

# Siblings Australia Submission to the ILC Commissioning Framework

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Please see our original submission on the policy Framework in early 2015

<http://siblingsaustralia.org.au/assets/submissions/ilc-submission-sibs-aus.pdf>

This current submission will follow up with further comments. Throughout the document I will underline certain words for emphasis. Also direct quotes from the Framework will be in italics.

The focus of this current consultation is on the proposed outcomes, but there is a need to go back to the activity streams in order to make the following discussion re outcomes clearer in relation to sibling needs. Therefore, this submission will provide some background by adding to the content in our initial submission (see above link) regarding 'Carer Support' and the 5 activity streams, and then comment on the proposed ILC outcomes.

## Background

*In July 2015, all governments across Australia agreed to the ILC Policy Framework. The Agency has been given responsibility for implementing the policy, which outlines two broad aims for ILC:*

- 1. To provide information, referral and capacity building supports for people with disability, their families, and carers that are not directly tied to a person through an individually funded package.*
- 2. To partner with local communities, mainstream and universal services to improve access and inclusion for people with disability.*

*The National Disability Strategy 2010-2020 provides a ten-year national policy framework for improving life for Australians with disability, their families and carers. It is envisaged that ILC will make an important contribution to the overall goals of the NDS as well as the NDIS.*

One of the main difficulties with the Framework is that there is still too much emphasis on 'carers'. Whilst the term 'families' is used throughout the Framework the detail is focussed more on 'carers', and there is a gap in the Framework regarding the impact on siblings over a lifetime and the different support roles they can play which may or may not necessarily be 'carer' focused. ILC has as one of its listed functions, 'Carer Support', as stated below:

### *Carer support*

*The ILC Policy Framework says ILC is intended to build the capacity of families and carers to sustain them in their caring role. This in turn will help people with disability. The kinds of carer activities that may be funded include:*

- linking carers and families to existing social and recreational activities that give carers a break from their caring role and connect them with the community*
- activities that promote carer wellbeing such as personal development, peer support and mentoring*
- linking carers into direct carer support services.*

In relation to the above, families are included in the first dot point but then the activities focus on 'carers'. Siblings have as big a need for activities that promote personal development, peer support, mentoring or links into direct sibling services as 'carers' do.

If ILC is truly committed to building the capacity of the whole family, the term 'carers' above should be replaced in all instances with 'families' or at least it should state 'carers and families'. There may also be a need to define 'carer' and 'family' in the early stages of the Framework. This would clearly be complex

and would need further consideration, but the definition should focus on 'family' that lives with the child/adult with disability.

ALL members of a family (especially those living together) are impacted by disability. If the goal is to have families care for children with disability in their own homes (as it should be) then governments, the community and programs such as the NDIS and ILC, need to recognise that and try to strengthen a family's capacity to manage the impacts, regardless of each member's individual role in that family.

Siblings experience much of the same stresses as parents when a child in the family has a disability. However, they are dealing with those stresses at an age when they may lack the maturity to understand and manage them. A young sibling may not be providing any care as such but be greatly impacted by the disability, especially if it involves difficult behaviour, both within the family home and in the community. Siblings are often given the message early on that the needs of others are more important, and that their role in life is to be a 'helper/carer', which can impact later relationships. Research shows that siblings are at risk for longer term mental health problems, regardless of whether they play a caring role.

They might lack information, feel isolated and have no outlet for the myriad feelings they may experience – grief, guilt, fear, responsibility, anxiety etc. They may need help with learning social skills or learning ways to relax and recover from the stresses of home. Some siblings have never had another child over to play, or gone on a holiday. Some are unable to take part in community activities as it is too difficult for parents to get them there. All of these things are a result of the disability and siblings should be included in early intervention approaches to ensure the whole family can function as best it can. Of course, some of the impacts will be reduced with NDIS services for the child with disability, but not all.

Importantly too, siblings are likely to be in the life of the person with disability longer than anyone – parents, special educators or therapists. It makes good sense to ensure that they are supported across the lifespan to ensure their own mental wellbeing but also to increase the likelihood that they will contribute to the social and emotional wellbeing of the person with disability. Even if not playing a 'hands on' caring role siblings can still contribute much in a range of other areas. And as the person with disability becomes older and parents are less able to provide care, siblings may take over some or all of the responsibility. It is quite unreasonable to expect siblings to take over these roles if they have been given no recognition earlier in their lives.

