



for siblings of children and adults with disability/illness

NDIS Quality and  
Safeguarding  
Framework  
Review Submission

May 2023

Siblings Australia welcomes the opportunity to contribute to the review of the NDIS Quality and Safeguarding Framework (the 'Framework'). The focus of this submission will be on the key elements of the developmental measures that were highlighted in the original framework, but which have not been carried through in practice. It is these developmental measures that help people with disability access the supports they need to live a 'good life' and be able to ensure their wellbeing, social inclusion and safety. There continues to be a lack of understanding of the importance of family, and especially siblings, in assisting in these processes, and the need for families to build their own capacity to contribute.

Siblings Australia recently provided a [submission](#) to the NDIS review, which outlined the challenges and needs of siblings, and their contributions to people with disability in more detail. This submission will briefly cover a number of topics and how they particularly relate to quality and safeguards, these topics are outlined as follows:

1. Empower and support participants through:
  - a. Providing participants information for decision-making
  - b. Building participants capability
2. Strengthen natural supports
3. Develop professional capacity to ensure best practice

## 1. Empower and support participants

The NDIS recognises that giving people with disability choice and control over their supports can help to improve their outcomes.

In previous consultations, stakeholders emphasised 'the importance of helping participants to understand information about their rights and options and building participants' skills to make decisions about their supports, negotiate with providers and stand up for their rights, when needed'.

The list of broader skills that stakeholders suggested should be fostered among NDIS participants included, among others:

- Informed decision making
- Communication
- Building healthy relationships
- Recognising good quality and in turn bad supports
- Recognising and responding to violence, abuse or neglect, and
- Making a complaint, suggestion or advocating

Many NDIS participants will need assistance to build their capability to access information, choose between providers, ensure their supports are delivered in a way that meets their needs, and make a complaint or change providers.

For people with intellectual or mental disability, or those with complex communication needs, the relationships that they can develop are crucial to them being able to develop capacity in the above. It is often families who assist with these activities. However, families also need to build their own capacity to contribute in this way.

In addition, and as the Framework acknowledges, people with intellectual disabilities and complex mental illnesses may be particularly vulnerable to social isolation and abuse and are often unable to recognise or report such abuse.

The Framework emphasises that ‘building the capability of participants and supporting them to make connections recognises that the actions people take themselves—or that their family, friends and others around them take—are likely to be the most important component of the quality and safeguarding system’.

It also states that ‘people who have family and friends around them on a regular basis, or who receive supports from several different providers, may be less vulnerable to abuse and dangerous practices than people who are isolated’.

Despite the significant role families (and in the longer term, especially siblings) can play in terms of risk assessment/reduction, there is no real acknowledgement in the Framework about what families/siblings might need to play this role effectively. For example, families might need assistance to understand the disability sector, the NDIS specifically, how to contribute to supported decision-making, how to assist a participant to make choices that increase their safety. Any future Framework must include actions that can ensure better outcomes for families and their loved ones with disability.

The next section focuses on supporting natural relationships.

## 2. Strengthen natural supports

Siblings Australia agrees with the premise in the NDIS discussion materials related to safeguarding, that ‘**participants with strong natural safeguards** are better supported to be safe than those with poor natural safeguards’. This is particularly important for people with disability that includes intellectual disability or communication difficulties, which means they might experience isolation but, also, they may not recognise or be able to articulate when they feel unsafe.

The first natural safeguard for a person with disability is their immediate family; their parents and siblings. Of course, extended family and friends can also contribute to this but the extent of that is dependent on the family itself. The strength of the relationships that are set up in a family set the scene for the wellbeing, social inclusion and safety of a person with disability, especially those with intellectual disability.

Siblings will likely have the longest relationship of any over the lifetime of someone with disability. Siblings Australia cannot stress enough the importance of considering

how to nurture and strengthen those family relationships from an early age. It is their childhood experiences that set the scene for all sibling relationships. When disability is involved, there may be more supports and intervention needed to ensure that siblings can interact, have fun together and build a bond with each other. A sibling might need to build their own capacity from the early years in terms of how to communicate and play with a brother or sister with disability, how to manage behaviours of concern etc. The Autism CRC has referred to siblings as being 'agents' in the development of children with autism, but this again is dependent on a strong relationship.

