

Siblings Australia welcomes the opportunity to contribute to the NDIA review of its ECEI approach: *Supporting young children and families early, to reach their full potential.*

Summary

Siblings Australia is the only national organisation that has a specific focus on the health and wellbeing of siblings of children with disability. Over a period of 22 years, it has developed a national and international reputation for its work with families and professionals.

The organisation recognises that siblings will likely be in the life of the child with disability longer than anyone and, if supported, can play a pivotal role in the wellbeing, social inclusion, and safety of a person with disability over a lifetime. Historically, siblings have been overlooked when the needs of families are considered. This submission will:

- provide some background with relevant documents to support this submission.
- outline why siblings need to be acknowledged in meaningful ways and supported. Such support, given early, can lead to longer term benefits for the child with disability, the family and the whole community.
- explore how despite the prevalence of the term ‘family’ within the ECEI space and its related documents, whole family approaches are not carried through into practice.
- explore the current situation regarding support for whole families, why there should be more focus on siblings, and some of the barriers to that process.
- provide recommendations for future directions in this space.

Background

The ECEI approach recognises the need to build on family strengths in order to improve a child’s development and wellbeing. There are a number of documents, relevant to this discussion, that emphasise the importance of family. It is important to reflect on these to provide context to the discussion that follows.

1. Current NDIS review of the ECEI approach

The current review has committed to investigating what is working well, understanding gaps and issues in the implementation of the ECEI approach. It 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.*

The NDIS aims to build on the current approach to *deliver a world leading model that delivers evidence based, high quality and timely supports to young children and **families**.*

Planned improvements include building knowledge and understanding of **family members** and others *who spend the most time with the child and have the greatest impact on their development.* Other improvements include a *more **family** centred, teamwork approach and more meaningful participation for children in their **family** and community.*

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.* Another (20) is to *undertake further ongoing research and study on the outcomes of young children after receiving early intervention support to inform future policy and operational changes.* It is a pity this does not include outcomes for the whole family given the emphasis on families in other areas of the material produced by the NDIA.

2. The Reimagine Early Childhood National Action Plan to 2030 (Action Plan)

One of the early steps in the NDIS review was to commission Reimagine Australia to develop a draft Action Plan. The following (in italics and with emphases added) is taken from that Plan.

The Reimagine Early Childhood National Action Plan to 2030 (Action Plan) is a 10-year road map to enable the human services sector:

- *to be a responsive, easy to navigate and holistic early childhood development support system.*
- *all children have opportunities to meaningfully participate in **family** and community life.*

*The 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. The parent or caregiver is responsible for representing and advocating for their child in the early years. **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.

In terms of developing best practice the Plan states; *Capturing aggregate data on outcomes for young children and their **families** supported by NDIS supports would improve the understanding and effectiveness of different interventions. Furthermore, it will aid the provision of information, services and resources to drive better outcomes. This research would also provide the evidence base to inform EC Partners and the NDIA on how to support **families** and participants in setting appropriate goals.*

3. Consultation Report Nov 2020

The Early Childhood Early Intervention (ECEI) Implementation Reset Project Consultation Report National Disability Insurance Agency (NDIA) November 2020 stated the following:

*The early childhood years are important for all children and **families**, regardless of disability and/or developmental delay.... A growing body of evidence emphasises the role of children's social and physical environments on development and health outcomes.*

The report highlights the importance of equipping others in *the child's life such as family, carers and educators who make up their environment*. It also highlights the importance of the social model of disability which moves away from a focus on diagnosis/deficits to a focus on supporting meaningful participation in family and community life.

The report also identifies how ECEI differs from the general Scheme, giving rise to the concept of the family as Participant.

The specific ECEI approach is a model of delivery differentiated from the general Scheme. It enables young children and their families to receive the right level and mix of best practice support, at the right time and for the right duration, through a family centred approach

As part of the report, Reimagine Australia, with support from the NDIS Sector Development Fund, 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. *Source: Reimagine Australia (formerly ECIA) National Best Practice Guidelines for Early Childhood Intervention*

a) Family

*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.*

b) Inclusion

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

The paper stresses the importance of *developing the capability of others to include the child*.

c) Teamwork

Best practice integrates a 'team around the child', including family, relevant ECI professionals such as allied health providers, and other professionals such as early childhood educators and health professionals.

