



NATIONAL DISABILITY INSURANCE AGENCY

Interventions for children on the autism spectrum

Submission from:

Scope (Aust) Ltd

Interventions for children on the autism spectrum

Introduction

About Scope

Scope (Aust) Ltd (Scope) is a leading provider of services to people with disability in Victoria, and one of the largest not-for-profit organisations in Australia. Our origins stretch back to 1948, when a group of parents who wanted better lives and opportunities for their children with disability established the Spastic Children's Society of Victoria.

Scope is today one of the largest not-for-profit disability service providers in Australia, supporting more than 7,000 people with complex intellectual, neurological, physical and multiple disabilities.

Scope's mission is to enable each person we support to live as an empowered and equal citizen.

Scope provides services including Supported Independent Living, Short Term Accommodation, Therapy and Lifestyle options across metropolitan and regional Victoria. Scope also works with corporate and community organisations to improve inclusiveness for people with disability.

Our response

Scope welcomes the opportunity to respond to the Interventions for children on the autism spectrum consultation paper, which builds on the independent research commissioned by the NDIA from the Autism Cooperative Research Centre (CRC) and released in November 2020. This research also provides a comprehensive review of existing evidence of early interventions available for children with autism.

We have responded to all of the consultation questions. The authors of this submission are senior allied health practitioners with considerable experience of supporting children on the autism spectrum

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Promoting best practice

1. *Which of these would you use to find information about choosing and accessing best practice interventions (or services) for children on the autism spectrum?*

- *NDIS website*
- *NDIS Operational guidelines*
- *Participant decision making guides (not yet developed)*
- *My usual NDIS or NDIS partner contact*
- *Autism organisations or peak bodies*
- *None of these*

As a provider of Capacity Building supports, we would use clinical reasoning, professional judgement, clinical assessments, professional journals, online literature libraries, peers and professional support and development.

Best practice interventions (or services) are individualised, based on ongoing assessment and collaborative planning with the child and family and recognise their unique needs.

2. *Where else would you like to find information about accessing best practice interventions (or services) for children on the autism spectrum?*

The CRC report highlights the need for additional and quality research of the interventions used with children on the autism spectrum and we hope the NDIA will contribute to further research.

We recommend there is a clear distinction made between the functions performed by the NDIA and the actions stemming from research that involves the Agency to avoid any perceived conflict of interest.

3. *Holistic planning is a part of the proposed funding framework for early intervention for children on the autism spectrum. A description of "holistic planning" is included in Section 7.4. How can we help families to find and connect with other supports outside of NDIS?*

Families are assisted to find and connect with other supports outside of the NDIS through thorough and holistic planning alongside a trusted early intervention professional. Providers of quality early intervention services embrace family centred practice and use family and child planning to guide the family to identify

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opportunities for gains in functional skills and to strengthen the child and family's community connection and participation. With the introduction of the NDIS we have observed a regression to single therapies, which cannot replace quality early intervention services with the inherent building of the team around the child and family.

Effective planning with families builds on the strengths of the child, family, and local community. This planning supports the harnessing of a suite of supports available to the child and family, while building their capacity to navigate and to be successful in different settings and relationships.

Effective planning is progressive. Holistic planning cannot be achieved from a single initial assessment. Effective planning requires disclosure and reflection, and this requires trust and confidence in the practitioner. It is not reasonable to assume this relationship can be achieved through a single, initial assessment.

Effective planning also requires the setting of meaningful and measurable goals. Breaking down the broader goals set with NDIA, and reflecting on the achievement of shorter-term goals, helps to build hope and confidence.

The functional capacity of the child is central to successful planning and using the child's age or life stage as a measure of the support they require is simplistic and does not support better outcomes.

Individualised and holistic planning is essential to meet the unique needs of each child, family, support network and community. Access to suitable early intervention is variable across a region, state or nationally and requires leadership and resourcing to give families information and choice to access these services.

We recommend the development and release of resources, including clear standards to support holistic planning with families, alongside information identifying the risks of medical style single therapies.

Reasonable and necessary

4. Building from the Autism CRC research the consultation paper outlines specific principles that the NDIS considers as early intervention best practice for young children on the autism spectrum (Section 6.1.) Is there anything you would like to add?

Best practice early intervention is universal for all children and families and we do not support separate frameworks for children with selected diagnoses.

