

Best practice interventions for children on the autism spectrum

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

Potentially, NDIS Operational Guidelines or Autism orgs / peaks if they were to promote a whole of family approach.

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

The above list does not address whole family support. All family members are affected by autism and all family members can contribute to the long-term wellbeing, social inclusion, and safety of a child/adult with autism. None of the above provide info on best practice interventions for families in spite of their importance so I would say I would like to see family support addressed somewhere.

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?

It is encouraging to see the NDIS talk about ‘holistic planning’ and to suggest that this ‘considers the full environment of the child and family which includes all of the supports that are available to the child and family. All early childhood intervention supports must be connected and interrelated to the child’s life and in the context of the families/care giver role’. However, it is disappointing that this paper does not consider fully the environment of the child/family. It overlooks both the contributions and needs of siblings, despite them likely having the longest relationship of all with the child/adult on the autism spectrum.

Holistic planning is only one part of the proposed funding framework for early intervention for children on the spectrum and their families. It is important to consider them all.

Evidence

The paper states that it is important to ‘continue to understand and grow evidence-based research and gather the appropriate data to improve our knowledge and understanding of best practice and support for children on the autism spectrum and their families.’ This paper nor the CRC research report discusses at all the research needed to understand best practice for families, including siblings, whether through the NDIS or outside the scheme. This must be included in future planning. At the very least there should be research to further understand the barriers and enhancers of sibling relationships. This should be done in conjunction with agencies that have the experience and expertise related to whole family, especially, sibling support.

Holistic planning

Holistic planning ‘considers the full environment of the child and family which includes all of the supports that are available to the child and family. All early childhood intervention supports must be connected and interrelated to the child’s life and in the context of the families/care giver role.... Holistic plans will include connections to health and early education services, outline the types of interventions, the role of all professionals and the family, care givers and support for all settings (for example centre based, home based, natural settings).’ There needs to be much more understanding of what these interventions look like and where they will be accessed. What does holistic planning look like in relation to the sibling relationship? The

first thing is to acknowledge siblings, the impact of the disability on them, and their possible contributions, and to ensure capacity building supports are accessible for them. For further discussion, especially in regard the ECEI space refer to the following submission, <http://siblingsaustralia.org.au/wp-content/uploads/2021/03/ECEI-reset-submission-23-Feb.pdf>

Outcome's focus

The paper states that 'Early intervention is all about giving children with disability, and their families, supports to enable the child to have the best possible start in life. Through early intervention children, their families, can get specialised supports and services. These services aim to promote the child's development, the family and child's wellbeing, and the child's participation in their community. We know that early childhood years are critical. They set the foundations for how children learn and develop. We want to support children and their families early to improve their outcomes later in life and reduce dependence on professional supports in the longer term.'

What data is available regarding outcomes for the whole family? Does the NDIS understand the impact and possible contributions of siblings? Does it understand the barriers/enhancers to sibling relationships? The paper refers to families as being key supporters in a child's life but focuses much more on the child developing friendships outside the family and being part of the community rather than considering relationships with siblings.

The paper also says that 'As children and families develop new skills and functional ability, their need for supports will generally decrease.' Certainly, if families, including siblings, can develop new skills in interacting with their brother or sister on the spectrum, they will be more able to support the child to experience inclusion, which may lead to a reduction in NDIS supports needed in the longer term. However, what are these skills and how will siblings learn them? And where will they access them? Siblings Australia would have much to offer the NDIS in this area.

The paper also says that 'Early intervention approaches are designed to build capacity for both the child and the family. In a child's first NDIS plan, capacity building supports will typically be higher in recognition of the importance of this early investment. Initially early intervention will focus on supporting families to understand their child's disability and get to know the child's strengths and interests.' Again, siblings are an important part of this process and outcomes for siblings need to be measured along with other family members.

Lifespan approach

A lifespan perspective and family centred approach is best practice in early intervention. This is particularly relevant to the relationship between siblings. If a sibling is supported to develop a stronger relationship with a brother or sister on the autism spectrum it is more likely they will remain in each other's lives. This might be for a period of upwards of 70 years. No other relationship will be potentially more important.

