



Siblings Australia Inc

Early Years Strategy Discussion Paper (EYDP)

April 2023

 **Siblings**
australia inc

for siblings of children and adults with disability/illness

Siblings Australia welcomes the opportunity to contribute a submission to the Early Years Strategy Discussion Paper (EYDP). It has been the only national organization to focus on the needs and contributions of siblings of children with disability over the last 24 years and has developed an international reputation for its work with families, professionals, advocacy and contribution to research.

This submission will include:

1. Introduction
2. Gaps in policy/programs
3. Gaps in data/research
4. Recommendations for future inclusion of siblings in both policy/programs, and especially within the Early Years Strategy (EYS).

It is hoped that the Strategy will be a starting point for further input from Siblings Australia.

1. Introduction

The EYDP states that 'Every child deserves the opportunity for the best start to life; a chance to achieve their goals and dreams.' It also says that, 'The early years are a window of opportunity to positively influence children's development, their sense of identity, health and wellbeing, learning, safety, and happiness. A strong start in the early years will increase the likelihood of success that can carry children in good stead throughout life.' The paper goes on to say that 'the early relationships, experiences and care they receive actively shape lifetime health, learning, and identity'.

One of the vulnerable groups cited in the EYDP includes those children with a disability or developmental delay, but there is no mention of their siblings.

In all situations where there is any kind of disability or illness, the whole family is impacted. And children who are siblings do not often have the emotional and cognitive maturity to cope with what is happening around them. Siblings Australia would argue that there needs to be more consideration given to the mental health and wellbeing of both the child with disability and their sibling(s) and also the strength of the relationship between siblings. Not only will this benefit the sibling but also a stronger relationship (given the sibling relationship will likely be the longest of any) will have huge impacts on the wellbeing, social inclusion and safety of the child with disability over their lifetime.

Siblings Australia agrees that the first five years are crucial to the long-term wellbeing, social inclusion and safety of children (then adults) with disability. This is also the case for siblings of these children, in terms of their own mental health and wellbeing and also in terms of the importance of the sibling relationship for a child with disability.

As diagnosis of a disability often occurs at birth or in the early years, siblings can be overlooked as family attention focuses on the needs of the child with the disability and their immediate needs. While understandable, the importance of the early years development for all children requires that siblings themselves be identified as a vulnerable cohort within this context, either in their own right or as a key sub-group, for the following main reasons:

a) Siblings of children with disability are vulnerable too.¹

The issues for siblings of children with disability can be complex. Each child has a unique set of internal characteristics and external challenges and there are several factors that affect their adjustment to these. Even within one family, siblings may respond very differently to what is happening around them. And their experiences and reactions will change over their lifetime.

It is well accepted that disability impacts the whole family. A 2008 Australian Institute of Family Studies report² found that parents of children with disability have higher rates of depression than the general population and siblings also had a significantly increased risk of depression, regardless of any caring role. Often these parents do not access services for themselves or their other children as the focus is on the child with disability. If they do recognize the challenges for siblings, support options are limited.

Siblings can experience significant stress, confusion, and difficult feelings like grief, guilt, anger, fear and embarrassment. There is also a lot of pressure on them to not 'make waves', to be perfect and not add to any stress for parents. They might try to squash any of the difficulties they face and rarely ask for help themselves, which then increases the risk of mental and physical health problems³.

As the RANZCP stated in an issues paper regarding siblings, *'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.'* (see this and other related documents via the following link: <https://siblingsaustralia.org.au/advocacy/other-advocacy/>).

Also, an article in the journal, *Pediatrics* (2013; 132: e476–e483Pa), reported significant impact on siblings and concluded that *'Health care professionals need to consider a family-based health care approach for families raising children with disability.'*

Siblings have been highlighted as being at risk in other publications from a mix of sectors (these publications are available upon request).

Siblings Australia's own [Mapping Project](#) from 2018 highlighted the contribution and needs of siblings, the gaps in services, and offered recommendations for the future. The [2012 – Report from surveys re: aggression](#), highlighted another concerning issue for siblings that is rarely discussed.

b) Siblings can play an important role in the development of children with disability.

The relationship between siblings is often the longest of any. If this relationship is

¹ 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

² 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

³ Hogan, D., Park, J., & Goldscheider, 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.

strengthened and nurtured from a young age it can set up better outcomes for both children going forward. A strong sibling relationship between siblings can enhance the wellbeing, social inclusion and safety of a child with disability.