As they become older, siblings may learn the key components of supported decision-making, how the disability sector works etc., as outlined above. Siblings Australia's 2018 [Adult Sibling Project](#) showed that siblings might contribute through direct caregiving, helping with transport or medical appointments, giving parents some support re caregiving, or countless other practical supports. Specifically, they might assist in the following ways to keeping a brother or sister safe:

- Maintaining connections with extended family for the person with disability which leads to further natural supports.
- Dropping in unannounced and regularly to any supported accommodation of their brother or sister.
- Showing support professionals that the person with disability is valued and that they have people watching out for them.
- Attending review meetings of what supports the person with disability needs to maintain safety.
- Accompanying the person with disability to some therapy sessions to ensure safe processes.
- Contributing to building capacity of their brother or sister with disability to stay safe.
- Contributing to activities like Circles of Support to broaden the network who take an interest in the person with disability.

Consider a person at say 50 years of age who does not have any family in his/her life compared to someone who has loving sibling relationships. Of course, there are many reasons why family bonds may break down but, within the disability sector and more widely, there is no real attention given to strengthening sibling relationships. At the very least there should be research into what the barriers to and enablers of such relationships might be. Regardless of caregiver related roles as outlined above, it is often the relationship itself that is the most crucial to outcomes for the person with disability. A strong relationship is not automatic.

Despite 'relationships' being a key theme in the NDIS, there is no priority given to relationship building, especially related to siblings, in any NDIS literature, whether directly related to safeguards or more broadly. The current framework gives no clear direction on how to support this important relationship. Sadly, it insinuates that people

with disability may be at risk from family members who try to control outcomes. Of course, there need to be safeguards that prevent that happening, but most parents and siblings love and care deeply about the person with disability and contribute much to their daily lives.

### **Recommendations for this Review**

The process of strengthening 'natural supports' must start early in a family's experience of disability and it needs a holistic approach. The following recommendations, in no particular order, should be considered as part of any plan for building natural safeguards for people with disability.

1. Further research the barriers and enablers of 'natural supports', especially related to siblings from early childhood, including the challenges that they may face.
2. Collect data on the number of siblings and the nature of their involvement, if any, in the lives of people with disability.
3. Recognise and value the sibling relationship and what it contributes, over the lifetime of the person with disability.
4. Emphasise the importance of building strong family relationships alongside improving community inclusion for young children with disability.
5. Develop professional development that includes ways to recognise and include siblings, through behaviour support or early intervention approaches, and to strengthen and nurture the sibling relationship.
6. Assist parents to understand sibling relationships when one has disability and how they might support both children and the relationship between them.

### **3. Develop professional capacity to ensure best practice**

There is still a lack of understanding within professional circles of the contributions and needs of siblings. Professionals can play a huge role in strengthening sibling relationships from very early in the life of both siblings. This might include supporting siblings to communicate, play or learn together. In addition to being playmates, a sibling might also play a role as mentor and teacher.

Professionals need specialist input into how siblings might be supported both as individuals and in relationship with a brother or sister with disability. Especially where there may be complex behaviour support needs, the sibling should be included in any approaches by a behaviour specialist. A sibling might contribute insight but also need support to understand the behaviour. Why does their brother or sister ignore them, or yell at them, or hurt them?

With greater understanding they are likely to contribute to strategies that might address the behaviours. If necessary, they may need support to keep themselves safe.

The original Framework included a summary of competencies for positive behaviour support practitioners that included (emphases added):

- develop positive behaviour support plans and provide oversight, advice and feedback to provider staff and families with responsibility for implementing the strategies contained in positive behaviour support plans.
- Practitioner seeks input from the participant, family members and other important parties, and has skills to assess and evaluate level of risk relative to response, and quality of life (including quality of family life).
- Practitioner has the ability to contribute to short-term and long-term planning as part of a whole-team approach and can provide specialist advice and training in behaviour support to staff (and families) responsible for implementing the strategies contained in the positive behaviour support plan.

Siblings Australia's understanding is that siblings are rarely included in such approaches, either as contributors or as needing their own supports. If the new Framework is to seriously consider the factors that contribute to the quality of services and safety of people with disability, then it should also consider the barriers and enhancers of such family relationships and best approaches to ensure they are as strong as can be over a lifetime.



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