

29 March 2022

Level 11, 257 Collins Street
Melbourne VIC 3000
PO Box 38
Flinders Lane VIC 8009
T: (03) 8662 3300

Autism CRC
Long Pocket Precinct
The University of Queensland
80 Meiers Road
Indooroopilly QLD 4068
Submitted via online form:

https://www151.griffith.edu.au/redcap/surveys/?s=WLJ7P9R9D9&j=1060165&sfmc_sub=219168364&l=103_HTML&u=21526478&mid=7286130&jb=5007&__startover

Response to the Autism CRC consultation survey about the development of a national practice guideline for supporting the development and participation of children with autism and their families (*Supporting Children National Guideline*)

Survey Question Responses

What do you think are the three most important things that should be addressed in the guideline?

- The importance of adopting a best-practice model of care that is family-centred, culturally responsive and provides continuity of care through a collaborative, multidisciplinary team of relevant professionals who can work together to address the broad range of needs for children with autism and their families.
- Providing recommendations to guide the selection and delivery of evidence-based therapy and supports to address the child's developmental, educational and behavioural needs.
- Outlining strategies for supporting children with autism and their families that are outcomes-based and aim to build capacities and inclusion for the child with autism and holistically support the family.

What are the potential benefits of having a guideline?

- Ensuring practitioners have appropriate knowledge and expertise to provide therapy and support to children with autism and their families.
- Giving practitioners confidence to provide best practice therapy and support to encourage more practitioners, particularly psychologists, to provide services which are desperately required to address long waiting lists.
- Ensuring consistency of approach in the planning and delivery of evidence-based therapy and support services to children and their families.
- Providing guidelines about the type of therapies and supports that can be beneficial for children and their families, and the critical importance of the timing of therapies and support (e.g., early intervention, developmental milestones, significant life transitions) to reduce the cumulative effects of limited, poorly timed or inappropriate therapy and supports.
- Providing the opportunity for targeted research based on best practice approaches to supporting children and their families.
- Providing clarity about therapy that does not have an evidence-base or might be harmful.

What concerns, if any, do you have about the development of a guideline?

Guidelines and recommendations for therapy and support services for children with autism and their families will be insufficient unless they address:

- Collaboration with people with lived experience of autism and their families and supports.
- The current evidence-base to reduce the risk of harm associated with inappropriate therapy and supports.
- A collaborative multidisciplinary approach that is inclusive of a range of professionals - psychology, occupational therapy, paediatricians, speech pathologist, educators and other allied health, and medical colleagues as needed.
- The needs of families and carers.
Cultural differences that may impact therapy and support.
- Any gender-based differences in presentation, therapy and support requirements.
- The impact of comorbidities (e.g., ADHD and mental health problems).
- Older children and adolescents with autism.

How important do you think it is to understand the child, their family, and their context when making decisions about therapies and supports for children on the autism spectrum?

- Extremely important

What information do you think is most important to collect to understand the child, their family, and their context?

- A biopsychosocial framework should guide the collection of information to ensure the child's needs, strengths and interests are understood within all aspects of their life, including, for example, home-life, education, social, physical, community etc. and the place of their family within this.
- This includes collecting information about the child and family's broader community to ensure an understanding of cultural and other factors that may impact on decisions about therapy and support.
- Also need to gather information about the child (e.g., severity of symptoms and adaptive functioning of the child with autism) and family factors (e.g., understanding of autism and trajectory through life, knowledge of evidence-based treatment, family and carer health and wellbeing, safety issues, motivation, grief, support network) that can influence the likelihood of treatment success.

What would you suggest practitioners (i.e. people working directly with the child on the autism spectrum) do to ensure they understand the child, their family and their context? Provide up to three suggestions.

- Ensure adequate information is collected to provide best practice therapy for the child and support for the family.
- Employ a holistic, collaborative and multidisciplinary approach to collecting information to understand the child, their family and their context, including being culturally sensitive and responsive to specific circumstances impacting on the child and their family.
- Explore interactions between the child and their family to better understand the context within which therapies and other supports are required.

How important do you think it is to select appropriate goals for therapy when working with children on the autism spectrum and their families?

- Extremely important

Who is important to involve (e.g., child, parents, practitioners, others) in planning, selecting, and prioritising goals to support the learning and participation of children on the autism spectrum and their families?

- The child with autism.
- Family members and other carers involved in the child's care.

- Community supports where indicated, especially where there are significant cultural contexts that influence decision making or where multiple members of a community provide care and support to the child with autism and their family.
- Health and therapy practitioners.
- Schools - specifically teachers and others involved in the child's education, including learning support and school psychologists.
- Around the time of transitions, involve key people in both the current and future context e.g., transition into early childhood education and care, school, secondary school and post school education and employment.