There is much discussion about the importance of natural environments as 'settings, where children learn and develop everyday abilities and skills, including the home, community, and early childhood centres'. Sadly, there is often more emphasis on the relationships that children with disability form in the community rather than in their home. The EYDP states, 'The way in which parents and caregivers engage children is critical for their overall development. Promoting responsive caregiving is therefore an essential first step in ensuring that children build secure relationships with caregivers and early childhood service providers.' However, siblings can play a huge role, sometimes even more than parents/caregivers.

The Autism CRC highlighted that siblings were significant 'agents' in the development of children with autism in their report [Interventions for children on the autism spectrum: A synthesis of research evidence](#)

There is much discussion about the importance of natural environments as 'settings, where children learn and develop everyday abilities and skills, including the home, community, and early childhood centres'. The EYDP states, 'Promoting responsive caregiving is therefore an essential first step in ensuring that children build secure relationships with caregivers and early childhood service providers'. Again, this is overlooking the important role and needs of siblings.

2. Gaps in policy/programs

There is a lack of government policy which recognises both the contributions and the needs of siblings. As a result, no one sector takes responsibility for them.

Siblings Australia has long argued that siblings should be included in any approach to support children with disability, but that they should also come under attention from health, mental health, education, child protection sectors to ensure they do not 'fall through the gaps' in terms of policy and programs.

It is pleasing to see that the Early Years Strategy will be a framework for action and reform and that it will be an integrated approach to the early years, including the reduction of silos.

In the case of siblings of children with disability the issue of 'whose responsibility' it is to provide support is unclear. The experiences of developmental vulnerability that the child with a disability may face may not be as clearcut for their siblings but are present. And the compounding nature of disadvantage referenced in the discussion paper can also be relevant to the sibling.

The government Strategies which would seem most relevant to siblings (as listed in Attachment A) do not include any mention of siblings alongside children with disability. There may be mention of 'families' but, most times, this just filters down to a focus on parents.

There has been some attempt to include siblings under the 'young carer' policy, but this is not necessarily in the best interests of siblings or the child with disability. Further discussion re this issue can be found within the Mapping Project report mentioned above, under Section 5.1 Policy Issues.

Within the EYDP, it states that the Strategy will *'acknowledge and respect the Commonwealth Government's commitments through the United Nations (UN) Convention on the Rights of the Child, the UN Declaration on the Rights of Indigenous Peoples and the UN Declaration on the Rights of Persons with Disabilities.* The discussion re 'young carers' raises some implications in respect to the UN Convention on the Rights of the Child.

The EYDP also claims that it will be inclusive. It states that, *'Children with disability or with developmental concerns deserve the same positive experiences and opportunities to thrive as all children. Australia's Disability Strategy and the Early Childhood Targeted Action Plan set out actions to ensure these children are supported to reach their full potential. The Strategy will complement these efforts and will be developed closely with the new National Autism Strategy.*

The Disability Strategy and the Early Childhood Targeted Action Plan do not include siblings in any meaningful way despite them having a key relationship with the child, then adult, with disability.

In the UK, siblings are recognised through legislation. The *Children Act 1989*, which provides a framework to provide support to children "in need" including those with disabilities, specifically states that the needs of brothers and sisters of children with disability should not be overlooked. The Act emphasizes that children with disability are part of their family. The guidance under the Children Act 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' (Great Britain Department of Health, 1991). In addition, the report, 'Aiming High for Disabled Children: Better Support for Families', often refers to the needs of siblings and stresses the importance of 'focused, effective support early in life and at key transition points, with early support for disabled children and their families, which promotes emotional and social development for disabled children and their siblings, to help to improve outcomes for all' (HM Treasury and the Department for Education and Skills, 2007).

In the EYDP it is suggested that one of the guiding principles could include being 'child and family centred' The family-centred approach has been in place across many jurisdictions for some time now. Sadly, it does not often include the whole family, but instead focuses on parents. Especially in relation to children with a disability, this should be a strong focus of any strategy, alongside any 'wrap around the child' approaches.

For children with a disability, the strength of family connections will be an important factor with regard to their wellbeing, inclusion and safety over a lifetime. Siblings will likely have the longest relationship of any with the child/adult with disability and so can play a huge role. There is much rhetoric regarding 'families' but, in practice, there is little attention given to whole families when a child has disability.

3. Gaps in data/research

Researchers and practitioners have developed many frameworks to guide policy and practice for the early years. However, there are many gaps in terms of data and research, in relation to siblings of children with disability.

In terms of data, the EYDP states that *'In Australia, we have rich sources of data about children and families that can be used to guide the priorities and performance of the Strategy.*

Sadly, the ones listed in the paper do not include information about siblings. Even in terms of

just numbers, these figures can only be determined by extrapolating data related to children with disability. The Longitudinal Study of Australian Children would have been a good opportunity to include such data, but this is lacking.