*The key worker also contributes to coaching and capability building with other **adults** around the child..... These practices focus on fewer, stronger relationships where the family is a true partner, and knowledge can be transferred across disciplines, and from specialists to carers and other important adults in the child's life.*

Whilst the above section emphasises the importance of family and building capability of 'others', the focus is very much on the adults in a child's life and overlooks the important contributions and needs of siblings

4. NDIA Act

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*
- *Appropriate information, knowledge, skills and expertise are in place to deliver quality supports to **families**.*
- *The capacity of the child, **family** and collaborating providers involved with the child is built through coaching, capacity building supports and collaborative teamwork.*
- *Feedback and learnings from the child, **family** and other professionals is used to improve support delivery*

5. Tune Review

Also, in response to the Tune Review, which 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.*'

Whilst all the above documents highlight the importance of family, the reality is very different in practice - the focus is usually on the child with disability and one or both parents. These policy positions and plans show a lack of understanding of sibling needs and contributions.

For example, in the Action Plan there is mention of support allowing a parent to take a sibling to basketball and that is good to see. Many siblings are limited in their capacity to take part in community activities due to the demands of the child with disability on parents. However, the issues are so much more complex than this. Siblings also need to be supported to manage the various stresses they experience and build their capacity to engage meaningfully with their brother or sister with disability when they are together.

Before exploring the gaps in practice, the following section will focus on why it is important to consider siblings in a much more meaningful way.

The importance of siblings

Research on sibling relationships in general highlight the influence of these relationships in the development of children. There is no reason to believe it is any different for families that include disability. ([1] McHale et al., "Sibling Relationships and Influences in Childhood and Adolescence" (*Journal of Marriage and Family*, Oct. 2012)

It is crucial to recognise siblings as important family members within ECEI for several reasons.

Siblings are impacted by the disability and need support to manage those impacts in ways that safeguard their own development and wellbeing. In the ECEI space, in particular, siblings are predominantly children with limited understanding of what is happening around them. It is these experiences that will shape any future relationship.

Siblings will likely have the longest relationship of any with the person with disability. The strength of that relationship, determined in childhood, can have a huge lifelong influence on the wellbeing, inclusion, and safety of a brother or sister with disability, not only in childhood but over their shared lifespan.

Also, parents often feel overwhelmed by the impacts on their family and can feel more confident in their role if they understand the needs of siblings and can provide support themselves or access support for their children outside the family. Support for siblings is an important part of supporting parents.

Meaningful and sustainable support for children with disability begins within the home context. ECEI plan goals are aligned with areas mandated within the Act, such as communication, social interaction and learning. These areas of development are dependent on strong family functioning and capability of all core family members, including siblings. A lot of funded supports focus on ways of strengthening communication, social interaction and learning outside the family context, within the community. However, these ECEI goals start within, and are contingent upon, family. Ultimately, sibling support means support for the child with disability.

The impact on siblings

Certainly, many siblings of people living with disability are enriched by the relationship with their brother or sister with disability. However, many can also face significant challenges. A 2008 Australian Institute of Family Studies report found that parents of children with disabilities have higher rates of depression than the general population and siblings also had a significantly increased risk of depression, regardless of any caring role¹. Also, a Position Paper from the RANZCP says, *'There is reasonable consensus that siblings of children with chronic conditions are at risk for behavioural, mental and physical health problems. If left unaddressed, the challenges which siblings face can increase their risk of developing longer term mental health problems, at considerable cost to them, governments, and the community.'*

Other studies from overseas have shown that these children have increased rates of physical health problems too².

Often parents do not access services for themselves or their other children as the focus is on the child with disability.

The following is a list of reasons why siblings may be vulnerable and need support, in no particular order:

- Parents being stressed or depressed. This can be exacerbated if the parent relationship breaks down (a heightened risk in families which include a child with disability)
- Ongoing stress due to the daily impacts of the disability, e.g., concern for the safety of the child with disability, the amount of support needed for a child to function in daily life, or difficult behaviour of the child with disability. Confusion can arise in a young child around the behaviours of a child who responds in different ways
- Possible trauma from seeing the impacts of the disability on their brother or sister eg seizures, 'meltdowns' etc.
- Whilst it is a difficult topic to discuss, some siblings are both physically and emotionally harmed by a brother or sister with disability, and this is often not reported by parents as they are fearful of what outcomes might ensue
- Teasing or bullying from peers; feeling the stigma
- Growing up with the needs of someone else always taking priority; they learn to put their own needs second which can also have implications for relationships over the lifespan.
- Education outcomes may be affected by anxiety, tiredness, depression, social stigma and worry for parents

¹ Edwards, B., Higgins, D.J., Gray, M., Zmijewski, N., Kingston, M. (2008). The nature and impact of caring for family members with a disability in Australia. *Australian Institute of Family Studies, 2008. Research Report, no. 16*

² Hogan, D., Park, J., & GoldschElder, F. (2003). Using Survey Data to Study Disability: Results From the National Health Interview Survey on Disability. *Research in Social Science and Disability, 3*, 185-205.