What type of goals are likely to be relevant to supporting the learning and participation of children on the autism spectrum and their families?

Establish holistic goals that develop a sense of belonging and which address:

- Developmental functioning of the child with autism e.g., communication skills, daily living skills, psychosocial skills (e.g., social skills, friendships, emotion regulation, self-esteem), motor skills, play skills, and addressing challenging behaviours.
- Learning needs of the child with autism.
- Mental health and wellbeing needs of the child with autism.
- Contexts and settings relevant to the child and family including education settings, home, community, work, leisure etc.
- Family needs e.g., parenting/bonding, health and wellbeing, safety etc.
- Strengths and interests.

What can practitioners do to ensure appropriate goals are selected? Provide up to three suggestions.

- Multi-disciplinary assessment of the child and their current needs, strengths and interests now and into the future, especially as transition points approach.
- Multi-disciplinary assessment of the environment, including family and broader contexts including cultural considerations and significant life transitions.
- Collaborate with the child, their family, community and professional supports to ensure all fully understand the assessment results, implications and recommendations ahead of working with the child and family to identify current and future priorities/goals.

How important do you think it is to select appropriate therapies and supports when working with children on the autism spectrum and their families?

- Extremely important

Who is important to involve (e.g., parents, practitioners, the child) in selecting therapies and supports for children on the autism spectrum and their families? (If your response is the same as goal setting, please type "See previous response" here.)

- See previous response

What types of therapies and supports are relevant to supporting the learning and participation of children on the autism spectrum and their families?

- Evidence-based therapies and supports should be prompt and personalised according to prioritised goals developed on the basis of a comprehensive multidisciplinary assessment of the needs, strengths and interests of the child and family¹.
- A range of evidence-based formal treatments (e.g., psycho-education, behavioural, cognitive, social, language), community resources (e.g., education, employment support) and everyday activities can address priorities and goals for the child and family¹.
- Therapies can be categorised as²:
 - Comprehensive programs that address multiple core deficits common to autism.
 - Focal interventions address more specific goals or key features relevant to autism e.g., language delays, social skills deficits or challenging behaviours.

- Mental health interventions address concerns commonly experienced by individuals with autism not considered as core features.
- Key reviews should determine therapy programs for children and families (see ¹⁻⁵).
- Modifications, including cultural adaptations, may be required, noting that evidence about adapted therapies may be limited¹.

What can practitioners do to ensure that appropriate therapies and supports are selected? Provide up to three suggestions. If your response is the same as for goal setting, please type “See previous section”.

- See previous section, and
- Be knowledgeable about the current evidence-base relating to therapies and supports for the child with autism and their family.
- Adopt and adapt therapies and supports based on comprehensive multi-disciplinary assessment and family-centred goal planning i.e., ensure they are culturally responsive, accessible and deliver priority outcomes for children and their family.

How important do you think it is to deliver therapies and supports in ways that are appropriate for children on the autism spectrum and their families?

- Extremely important

Is there a standard amount of practitioner-delivered therapy and support that you think children on the autism spectrum should have access to? This includes therapies and supports provided directly to the child, supports provided to upskill parents/caregivers to support the child and supports to upskill other members of the community (e.g., a child’s teacher) to support the child.

- A family-centred, personalised approach is required to ensure appropriate types and adequate amounts of therapy and support is delivered, particularly as a child’s and their family’s needs may change over time and throughout various developmental stages and changes in family circumstances e.g., parental separation.
- Intensity of support should be regularly evaluated against the goals established with the child and their family, and other relevant parties (e.g., teachers), rather than increases or decreases in treatment and support determined by a “standard amount”.
- Support services for families would ideally be unlimited, as they provide the unpaid, ongoing care for the lifetime of the child in many circumstances.
- Educators also require upskilling specific to a particular child’s needs – a ‘one size fits all’ training program may not adequately address the intensive needs of a child at different transitional stages, such as entry to kindergarten, school, secondary school, as well as onset of puberty, and gaining work experience.

What is an appropriate amount of practitioner-delivered therapy and support you think that children on the autism spectrum should have access to?

- As above

In what settings do you think it is appropriate to deliver therapies and supports?

- Clinical settings
- Home
- School/educational settings
- Community and naturalistic settings, e.g., play groups, childcare facilities etc

Who is important to involve (e.g., parents, practitioners, the child) in the delivery of therapies and supports? If your response is the same as previous sections (goal setting, planning), please indicate “see previous sections” here.

- See previous section

What can practitioners do to ensure that appropriate therapies and supports are delivered? Provide up to three suggestions. If your response is the same as previous sections (goal setting, planning), please indicate “see previous sections” here.

- See previous section

How important do you think it is to monitor the delivery of therapies and supports for children on the autism spectrum and their families? This includes ensuring the goals, therapies, and supports continue to be appropriate.