Siblings Australia has developed and contributed to several research studies related to siblings and these are available through the organisation's website linked [HERE](#)

International research also shows that these children are vulnerable. This research is available on request.

However, this research has not been considered when such frameworks as above have been developed.

4. Recommendations for future inclusion of siblings in both policy/programs and especially within the EYS

a) **Greater identification** of those children who are more vulnerable amongst the population.

There needs to be better identification, through systematic and organised outreach, of children at risk, including those that are not obvious or who do not speak up about their struggles. This needs to be through all the settings in which a sibling operates – family, school, community – and not left to parents to manage.

Ideally any assessment of children with disability/health issues would always raise a 'red flag' regarding the needs of siblings as well. There needs to be recognition that those needs will change as the child ages and family circumstances change. Such identification/assessment could be through newborn baby health checks, GPs or disability agencies.

When a child is diagnosed with disability or illness, the question should follow: Does the child have siblings? What are their needs?

As the child with disability and siblings age, not only disability settings but also other early childhood, health settings can identify children who are siblings. Over time, the needs of the child with disability and their siblings will change.

GPs and paediatricians could also provide a useful touchpoint – as parents of children with disability are likely to come into contact with them routinely, and they are well set up to share information and provide referrals to other health and support services.

The key is that professionals assume that siblings of children with disability are a group at risk and that support is put in place either directly or via referral.

b) **Prevention.**

Intervening as early as possible in a child's development enhances the preventative effect and improves the impact of the intervention.

It is far better if a child who is facing challenges is identified early, regardless of whether they seem to be coping or, indeed, struggling. As mentioned, siblings often hide their problems. Putting in place some preventative actions, will have far greater benefits than waiting until they are struggling. The very nature of being a sibling of a child with a disability puts them more at risk. If these children are not identified early, there will be no action until they present at the 'struggling/unwell' stage of the continuum.

c) **A whole family approach**

must be taken when a child presents with disability or chronic/mental illness. It is the whole family that is impacted and the whole family that can play a significant role in the outcomes for all children.

d) **Data/research**

Siblings need to be included more effectively in data collection and research. The Longitudinal Study of Australian Children, 'Growing up in Australia' has been a missed opportunity to gain more knowledge about this group of vulnerable children.

At a more general level, research on families of children with a disability tends to focus on the child with disability and parents (usually the mother). Siblings are largely overlooked. Outcomes and indicators in relation to family research must include individual outcomes as well as those for the whole family.

Whilst there is compelling evidence that siblings are at risk, alongside their brother or sister with disability, there needs to be more comprehensive research – e.g., are some siblings more at risk than others? What are the key factors for adjustment? Which approaches work more effectively than others?

There also needs to be a central clearinghouse of research, data and best practice approaches for this group.

e) **Policy**

Siblings of children and adults with disability should be recognised within government policy as an 'at risk' group and their needs are acknowledged accordingly. They are also acknowledged for the contributions they make to the lifetime wellbeing of a brother or sister with disability.

This should include universal services that apply to all families and children, targeted support for families and children who face particular challenges, and tertiary interventions where needed to help address challenges to achieving the best outcomes for children in the early years.

Including siblings in the Early Years Strategy would result in greater imperative for various sectors to address the needs of siblings.

f) **Strengthening workforce**

Any workforce development included within the Early Years Strategy across various sectors (education, health, disability etc) must include actions to increase understanding of the challenges for siblings but also the contribution they might make to the child with disability. Models that include cross-sectoral responses, a kind of 'team around the child' approach, can identify the 'red flags' for risk and know exactly what pathways of support might exist. There need to be clear pathways regardless of how a family enters any one sector.

Assessments at intake (or at whatever level contact is made) should explore which family factors might affect each child's development, mental health and wellbeing, as well as their social and learning experience.

In relation to siblings, questions might include: Does this child have a brother or sister with disability? What is their role in the family? What impact does disability have on the sibling?

If in an education setting, further questions might include: Are they able to complete homework at home? Do they lose sleep leading to tiredness? Are they anxious about what is happening at home? Are they teased or bullied, or do they also become upset because they see their brother or sister with disability (or other children with disability) being teased or bullied? Do they struggle to make friends if their social skills are impacted by growing up with a child with disability? Do they feel different to their classmates? Are they unable to take part in extra-curricular activities as it is too difficult for parents to ferry them back and forth? As the sibling role and experiences changes, it is important that education settings review family information on an annual basis.

At the same time, siblings might have important perspectives or information to share about their brother or sister with disability. If included, they can learn new ways of interacting with the child with disability, for the benefit of both children.

As with parents, siblings benefit hugely from peer support. Different sectors should explore what resources are available to assist with this, both formal and informal, alongside other supports.

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