word limit: 100 words)

[Recommendation 55](#)

Practitioners should deliver supports in the mode(s) (e.g., in person, telepractice) that are likely to lead to the most meaningful and sustained increase in the child's learning, participation, and wellbeing.

Endorse

(Word limit: 100 words)

[Recommendation 56](#)

Practitioners should deliver supports in an amount and duration that is likely to lead to the most meaningful and sustained increase in the child's learning, participation, and wellbeing.

Endorse

(Word limit: 100 words)

[Recommendation 57](#)

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

Endorse

(Word limit: 100 words)

Outcomes, Quality, and Safeguarding: Feedback on Recommendations

Recommendation 58

The child, their family and the practitioner(s) should be involved in determining who will be involved in monitoring and review of supports.

Endorse

(Word limit: 100 words)

Recommendation 59

Practitioners should monitor the extent to which the supports were delivered as planned.

Endorse

(Word limit: 100 words)

Recommendation 60

Practitioners should monitor the child's and family's progress towards goals.

All of the recommendations from 60-68 should be reframed as a joint responsibility of families, child and professionals, not of professionals alone or primarily.

Recommendation 61

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

Reframe as a joint responsibility of families, child and professionals, not of professionals alone or primarily.

(Word limit: 100 words)

Recommendation 62

Practitioners should monitor the costs and benefits to the child and family of receiving the supports.

Reframe as a joint responsibility of families, child and professionals, not of professionals alone or primarily.

(Word limit: 100 words)

Recommendation 63

Practitioners should monitor for unplanned outcomes associated with the supports they deliver.

Reframe as a joint responsibility of families, child and professionals, not of professionals alone or primarily.

(Word limit: 100 words)

Recommendation 64

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

Reframe as a joint responsibility of families, child and professionals, not of professionals alone or primarily.

64.1 Monitoring should include direct report from the child..... At what age is a child reasonably expected to reflect on their progress toward a goal? Include a modifier 'As appropriate'

(Word limit: 100 words)

Recommendation 65

Practitioners should monitor progress through child observations.

Reframe as a joint responsibility of families, child and professionals, not of professionals alone or primarily.

(Word limit: 100 words)

Recommendation 66

Practitioners should monitor progress through reports from others.

Reframe as a joint responsibility of families, child and professionals, not of professionals alone or primarily.

(Word limit: 100 words)

Recommendation 67

Practitioners should monitor progress through the collection and evaluation of outcome data.

Reframe as a joint responsibility of families, child and professionals, not of professionals alone or primarily.

(Word limit: 100 words)

Recommendation 68

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

Reframe as a joint responsibility of families, child and professionals, not of professionals alone or primarily.

(Word limit: 100 words)

Recommendation 69

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

Information re progress does not need to be shared with parents if it is done collaboratively – they will have all the information already because they have been part of the process of generating it these recommendations are redundant.

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.

Information re progress does not need to be shared with parents if it is done collaboratively – they will have all the information already because they have been part of the process of generating it these recommendations are redundant.

(Word limit: 100 words)

Recommendation 71

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

Endorse – but clarify at what age a child can reasonably expected to reflect on whether to continue, change or stop supports. After what period of time? Include a modifier 'As appropriate'.

(Word limit: 100 words)

Recommendation 72

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

This should be reframed as a two-way process – the parents may be the ones who know when the service is no longer needed..

Recommendation 73

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

Endorse

(Word limit: 100 words)

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.

Endorse – but note that many therapists (particularly new grads and sole practitioners are often providing services to a range of children with a range of disabilities, and may not be “experts” in autism, or have an up to date knowledge of the effectiveness and feasibility of every condition they work with.

This is a ‘Strong’ recommendation, but similar recommendations in other parts of the document have been conditional. There is a lack of consistency throughout in the use of these strength ratings.

(Word limit: 100 words)

Recommendation 75

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

Endorse

[Recommendation 76](#)

Practitioners should have recent experience working with autistic children and their families, and engage in continuing professional development.

Endorse

(Word limit: 100 words)

[Recommendation 77](#)

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

Endorse

(Word limit: 100 words)

[Recommendation 78](#)

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

Endorse

[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.

Endorse

(Word limit: 100 words)

[Recommendation 80](#)

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

Endorse

(Word limit: 100 words)

[Recommendation 81](#)

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

Endorse

[Recommendation 82](#)

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

Endorse

(Word limit: 100 words)

[Recommendation 83](#)

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

Endorse

(Word limit: 100 words)

[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.

Endorse

SECTION 3: Other Feedback

Please provide any other feedback that you feel is important for us to consider.

Maximum word limit: 150 words (to ensure equal opportunity, the Guideline Development Group will not read beyond 150 words).

- The document is long and repetitive. We suggest combining and synthesising some of the sections and practice points to make the document more succinct and useful for practitioners.
- The recommendations tend to be framed with older children in mind. The developmental needs of very young children and the information and support needs of their families are often different. We recommend that whole Guideline be reviewed with this in mind, and revised where necessary to acknowledge these differences.
- Either provide a clearer definition of what the Strength of Recommendation means, or omit it altogether as it is confusing, and is used inconsistently throughout.
- In the Glossary, the definition of what “sensory” means should be expanded to include proprioception and interoceptive awareness.
- Child and family centred practice be included in Table 5 (p. 124) as a practice that may be more likely to lead to improvements in outcomes.

A note from the Guideline Development Group (GDG)

Thank you very much for telling us what you think about the draft Guideline. The information that you and others provide will be considered in the final version of the Guideline.

The next step for the GDG will be to read, review and consider all of the information provided. The GDG will then make the necessary amendments to the Guideline.

If you have not already done so, please register with the Autism CRC to receive updates about the guideline. You can do so here <https://www.autismcrc.com.au/supporting-children>

Before we finish, we want to take a moment to acknowledge the time it takes to complete forms like this. While we are not able to send a personal response to each person who provides feedback, please know that we genuinely value the information you have provided and will be reading every word.

Thank you for helping to make the Guideline the best it can be.

We look forward to sharing the Guideline in due course, via the Autism CRC website.

Sincerely,

David, Andrew, Hannah, Sarah, Kandice and Rhylee on behalf of the Guideline Development Group.