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We note the consultation paper refers to early intervention being for children under 13 years. Diagnostic services for children are very limited and costly and some children do not receive a diagnosis of autism spectrum until they are much older, giving them limited access to services in the early years. There should not be an assumption that intensive supports are available to all children at an early stage.

We support the principle of Individual and Family-Centred services. This is the keystone of early childhood intervention and has worldwide support.

From the CRC paper, we support the principle of Lifespan Perspective while recognising that the appropriateness of interventions over a life-course is individual and dependent on many factors, including age at diagnosis, access to appropriate services, family and community strengths and opportunities.

We support the principle of being evidence-based and endorse the importance of practice-based evidence and of effective planning and goal setting. There is a need for appropriate research of therapeutic interventions more broadly and we support collection of data by the NDIA to support this.

Our feedback on the seven key principles presented as being best practice for children under 13 years on the autism spectrum is outlined below:

1. The intervention is based on a good understanding of autism.

The examples provided are not aligned to the stated principle. We recommend amendment as follows: "The intervention is based on current knowledge of the autism spectrum".

2. The people who deliver the intervention know the person well and respect their feelings and views.

- Agreed. Interventions (services) should be suitable and delivered with sensitivity and respect.
- All professional codes mirror this principle.
- This principle supports the need for ongoing assessment alongside collaborative planning of goals and interventions.
- To achieve greater clarity and objectivity, we suggest this principle be amended to: Services should always be planned and delivered in partnership with the child and their family.
- Continuity of service is important, but it cannot always be achieved given the current shortage of qualified practitioners.
- Services delivered as a team will help to achieve continuity of support.

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3. The intervention is adapted to the needs of the person receiving it.
 - This principle seems to be unnecessary. All interventions are selected and continuously adjusted and individualised to meet the needs and goals.
 - It is not clear how an intervention would be assessed against this principle and therefore ask if this principle is useful.
4. The intervention is based on a theory that is logical and scientifically plausible.
 - The example of homeopathy in the paper is not relevant in this context.
 - By limiting service delivery to registered and accredited practitioners, services will be delivered based on the best available evidence and the needs of the child and family.
 - The inclusion of clinical reasoning, goals and strategies in the outcome review reports will identify interventions that do not meet this principle.
5. The intervention works in the real world, not just in a research laboratory.
 - Services are delivered in the real world and always with the child, family, and community, therefore we believe this principle is unnecessary.
 - Outcome review reports and shared intervention plans outline the selected interventions, their implementation, and outcomes – relative to specific goals.
6. Research evidence shows the intervention can work for people on the autism spectrum.
 - All interventions are selected on the best available evidence. The CRC research shows the gaps in evidence therefore many interventions cannot be supported by research evidence for people on the autism spectrum.
 - Regular and consistent review of individual goals and the reporting of progress supports the assessment of what is reasonable and necessary.
7. The intervention supports mainstream and community participation.
 - Agreed. This principle is most important and could be numbered "1".
 - Successful participation in mainstream and community settings is supported by interventions in these settings, which requires adequate funding for provider travel.

5. *Building from the Autism CRC research the consultation paper outlines specific standards that the NDIS considers as early intervention best practice for children on the autism spectrum (Section 6.2.) Is there anything you would like to add?*

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Our responses to the standards in the consultation paper are outlined below:

1. The intervention is delivered by, or supported by, appropriately qualified and experienced professionals.
 - The comment '...professionals have an appropriate level of experience, that is, they have actually worked successfully with children on the autism spectrum' can be interpreted literally so that new graduate practitioners will not be able to work with children on the autism spectrum as most will have had limited or zero experience on their clinical placements. This presents a serious threat to the future workforce to deliver services to people on the autism spectrum.
 - We are acutely aware of the lack of qualified practitioners, and we expect this will continue for the foreseeable future.
 - It is important to acknowledge that less experienced practitioners and Allied Health Assistants, with appropriate supports from experienced practitioner, will be part of the workforce solution moving forward.
2. The people delivering the intervention follow established guidance.
 - The term established guidance is unclear. Only a limited range of interventions are packaged with a user-manual therefore this standard may mislead parents.
 - Most interventions are delivered using current practices and best available evidence.
 - Collaborative planning, goal setting and evaluation with families, alongside best available evidence and practitioner skills and knowledge is the established guidance.
3. The intervention provides significant and lasting benefits.
 - This standard also highlights the importance of setting clear goals and the shared evaluation and reporting of progress.
 - Defining and assessing for a significant benefit is very individual and will be influenced by co-morbidities and environmental factors.
 - Achieving slow progress does not mean this progress is not of significant benefit to a child and therefore this standard may be seen as subjective.
 - Many children on the autism spectrum take many years to develop the foundational learning skills that allow them to benefit from interventions and this may not be until school age.
 - It is unclear in this standard, how and who will assess the significance of the benefits.