In summary we need to consider siblings in a meaningful way before we can discuss how to help families connect with relevant services outside the NDIS.

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?

It is alarming that the principles included in section 6.1 of the consultation paper do not include any mention of families and/or siblings. The principles should include a 'whole family' approach.

Various current policy directions within the NDIS and beyond recognise the need to build on family strengths in order to improve a child's development and wellbeing.

The recent [ECEI approach reset](#) acknowledges the 'early years as important in a child's development and supports children with developmental delay, disability, and their **families** to achieve their best outcomes'. (emphases added)

One important recommendation (17) is to introduce a ‘capacity building support in natural settings’ item in the NDIS Price Guide to encourage **families** and early childhood providers to prioritise supports delivered at home or other natural settings.

The Reimagine Early Childhood National Action Plan to 2030 (Action Plan) aims to ‘support the development of children, optimise social and economic outcomes for children from birth to six years with developmental delay or disability **and support their families in a broad range of evidence-informed and innovative approaches**’.

*Children live and thrive in the context of their families.... **Family is an essential support system in the child's life.***

*What is required is an ecosystem that is designed upon a **whole-of-family approach** and that is centred around **family capacity building and family goals**, as well as parents and **sibling goals**.*

*A **family-centred** approach, rather than only a child-centred plan and approach in the early childhood years would ensure the entire family unit is viewed and supported as a whole, rather than in select parts.*

*Importantly, outcomes for children would be outcomes for the **whole family**, which would drive early childhood development services and supports to wrap-around the whole, rather than the individual.*

*A central priority of the Action Plan is that parents and caregivers have access to a system *designed and delivered through the lens of the development and wellbeing of their **whole family***, which will enable *optimised outcomes for families and their children*.*

The Early Childhood Early Intervention (ECEI) Implementation Reset Project Consultation Report National Disability Insurance Agency (NDIA) November 2020 emphasised ‘the importance of equipping others in *the child's life such as family, carers and educators who make up their environment*’. It also developed national **guidelines for best practice** in early childhood intervention. These guidelines distil three key quality areas of best practice: **Family**, Inclusion, and Teamwork and align closely with international guidelines. In terms of family they recommend ‘*Intervention strategies focused on the **family** and/or caregivers is the foundational principle of best practice. Family-centred, strengths-based practice recognises the **whole family as the ‘client’ of ECI services**, and further recognises the family as an intervention unit*’.

*Family-centred practice considers family strengths, specificities of family life and family priorities to shape interventions. This also recognises the critical role of the **family** as change agents in children's lives, and their ability to shape outcomes.* It should be noted that the CRC research report on interventions for children with autism lists siblings as ‘agents’ on a number of occasions.

Furthermore, ‘*Inclusive practice centres the child's right to participate in their **family** and community as other children would so that they can live an ‘ordinary life’.* Children with disability and/or developmental delay may have additional needs that should be recognised and met in the supports that they need.

If a broader view is taken, in relation to the NDIA Act, one of the aims listed under the ‘purpose of the NDIS’ is to:

- *facilitate the development of a nationally consistent approach that provides support to eligible Australians, ensuring that people with disability and their families (emphasis added) get the support they need when they need it.*

The General Principles of the Act include:

- *the role of **families**, carers and other significant persons in the lives of people with disability is to be acknowledged and respected (section 4(12));*
- *the supportive **relationships**, friendships, and connections with others of people with disability should be recognised (section 5(e)).*

In addition, the NDIS Practice Standards (Early Childhood Supports Module) apply to NDIS providers who are registered to provide early childhood supports to NDIS participants. These standards also include a focus on the active involvement of the participant's support network in the participant's development. They include:

- *The strengths of the **family** are promoted and developed*
This might include the family, including siblings, being given the skills to develop their own strength but also to contribute to the development of the child with autism
- *Appropriate information, knowledge, skills and expertise are in place to deliver quality supports to **families**.*
This must include the whole family, including siblings.