## ***Delivering ILC: The Five Streams of ILC***

*There are five streams of ILC which provide support to people with disability, their families and carers, and community and mainstream services. The streams are:*

- 1. Information, Linkages and Referrals*
- 2. Capacity building for mainstream services*
- 3. Community awareness and capacity building*
- 4. Individual capacity building*
- 5. Local area co-ordination (LAC)*

### ***Stream one: Information, linkages and referrals***

*Information, linkages and referrals will connect people with disability, their families and carers with appropriate disability, community and mainstream supports. People usually need information before they can access services and supports. The types of information that people with disability, their families and carers, may seek include:*

- Information about specific disabilities and the impacts of diagnosis*

This is crucial for the whole family. Often siblings, especially when young, lack information about the disability and can make up all sorts of beliefs about it eg they 'caused it' or they will 'get it', or that the child with disability doesn't care about them – the child with disability might not talk to them or might hurt the sibling – and information can help the whole family manage the disability and their responses to it more effectively. Siblings may not seek this information but they should be given it. As they become older they may have a range of fears and anxieties around the disability and its impact on them and their brother/sister, not only in their home but out in the community. And as they move into adulthood there may be other questions that arise – eg is there a genetic component to the disability, should the sibling have children of their own, will their brother or sister be able to live independently?

- *Information about targeted supports for people with disability, their family and carers, as well as generic community-based supports*

Parents regularly contact Siblings Australia to find out about supports for siblings. However there are very few – partly because of funding restrictions in a climate where there is no imperative to provide holistic family support, in particular, sibling support. There is a lot of rhetoric about providing ‘family’ support in the disability sector but no real action. In terms of community-based supports there are even fewer targeted to siblings due to a lack of awareness of the need.

There needs to be access for parents to:

- information on what sibling services are available in their local area
- information on how they, themselves, can support siblings, including links to relevant and reliable resources

- *information on specific disabilities that aims to help people with disability, as well as their families and carers, to best use available supports to promote independence and enhance their capacity to self-navigate service systems.*

Most siblings care deeply about their brother or sister with disability. As the person with disability (PWD) moves into adulthood, siblings often take more of a role in supporting the PWD. Many struggle to find a balance in aiming for a good life for the PWD and themselves. Some parents won’t talk with siblings about plans for the future. Sometimes siblings are left with the responsibility suddenly when a parent dies and they might have no idea about the specific needs of a brother or sister, how the system works, and the informal/formal roles they might need to play. Many find resistance in the sector to them being the ‘person responsible’. In situations where the PWD has an intellectual disability, in particular, siblings may need to investigate more formal roles such as guardianship but there are many barriers for them in pursuing these. There is also a lack of information available to siblings about when and if such roles are needed. Would more informal roles be sufficient or not?

There needs to be access by adult siblings to information about:

- support services available to manage the challenges
- services for their brother or sister with disability
- information about the different roles that siblings might play, both informal and formal, how they might advocate more effectively for their brother or sister, how to talk to parents about the future, how to engage with services, how to manage the needs of their brother or sister alongside their other commitments

Siblings need access to support via sibling focused agencies – the experiences and needs of siblings can be quite different from those of parent carers seeking information. Of course there will be some overlap but this is not complete. No-one understands the sibling experience as well as another sibling. They can provide each other with emotional support (when some adult siblings finally make contact with other adult siblings via the Siblings Australia online services, they are often overwhelmed with emotion, calling such contact a ‘lifesaver’) but also practical support and information about the system that supports their brother or sister with disability. This support also needs to come early, before siblings might take on any of this responsibility. From an early age siblings have much to gain from being in contact with others who are on ‘similar journeys’. Early intervention is crucial for siblings too – in order to enable them to adjust to the impact of the disability on their family.

### ***Stream two: Capacity building for mainstream services***

*People with disability, their families and carers, like all community members, access and interact with mainstream and universal systems and supports. An NDIS objective is to ensure people with disability connect with and access mainstream supports.*

This stream should also include an imperative for the whole family to be able to ‘connect with mainstream supports’. In relation to ‘building the capacity of mainstream and universal providers in meeting their responsibilities’, there should be greater emphasis on the whole family needing support. Currently, there is a lack of awareness of the needs of siblings across sectors. As mentioned, even in the general disability sector, there is a lot of rhetoric about family support, but the practice is very parent/carer focused. Many of the broader mainstream services such as family, mental health and education are not sufficiently aware and skilled in supporting siblings. Siblings have been known to come away from mental health services saying ‘what would they know?’

Millions of dollars are spent on parent/carer programs within both disability and mainstream services. Within these services there is some imperative for carer support via policy or practice guidelines. This is not the case for siblings, who can go through a lifetime without support of any kind. There is a need for workforce development around sibling issues in disability, health and education sectors. There is also a need for such holistic family approaches to be seen as part of the responsibility of organisations. As soon as a diagnosis is made the needs of siblings should be considered. The question should be asked regularly, ideally annually, 'What is the impact of the disability not only on the child with disability but also parents and siblings?' And, 'what do we need to do to ensure a good life for the child with disability and the whole family?' The answers will change over the years.

Siblings Australia has been providing training for many years but only to a small proportion of the sectors, again because there is no imperative for such services to increase their capacity in this area due to a lack of policy. Where there is an effort to provide sibling support it is mainly due to the commitment of individuals. The organisation has developed a number of resources for both disability and mainstream services eg the evidence based *Sibworks* peer support program, *Stronger Siblings* DVD, online resources.