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4. The intervention is carefully monitored and reviewed on a regular basis.
 - Agreed. The regular and consistent review of interventions against agreed goals is essential.
 - From this section of the consultation paper, we would like to note that Augmentative and Alternative Communication (AAC) apps are not 'therapy' and should not be considered as such. They provide communication for the child and should not be considered screen-time. Intervention would teach the child and family to use the communication app correctly and successfully.
5. The intervention does not cause **significant** physical or emotional harm.
 - This standard is difficult to reconcile. An intervention should not cause physical or emotional harm. Is it necessary to include this standard for parents?
 - We note the CRC research include very little information on adverse effects of interventions.
6. The benefits outweigh any costs (including risks).
 - It is unreasonable to base a standard around what cannot be predicted. We suggest this standard be removed or amended to: Interventions do not contribute to child or family stress.
 - Standards 3 and 7 give sufficient reference to benefit and value.
7. The intervention is good value for money and time invested.
 - We note the consultation paper is not clear what period the recommended 20 hours references (week, month, year, etc).
 - We suggest the deletion of the word good as it is not meaningful.
 - The intent of this standard is consistent with the principles of the NDIA, and we suggest it be changed to: The intervention offers value for money and time invested.

6. *"Reasonable and necessary" is a term from our legislation. Appendix one of the consultation paper includes case studies which might be used to explain reasonable and necessary. Do these case studies help you to understand what we mean by "reasonable and necessary"?*

We find the case studies as examples of reasonable and necessary to be over complicated with too much detail and inconsistent structure. As written, many readers will find the case studies difficult to read and interpret. There is a risk the

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reference to funding Levels will be confused with the levels of severity used in the DSM IV diagnostic criteria (Levels 1-3).

- Case study *Jenny* – there is insufficient information to assess if it is reasonable to ask Jenny's family to support Jenny in the swimming lessons. It may not be reasonable if there are other young children in the family and highlights the need to assess all requests against the individual situation.
- Case study *Aron* – high functioning Autism is not recognised. Aron's anxiety is linked to his disability. Children with autism spectrum have a desire for sameness and have difficulties with change. It is not appropriate that parents must use a Medicare plan to access support for this.
- Case study *Jackie* – we support the intended message in this Case Study: opportunities to practice and learn skills are available across the day, week, and settings. Jackie's parents would benefit from access to accurate clinical evidence to contradict the idea that 20 hours of paid support is required each week.

7. Do you have any other feedback about how we explain "reasonable and necessary?"

- Using historical funding arrangements to inform a funding framework for children on the autism spectrum may paint an inaccurate picture. In Victoria, children on the autism spectrum were able to access the \$12,000 HCWA package (with unchanged value since 2011) and block funded early childhood intervention. The block funding was flexibly allocated based on child and family priorities, need and choice. Intervention plans were developed in partnership with families through the lens of reasonable and necessary.
- The CRC research highlights multiple gaps in evidence supporting interventions. The analysis by CRC is at a broad level and does not recommend services on an individual level. Interventions for an individual should be selected using the best available evidence, including clinical practice, as well as child and family preferences and priorities, alongside the reasonable and necessary requirement.
- Despite referencing evidence-based interventions throughout the consultation paper, we note there is no evidence cited supporting the claim that many children will benefit from short term interventions. We support early intervention that gives families information and helps them to connect to community resources, but this cannot replace interventions that address specific developmental skills. It is most important that appropriate child and

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family supports are in place from the earliest age that facilitates stimulation and experiences (prior to age 3 years) to promote brain development and skill acquisition.¹