- *The capacity of the child, **family** and collaborating providers involved with the child is built through coaching, capacity building supports and collaborative teamwork.*
Again, this must include each member of the family
- *Feedback and learnings from the child, **family** and other professionals is used to improve support delivery*
Siblings might have useful insights, knowledge themselves to feed into this process

And finally, the [Tune Review](#) emphasised the need to build capacity in families, the government has reiterated that, ‘*The NDIA has an important role to assist **families** and carers of people with disability to identify, and in turn engage with or strengthen the **natural relationships** that exist within their home and community.*’

Again, it is concerning that the principles do not reflect any of the above.

Siblings will likely have the longest relationship of any with the child/adult with disability. They also face their own challenges/stresses which can make them more vulnerable to mental and physical health issues. To be able to develop a ‘good life’ for themselves and contribute to a ‘good life’ for their brother or sister they need capacity building activities. These principles must include some reference to the importance of whole families – a child does not stand alone, and external therapists might provide all the best intervention in the world but without a strong family the benefits are likely to be limited and short term.

Section 6.1.2 states that ‘People who deliver an intervention (professional) should know the person they are working with well – because every person on the autism spectrum is different. People delivering an intervention should work very closely with the child/families as equal partners.’ It misses the mark by not saying that people delivering an intervention should value the knowledge of each family member. Also, in 6.1.6 it states, ‘Caregiver involvement in an intervention has a similar, and at times greater, effect on child outcomes compared to interventions delivered by clinical practitioners alone.’ This is a true statement except it should say ‘family involvement’ and furthermore, this involvement is more likely to occur if each family member is supported.

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?

Again, as in question 4, these standards should include a ‘whole family’ approach if interventions are going to be ‘best practice’ for the child on the autism spectrum.

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”?

The NDIS acknowledges ‘the breadth of the spectrum and its impacts on individuals and their **families**’. But it seems that in this consultation paper siblings are not included in that definition. The case studies provided do not assist at all in understanding ‘reasonable and necessary’. They, and the whole paper, completely overlook siblings (apart from what seems a photo of siblings on the cover) – a significant missed opportunity. There are very few families which do not include other children besides the child(ren) with autism and so this is a very unrepresentative sample.

The emphasis seems to be much more on strengthening relationships external to the family, whilst overlooking these crucial relationships. Siblings might be mentors, prompters, teachers, playmates etc. The Autism CRC report emphasised the importance of peer support in best practice for a child with autism. What better peers are there than siblings? The report also mentioned siblings as ‘agents’ on several occasions. Siblings might be mentors, prompters, teachers, playmates etc. Siblings can add to the wellbeing of, and enable social inclusion for, a child and later adult, with autism. But they need assistance to be able to do these things. Again, it is a pity that this consultation paper does not recognise this at all.

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

The idea of ‘reasonable and necessary’ is explained in an adequate manner but the examples used in case studies and elsewhere do not consider the importance of the whole family, including siblings and the relationship they have over a lifetime with the PWD. This is a major oversight.

Of course, the NDIS should not fund supports that are the role and purpose of other funded systems or what is reasonable to expect families, carers, informal networks, and community to provide (NDIS Act s.35 and s.36). The NDIS should fund supports that meet certain criteria, e.g., the support is related to the disability, will help a PWD to pursue goals and aspirations, will increase social and economic participation, is value for money, is likely to be effective and beneficial, and complements informal supports.

There seems to be hesitancy on the part of the NDIS to acknowledge siblings. Maybe there is a fear that sibling support might represent a ‘slippery slope’. However, it is important to apply the notion of ‘reasonable and necessary’ to sibling support too. Another criterion in determining whether the support should come from the NDIS or elsewhere, might be whether it benefits the person with disability directly. For example, a sibling might not be able to attend extra-curricular activities due to the parent being too time poor due to the needs of the child with disability. Is this impact on the sibling related to the disability? Yes, it is. However, the sibling’s attendance at these activities should be supported elsewhere, e.g., from the sibling’s school or other community groups to ensure they can attend sport or music.