- Confusion about their feelings – on the one hand, love and protection towards their brother or sister, but at the same time, they may feel resentment, embarrassment, guilt, sorrow and fear. Such feelings can lead to low self-esteem, shame or a sense of worthlessness³
- As they become older, they might worry about their brother or sister and the support roles they, as siblings, may need to play in the future and balancing that with other aspects of their life. For example, is it ok to move away to follow a career? Will they find a partner to share the responsibility? Should they have children themselves?

All these difficulties are exacerbated by limited access and availability of appropriate services and the practicalities of family life where the needs of a brother or sister take greater priority.

The Gaps

Despite the emphasis on ‘families’ within documents relating to ECEI, the reality is very different. A recent Mapping Project (conducted by Siblings Australia and funded through the NDIS) further confirmed what the organisation had found over many years, as follows:

- Very few siblings access any support services
- Very few parents are assisted to support their children who are siblings
- There are no policies or strategic national approaches to sibling support
- Current mental health/disability programs/policies for young people do NOT meet the needs of siblings
- There are no standard, co-ordinated policies with regard sibling support approaches
- There are no clear pathways to fund capacity building supports for siblings, either through the NDIS or mainstream services
- There has been little evaluation done of existing programs; no best practice guidelines
- There is no national co-ordination of services for siblings, little, if any, collaboration; local programs are rare and sporadic
- There are significant deficiencies in both the understanding and skills of practitioners regarding sibling contributions and needs, across all sectors

As mentioned above, ECEI plan goals are aligned with areas such as communication, social interaction and learning. However, most funded supports focus on ways of strengthening communication, social interaction and learning **outside** the family context, within the community. There is a gap in understanding of why this approach is missing such a fundamental aspect of family life, that is, that family members might need this support too, in order to strengthen family relationships.

If a child with disability has difficult behaviours, there are relevant therapists who engage with the child to support their social development. It is unlikely that such approaches would centre on siblings, to help them understand the behaviour of their brother/sister, or to nurture and strengthen the relationship between them.

One of the key themes of the NDIS is ‘relationships’ but again the emphasis is on strengthening relationships within the community rather than in the family. Whilst there is a line item within the NDIS for ‘parent/carer training’ there is nothing to recognise increasing the capacity of siblings to manage their experiences and to strengthen their relationship with their brother/sister.

Why siblings are overlooked

Despite all the above, siblings are still very overlooked in practice and there are several reasons for those gaps.

1. Siblings are not good self-advocates

It can be difficult for siblings to ask for help when they see a brother or sister struggling, and they may grow up feeling that their needs are less important. Often, they are given – and believe – messages that they should feel lucky. They don’t want to add to the considerable stress of parents so, in many cases, they try to be the ‘good’ child and not ask for help. Even into adulthood, many siblings have difficulty expressing their own needs.

2. Families are stretched

Many parents are mindful of the impacts on siblings. Others, when under stress, may be too focused on the child with additional needs to recognise the challenges for siblings. In some cases, parents are struggling with their own stress, grief and acceptance and their emotional resources are stretched to the absolute limit.

3. Issues are not recognised by service providers

³ Lamorey, Suzanne. (1999). Parentification of Siblings of Children with Disability or Chronic Disease. In Nancy D. Chase (Ed.), *Burdened Children: Theory, Research and Treatment of Parentification*. Thousand Oaks, California: Sage Publications

Professionals may lack understanding of the issues for siblings. This can hinder their ability to respond to a sibling in a supportive way. It is relatively easy for professionals to understand the effects on a child whose family experiences a range of other challenges but, in relation to siblings, the issues can be complex and less clear.

4. Lack of resources

Due to limited funding, professionals who do understand sibling issues are often restricted in what they can do. The change in the disability funding model to the NDIS, removed block funding to organisations and resulted in less flexibility to support the whole family. If they can access funding for such purposes, it is likely to be time-limited or sporadic.

5. Lack of government policy

Whilst there is much evidence to indicate that siblings need support and that many parents are very keen to access support for their 'other' children, siblings are nowhere to be found in government policy. There is still no co-ordinated approach to sibling support. Without policy, there is no imperative for agencies to provide support to whole families. And the lack of resources mentioned above exacerbates the situation.

Many government inquiries have explored the needs of families affected by disability and Siblings Australia has provided submissions over many years. Despite this, inquiries and subsequent reports give little, if any, reference to the impact on siblings.

By contrast, in the UK, the *Children Act* provides a more comprehensive framework for the support offered to children 'in need', including those with disabilities. It emphasises that a child with disability is part of their family. The guidance issued under the *Children Act* (Great Britain Department of Health, 1991) states that 'the needs of brothers and sisters should not be overlooked, and they should be provided for as part of a package of services for the child with a disability'. Siblings are provided for at the policy level, meaning there is an expectation they will be considered by agencies.