- A diagnosis of autism spectrum is only made when there is a severe and pervasive impact on functional capacity. There should be no need for a 'wait and see' or short-term approach.
- We understand access to adequate short term early intervention is variable across geographical areas and, therefore, is not an acceptable alternative to ongoing services.
- The example of a child being offered a second year of short-term support if they develop more severe and persistent functional impacts is concerning. There is clear evidence that the short-term supports are not providing significant and lasting benefits and therefore needs to be changed.
- The sentence 'This includes the type and level of early intervention supports...' (Page 17): The word 'type' suggests parents may have limited choice and control in choosing the supports they want their child to access.
- The example that the NDIA will not fund two speech pathologists is not ideal. (Page 19). The introduction of different foods is a specialist area that requires additional training. We believe it is reasonable for two practitioners to support the same goal where there is communication between the practitioners. The specialist practitioner can build the capacity of the local practitioner and the family using a consultative approach.
- We agree supports should only be delivered by qualified and accredited practitioners, while also recognising the benefits and effectiveness of transdisciplinary or collaborative approaches. The example describing speech and language interventions being delivered by another person may be confusing for parents. For example, services may be delivered by a speech pathology student or an occupational therapist, but the interventions are developed and supervised by a speech pathologist.²
- The fifth point on Page 19 is unclear. Does it mean that NDIA will not pay for supports if the child is withdrawn from educational settings to receive supports? Some parents do choose to withdraw their child from school for appointments with allied health practitioners if they cannot attend or if there are no available appointments before or after school. Capacity building supports are delivered during school hours if it is not possible or reasonable

¹ www.aedc.gov.au/resources/detail/brain-development-in-children

² <https://www.ndis.gov.au/providers/working-provider/allied-health-providers/allied-health-practitioner-students-and-provisional-psychologists>

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to deliver them in the school environment, the availability of services after school is limited, or the child has social or sporting commitments after school.

- We support the allocation of fair and equitable budgets that are linked to each child's functional needs, alongside family priorities and needs. We expect plan utilisation is impacted by thin markets or lack of available service providers.
- We hope that families will be provided fair and equitable access to services with distribution of resources based on functional need, rather than family self-advocacy ability, which discriminates against those with disadvantage. It follows that we support a focus on reasonable and necessary service provision based on holistic planning, looking at available informal supports and family resources. There is significant research to support this approach and it is important that there is recognition that the supports available to families in community are a vital component of the holistic supports and that these too must be resourced adequately.
- Reasonable and necessary supports for children with developmental delay and disabilities should only be assessed on an individual basis and in the context of their family and community.
- We endorse the principle that NDIA should not fund a mainstream or routine family expense and recommend families be provided with clear information about what services or supports are and are not funded by the NDIA. We recommend close monitoring by NDIA of funding claims, intervention plans and outcome reports.
- It is our understanding that a child older than 7 years and diagnosed with autism spectrum Severity Level 2 or 3 has access to one NDIS plan and if less than 7 years, they would certainly be eligible to early intervention supports if they present with severe and persistent functional impacts.

8. *Table 2 (0-6 years) and Table 3 (7-12 years) are an example of how we might explain Indicative level of funded support for children on the autism spectrum (Section 7.5.) Do these table/s clearly explain the indicative levels of funded supports?*

- Having a funding framework for children on the autism spectrum appears discriminatory and denies the human right to equitable supports.
- The proposed funding levels appear simplistic and it is not clear how they sit with the proposed standards and principles in the consultation paper.
- The CRC paper highlighted a lack of high-quality research as evidence supporting different types of interventions. We cannot see the link between the available evidence and the use of the funding levels presented.

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- The spectrum of autism makes it difficult to apply a framework to any group of children and families.
- We note there is a risk the reference to funding Levels will be confused with the levels of severity used in the DSM IV diagnostic criteria (Levels 1-3).
- Is NDIA proposing additional allowances to support provider travel, funded time to collaborate with other providers and mainstream supports?
- We observe duplication of services between providers of NDIS funded supports and education funded services. This does not mean a child needs less NDIS capacity building supports when they commence school, it highlights the need for joint planning, communication, and clear areas of responsibility.