On the other hand, there will be supports that a sibling needs that should come via the NDIS. For example, a child with autism may not respond to a sibling and the sibling, in turn, may switch off trying to engage. Or there might be other confusing or stressful behaviours. Is it reasonable to expect that a 5-year-old will manage their responses to the stress around them or understand the behaviours of their brother or sister on the autism spectrum without some intervention?

If a sibling could access capacity building supports to understand themselves better, as well as the child on the autism spectrum, to learn how to engage more effectively, to understand how to respond to friends who may then respond in a kinder way to the child with autism, what a difference the trajectory might be for the child with autism over a lifetime. If the sibling is not supported, they might develop a range of feelings like grief, guilt, resentment, isolation, and confusion, leading to their own mental health problems. They might, as a result, disengage with their family and, eventually, move away from the family. This can result in a person with autism having poor wellbeing, being social isolated and vulnerable to harm.

A small investment early, with parents and siblings, to build capacity and improve family functioning would be of huge benefit over a lifetime for the whole family, but especially the child on the spectrum. Approaches might include peer support from other siblings of children on the autism spectrum, capacity building supports to strengthen siblings’ understanding and confidence in managing not only the way they interact with their brother or sister but also how to manage others’ reactions etc. All of these will not only strengthen the relationship but also improve the sibling’s capacity to support their brother or sister and should be part of the NDIS.

An initial assessment of an individual’s strengths, challenges, goals, and preferences is critical to developing intervention targets that are meaningful to the child and family. This assessment must also include the impacts along with the possible contributions of the whole family, including siblings.

It also notes that the overall success and sustainability of the National Disability Strategy relies on ‘people accessing their informal support network to get the help they need from day to day’. This informal support network and the roles they play will change over time. Young siblings will play an important role just as a sibling, sharing family activities, but they may also play roles mentioned above such as mentoring, coaching. As siblings grow older, they may in fact provide practical supports like transport, helping with finances, medical. The NDIS has little knowledge or understanding about the roles that siblings play over a lifetime. At the heart of such a network, it is the relationships involved that are the most important for people with disability, more so than for those without disability. These are important regardless of any carer role a sibling may or may not play. In fact, one of the key themes of the NDIS is ‘relationships’ but this is not reflected in the supports available to participants aside from possibly behaviour support. Nurturing relationships requires capacity building supports stemming from a range of approaches and disciplines.

A suitable goal for a child on the spectrum might be 'to strengthen the relationship with my siblings'. Another might be, 'to learn to interact and communicate with my siblings to develop skills that will help me have better relationships within my family, as well as extend these skills out further to relationships outside my family, with other people within my community'. Goals will depend on the individual needs of the child and the family.

The [NDIS Independent Advisory Council](#) advised the NDIS that all Australians, including people with disability, should have an 'ordinary life', that the NDIS needs to think about the idea of an ordinary life when principles are applied and funding criteria set. They stress the importance of common things that can improve the quality of lives and help PWD participate equally. For example: positive relationships – with families and informal support networks; a sense of belonging – to our families, friendship networks, communities, workplaces and society; active involvement and contribution to society and your community.

An 'ordinary life' in the context of the NDIS involves supporting a PWD to have and maintain good relationships; belong and participate in the community; be involved in making choices.

The NDIS criteria also considers 'value for money'. What price should be put on the value of a person on the autism spectrum having a sibling involved in their life over a lifetime, against someone who does not have a sibling in their life? A small investment early can provide considerable savings to the scheme if a sibling is supported to be their best and contribute to the best life for their brother or sister with autism. The economic costs to the scheme of participants not having siblings in their lives, in terms of general wellbeing, social inclusion and safety, are difficult to measure but are likely to be significant. What value cost can be put on a sibling dropping in unannounced regularly to check on a brother or sister in an independent living situation? What value can be put on a sibling and person on the autism spectrum enjoying activities together or with a group of others?