- Extremely important

What aspects of therapies and supports provided, and the child and family’s experience, should be monitored by practitioners?

- All aspects of therapies and supports and the child and family’s experience should be monitored by practitioners within a multi-disciplinary, integrated and coordinated approach to the goal setting, planning and delivery of therapies and supports.
- Family and child satisfaction with goals, the practitioner’s approach, and outcomes.
- The multi-disciplinary collaborative approach to ensure it continues to address the priority needs of the child and their family.

What can practitioners do to ensure the appropriate monitoring of goals, therapies and supports? Please provide up to three suggestions.

- Formally and informally evaluate outcomes from therapies and supports in a regular and ongoing manner against original goal setting, planning and delivery, with the child and their family and other practitioners.
- Seek regular input and feedback from children with autism, their families and other relevant parties (e.g., end of session feedback).
- Maintain knowledge of best practice evidenced-based therapies and supports and ensure they are being implemented appropriately via peer review and ongoing learning and development.

How important do you think it is to ensure that the safety and wellbeing of children on the autism spectrum and their families is ensured when accessing therapies and supports?

- Extremely important

How can practitioners support the safety and wellbeing of children on the autism spectrum and their families when accessing therapies and supports?

- Ensuring that practitioners providing therapies and supports belong to a regulated workforce and work according to ethical guidelines.
- Ensuring the ‘right’ practitioner, with the appropriate qualifications, is undertaking fit-for-purpose assessment, therapies and supports.
- Ensuring practitioners refer to established guidelines for physical, functional and psychological therapies and supports which are evidence-based.
- Employ quality assurance measures and standards in the assessment, goal-setting and delivery of therapies and supports.
- Practitioners need to ensure that they are well-supported with quality professional supervision, peer support and ongoing CPD to remain up to date with evidence-based practices.
- Practitioners should have ongoing conversations with the family of the child with autism about issues relating to their safety and wellbeing when accessing therapies and supports.

Please describe any risks you see for children and families in accessing therapies and supports.

- Families may be vulnerable to unproven claims about treatments that are not evidence-based.
- Stigma, discrimination or limited knowledge of services and supports may be a barrier to families seeking timely and appropriate help for their child.

- Professionals may lack of understanding and/or sensitivity to cultural contexts for children and their families and how this may impact on the approach required to ensure appropriate therapies and supports.
- Substandard assessment, goal setting, and delivery of therapies and supports resulting in inadequate or inappropriate therapies and supports and poor outcomes.
- Inadequate funding and availability of services to ensure appropriate and timely therapy and support for children and their families.

Please provide any final comments below.

- There is a need for services to be coordinated to ensure safe and timely care. It can be very stressful for families to manage accessing therapy and supports if the child or young person does not qualify for funded supports e.g., NDIS.
- Consensus appears to be that the most favourable outcomes for individuals with autism occur when intervention commences early (before the age of 5 years) with frequency and intensity dependent on individual needs. This does not mean that therapy and supports for younger children should be prioritised over older children and adolescents. Greater intensity might be required for those with more profound and pervasive delays^{2,3}.
- In the interests of brevity, our responses to the survey refer to autism (rather than autism spectrum disorder) and use person-first language i.e., children with autism. We are aware of the importance of language and suggest that the community of children with autism and their families are best placed to decide what language they prefer.
- We highly recommend the guidelines be developed with reference to the most current resources based on an extensive review of the literature. Below are examples that have informed our responses to this survey:

References

1. Lord, C., Charman, T., Havdahl, A., Carbone, P., Anagnostou, E., Boyd, B., Carr, T., De Vries, P. J., Dissanayake, C., & Divan, G. (2022). The Lancet Commission on the future of care and clinical research in autism. *The Lancet*, 399(10321), 271–334.
2. Australian Psychological Society (APS). (2021). *Autism Spectrum Disorder (ASD) practice guide*. APS. <https://psychology.org.au/>
3. Prior, M., & Roberts, J. (n.d.). *The Early Intervention for children with Autism Spectrum Disorders: 'Guidelines for Good Practice'*. <https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/early-intervention-for-children-with-autism-spectrum-disorders-guidelines-for-good-practice-2012>
4. Australian Government, Department of Social Services. (2011). *Early interventions table (Helping Children with Autism (HCWA) Package)*. <https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/early-interventions-table>
5. Prior, M., Roberts, J. M., Rodger, S., Williams, K., & Sutherland, R. (2011). A review of the research to identify the most effective models of practice in early intervention for children with autism spectrum disorders. *Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA)*. Australia.

Kind regards,

Dr Zena Burgess, FAPS FAICD

Chief Executive Officer

Australian Psychological Society

The APS would like to acknowledge and sincerely thank the members who so kindly contributed their time, knowledge, experience and evidence-based research to this submission.