9. *Do you have any other feedback about how we explain the indicative levels of funded supports?*

- The indicative levels of funded supports appear to be in conflict with choice and control and improved flexibility in how a plan is used.
- We welcome increased transparency of plan budget decisions but believe the use and communication of a funding framework will contribute to family stress. The focus must remain on the functional needs of each child and the supports, needs and priorities available to the child and family.
- The scenario presented as Level 1 in Tables 2 and 3 is inappropriate. A high area of need with language and communication would not be related to rate, rhythm and pitch of their speech. A high area of need would be a child who is minimally verbal and needs to learn to use an alternative form of communication. This requires intensive and ongoing support, not intervention for 6-12 weeks and then fortnightly visits.
- The scenarios used in Tables 2 and 3 suggest the use of high intensity interventions for 6-12 weeks. Page 98 of the CRC paper states: "The current research literature does not provide clear information on this minimum or maximum amount, nor how this is distributed in terms of intensity (e.g., hours/week) and total duration of the intervention program." Practitioners with a good understanding of the child, family and community are best placed to recommend the amount and intensity of support.
- We estimate many families will be unable to engage in high intensity support.
- The example of plans across years in the Appendix (Page 38) presents the development of children with autism as linear. It would be helpful to present the evidence to support this assumption.

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10. There may be situations where families or carers need extra NDIS supports such as during first plans, or where plans reduce in value due to the impact of mainstream services. What do we need to consider in those situations?

- Plans should be tailored to the child, family and community and consider evidence of goal achievements, supports used and the best available clinical evidence.
- The utilisation of previous Plans and access to suitable providers is an important consideration.
- Recent progress towards planned outcome and recommendations from current providers.
- Significant changes to family structure or available informal supports as this will impact capacity to implement interventions and may directly change a child's performance or participation.
- Changes in child functioning or behaviour and possible causal factors.
- Be clear in any communication that it is time limited or requires a timely response.

Supporting parents and carers to exercise choice and control

11. We want to support children and parents with implementing plans using the Autism CRC research and best practice. In Section 8.2 there is a suggested list of questions for parents and carers. These can be used to understand the best intervention for a child and their family and how a provider is delivering an intervention. Are these questions helpful for parents and carers when selecting providers?

- Yes. Add additional questions to cater for less experienced practitioners: Add to Q.2: What kind of support do you get to deliver this intervention?
- Add to Q.3: What improvements do you expect to see in children using this intervention?
- Add Q. 7. Does my child and family have the time and energy to participate fully in the intervention?
- Add Q. 8. How will I help my child to use the strategies in everyday life?

12. What other guidance or tools do families need to feel confident to implement plans in line with the Autism CRC research and best practice?

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- Families need to be involved in developing a family service and support plan (0-6 years) and an intervention plan (7+ years). These plans should link to the NDIS plan (and the broader goals) and be jointly reviewed and documented at agreed intervals.
- Some information about goal setting may be helpful. This would include guidance in selecting goals, measurement, and timelines, and agreed strategies.

Conflicts of interest

13. This question relates to Section 8.3 of this paper: "Addressing conflicts of interest." How can we support families and carers to feel confident to make decisions about what is in the best interest of the child and family?

- Have goal-setting tools to help families be confident they have selected the most appropriate goals and they have a clear view of their strengths, resources, and opportunities.
- Supporting access to evidence (or lack of evidence) for specific interventions.
- Supporting the active selection of a provider based on the answers to questions above (question 12).
- Suggest families ask for references from other participant families.
- Current workforce recruitment issues mean high demand for providers so less participant choice. Most providers are ethical and manage conflict of interest through active planning with families and provision of information.
- NDIA's early year partners and local area coordinators can assist by giving information to families and by facilitating local networks of providers and participants.

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Scope recommendations

There is a clear distinction made between the functions performed by the NDIA and the actions stemming from research that involves the Agency to avoid any perceived conflict of interest.

Develop and release resources, including clear standards to support holistic planning with families, alongside information identifying the risks of medical style single therapies.

The key principle that "the intervention is based on a good understanding of autism" be amended to "the intervention is based on current knowledge of the autism spectrum".

For greater clarity and objectivity, the key principle that "the people who deliver the intervention know the person well and respect their feelings and views" be amended to "services should always be planned and delivered in partnership with the child and their family".

Either remove the standard that "the benefits outweigh any costs (including risks): or amend to "interventions do not contribute to child or family stress".

Amend the standard that "the intervention is good value for money and time invested" to "the intervention offers value for money and time invested".

Families be provided with clear information about what services or supports are and are not funded by the NDIA

Recommendations are also made in answer to Questions 10-13.