The NDIS has considered historical funding arrangements for comparable early childhood and early intervention services that existed prior to the NDIS. This is important to consider regarding siblings too. Pre-NDIS, organisations could provide capacity building supports to siblings via flexible block funding arrangements. However, the new NDIS allows for parent/carer training but not for the whole family, including siblings. This is despite siblings being identified as 'agents' by the Autism CRC report.

There needs to be greater clarity around the term 'families' and the capacity building supports available to them, including siblings, regardless of any caring role they may or may not play. The relationship itself is what should be supported and nurtured above all else.

Siblings are a key part of the network around a child/adult with disability; they contribute enormously to the development and wellbeing of a person with disability over a lifetime. Although the term 'families' is used repeatedly it is not particularly meaningful as siblings are not acknowledged at all.

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?

These tables are not very useful.

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

No. In terms of levels of funding, a key focus is 'to build the child and family capacity in daily activities and everyday settings.' Again, there needs to be a much clearer picture of what this looks like for the whole family, not only to sustain their caring role but to also strengthen family relationships for their own sake. The support item 'parent/carer training' should be changed to 'family training', or 'family capacity building'. Also, there need to be clearer guidelines about whether the supports come from core or capacity building.

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?**

In the early years after diagnosis, the whole family is adapting to their situation. Parents can feel overwhelmed by the impacts on the whole family. They can feel more confident and effective in their role if they understand the needs of the whole family, including siblings. Sometimes they need others to be aware of the impacts on siblings and to help them as parents support all their children or access support elsewhere. Support for siblings is an important part of supporting parents. If we consider children on the autism spectrum, their siblings are

also predominantly children with limited knowledge/understanding of what is happening around them. It is the support they can access during these early years that will shape their future knowledge and the sibling relationship.

Meaningful and sustainable support for children with disability begins within the home context. It is important to put more effort and resources into families in these early years to ensure strong family functioning and capability. Families need help to identify goals for the whole family around capacity building – increased capacity will enable whole families to contribute both relationship and/or caregiving to a child/adult on the spectrum.

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?

The key questions that should be included here for families are ‘How do you incorporate a whole family, including siblings, approach into your practice? Do you have experience in assisting a family to develop goals for the participant that strengthen his/her family relationships? Or that build capacity of all family members to support the participant?’

Plan implementation support will be adjusted ‘to ensure supports are tailored to each child and their family’s individual needs and preferences’. There needs to be more clarity around this statement.

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?

Again, given the fact that siblings are identified as agents in the CRC report, families must be able to access supports for these children/adults to build their own capacity before they can be effective agents. The term ‘agent’ is not a particularly edifying term for what is such a fundamental relationship, and it shows again the lack of understanding of the importance of the relationship per se regardless of their capacity to be ‘agents’. The term agent here means an individual with the capability to empower change. However, it goes without saying that to do this work, and do it well, ‘agents’ need intentional support and skill building from knowledgeable practitioners, to unlock this powerful quality they possess. Families need to trust that providers will think of them in terms of a family first with the diagnosis second.

As a final note, siblings are a key part of the network around a child/adult with disability; they contribute enormously to the development, wellbeing, social inclusion and safety of a person with disability over a lifetime. Although the term ‘families’ is used repeatedly in this and other documents, it is not particularly meaningful. There continue to be very few supports for siblings. As the 2017 Mapping Project carried out by Siblings Australia showed, such support has dwindled even further since the introduction of the NDIS. Furthermore, a sibling reading any of the literature that comes out of the NDIS, would not feel at all valued.

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?

Again, families are seeking to support their whole family on their own particular journey. Parents can feel very vulnerable especially in the early stages after diagnosis. They need support and information relevant to their circumstances that is impartial and that will assist them in making the most useful choices. If a provider is giving information about services, they need to give all options and not just those in their own interests. Relevant and easy to understand info needs to be given at the planning stage about the types of services out there and who can provide them. Maybe a directory in each region of each State to make it simple for families?

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