Current policy concerns

As an aside it is important to consider current policy and how this can add to the confusion around sibling support. For example, some people believe that sibling support is covered by 'young carer' policies. However, this is not the case and nor should it be. The issues for young people caring for parents (the original 'young carer') and those for siblings can have some overlap but also have some major differences.

Whilst many siblings do provide some caring roles for a brother or sister, it can be detrimental if they are labelled as 'young carers'. Many siblings already have a heightened sense of responsibility and this term can add to their anxiety about the role they might be expected to play, even from a young age. It can also add to the difficulty in developing an identity that is not totally focussed on being a 'helper' and putting the needs of others first.

The majority of siblings do not provide care, as the parent carer is present, and so we would miss many siblings who need support if we went down that policy path. Many siblings, rightly so, are not eligible for carer programs. They need policies that focus on their unique needs from a young age and across their lifetime. If siblings do provide caregiving, and this is kept in balance, it can be a positive experience for them, but there can still be other challenges that create more stress for them.

And finally, over the long term, such terminology does not add to the dignity of children and young people with disability. What 12-year-old boy wants his 10 year old sister to be known as his 'carer'? All family members need support, regardless of any caregiving role they may or may not play.

The benefits of sibling support

develop strength, resilience and tolerance, and less likely to feel isolated or develop ongoing health issues.

Access to relevant information and support programs enable siblings to:

- understand issues pertaining to their brother or sister's disability
- develop greater capacity to be a support to their brother or sister
- develop a stronger relationship with their brother or sister with disability
- enhance their own development and wellbeing
- understand that they are not alone with their particular concerns and feelings
- accept that it is normal to experience a range of mixed feelings, including love, sadness, guilt, anger
- express and try to manage these feelings in healthy ways
- learn skills to manage the other challenges, both within their family and in the community
- develop a stronger relationship with their brother or sister with disability

As mentioned, siblings will likely be in the life of the child with disability longer than anyone. They have much to contribute to the social and emotional wellbeing of the child with disability. They can also contribute to the

understanding of professionals who work with the child with disability. And over time, if supported in childhood, they can be a crucial player in the longer term wellbeing, social inclusion, and safety of the person with disability. Sadly, many siblings move away from their families. If intervention occurred earlier and the sibling relationship nurtured, outcomes might be very different, both in childhood and beyond.

There are also economic benefits. If it were possible to compare the trajectory over a lifetime of a child with disability who has one or more siblings involved in their lives, to that of someone whose siblings have moved away because of the various pressures and lack of support, it would likely show not only social/emotional benefits to people with disability but also huge economic benefits to the NDIS overall.

Recommendations

The following recommendations should be considered in any future Action Plans for ECEI, to ensure meaningful change for families:

Family support

- include relevant supports to the whole family at time of diagnosis and early critical period when relationships, especially between parents, can be particularly vulnerable
- recognise siblings' important role in the development and wellbeing of young people with disability, not only as children but also over a lifetime
- consider siblings' own development and wellbeing, as well as their potential contributions
- consider the rights of siblings alongside other family members
- recognise the vulnerability of siblings, due to the impacts of disability in the family, and avoid long-term impacts by taking a preventative approach
- ensure that siblings receive the right level and mix of best practice support, through both a family centred and whole of family approach
- ensure goals focus not only on developing relationships outside the family but also on strengthening those within the family
 - as recommended in the draft Action Plan (Rec 17), 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 and also ensure the whole family is included in that process

Workforce

- call for significant workforce development to ensure all sectors have the necessary skills and training to understand the issues for siblings and support them appropriately
- develop new guidance about what is considered 'reasonable and necessary' when making decisions around capacity building supports for whole families
- include clear guidelines on what role Early Intervention services can and should play in addressing the needs of siblings
- consider a range of mechanisms that will enhance compliance of providers with the *NDIS Practice Standards on Early Childhood Supports* which emphasise capacity of the whole family and increase awareness by families of providers that adopt that best practice framework
- undertake an inquiry into what resources ECEI agencies need to be able to provide support to siblings as part of these best practice approaches

Data

- ensure relevant data is collected about siblings and their needs
- ensure that outcomes for families through the ECEI process (and the above practice standards) are measured appropriately and meaningfully, with a focus on the whole family, not just the child with disability and parents

Policy/strategic directions

- ensure siblings are recognised and have their needs addressed through national policy, frameworks and strategic directions
- recognise the importance of a national body that co-ordinates the relevant research, guides policy and develops 'best-practice' approaches to sibling support across the lifespan