Some of the information given out by very well-funded and respected mainstream services in relation to sibling support is less than desirable. A mainstream service might have expertise in parenting, for example, but it doesn't mean that they have expertise in other areas. At the moment there are no safeguards or quality assurance in this space which is very regrettable, especially as many parents access these services for information.

This then feeds into 'Quality and Safeguards'. Certainly ILC activities, through strengthening informal supports will make an important contribution to the informal safety net surrounding people with disability. Many siblings become strong advocates for the person with disability and fight to ensure that they are safe.

However, we also need to be mindful of the safety and quality assurance for sibling support approaches too – they are not necessarily all 'best practice'. A 2009 Siblings Australia Scoping Project showed that not only was there a paucity of sibling support programs but also the sibling support 'system' was uncoordinated and lacking in capacity, evaluation and 'best practice' approaches. How do we know they are providing benefit and not doing harm? Providers highlighted a need for further training and resources.

ILC may not be the appropriate avenue but consideration should also be given to the safety of siblings in their own home when a child with disability is aggressive. The Siblings Australia report on this issue is available [here](#)

### ***Stream three: Community awareness and capacity building***

*Investing in community awareness and capacity building will create opportunities for the social and economic participation of people with disability, their families and carers, improving personal outcomes and strengthening the connection between people with disability and their communities.*

There is little or no commitment by the community to make sure that these principles apply to whole families. The community does not have capacity to 'understand of the needs of families and carers'. There is some understanding of carer needs within the community, due to major funding of awareness campaigns and other activities, but little if any understanding of the sibling experience and their needs. Even within the disability community there is at best a lack of understanding, and at worst hostility. Posts on various NDIS/disability related discussion boards about the need to support siblings are often met with the claim that siblings are just looking for a 'pity party'. It is a very narrow view that is, unfortunately, widespread and regrettably has huge impacts on the overall life experience of both siblings and people with disability. On the one hand the NDIS/disability services are encouraging families to continue as 'informal supports' for the person with disability, but on the other hand there is a resistance to incorporate actual direct supports for siblings. There needs to be a commitment within the NDIS and the ILC to improve their knowledge and understanding of the experience of siblings, through ongoing meaningful research, and make this available to the community.

## ***Stream four: Individual capacity building***

*Individual capacity building fosters the principle of choice and control, improving outcomes for people with disability, their families and carers.*

Many siblings do not feel they have been given any choice or control. As mentioned earlier most siblings love and care about their brother or sister, and many choose to be active in their life – it can be a very mutually satisfying relationship. At the same time some have talked about being ‘groomed’ from a young age to take over the care of a brother or sister with disability, at the expense of their own life goals. There needs to be support for siblings to manage their own life alongside the needs of their brother or sister. For some the balance becomes very unhealthy, with them not developing their own potential, creating their own families, nor being fully active in the workforce.

Currently, siblings do not have much of an opportunity to have a ‘voice’.

With many people with disability at risk of becoming isolated, there is a huge need for the NDIS/ILC to engage with siblings; they have much to contribute.

Examples of individual capacity building supports are included in the Framework but the focus, apart from people with disability, is carers. For example:

- *programs for carers and counselling for people who are caring for someone with disability).*
- *parent breaks and programs to provide parents with skills and information about disability*
- *professional development for example for parents and education providers*
- *decision making supports and supports for self-advocacy, helping people with disability, their families, carers and communities to work together with and for people with disability; and*
- *fund and facilitate carer capacity building and support programs*

Currently, there are a range of existing supports available to parents to improve their capacity. Millions of dollars are spent on particular capacity building approaches via carer organisations, the MyTime program and other locally based parent support programs. Within the NDIS there is a support item ‘parent training’. There is nothing spent on sibling support at a national level and there is nothing within the NDIS support items that relate to siblings specifically. If there is such support for parents via the NDIS why is there not a similar item for siblings who are experiencing many of the same challenges as parents? Whilst the NDIS states that it supports families and strengthening of ‘informal supports’, this is not followed through with any real action.

Another issue is that Siblings Australia is registered to provide parent training in how to support siblings but there is little awareness throughout the disability/NDIS sector that this is important.

If the NDIS is interested in individual capacity of siblings as well as PWD and parents, then the agency or ILC needs to:

- Research what is available in the community for parents and for siblings and assess where siblings are catered for within the different funding streams of the NDIS.
- Research what roles adult siblings play, how many are involved and how many move away, and what the barriers and enhancers are to siblings remaining involved. This is crucial research that the NDIS should be carrying out in order to understand the capacity of the ‘informal supports’ that it so readily encourages.
- Ensure that the voice of siblings is heard via sibling based advocacy organisations, and that they have some ‘choice and control’. (The only organisation that actively advocates for siblings, Siblings Australia, has no funding.)
- Encourage the availability of sibling support approaches provided by ‘siblings for siblings’ to enable them to develop their own capacity, to ensure greater capacity to support their brother or sister with disability.

## ***Stream five: Local area co-ordination (LAC)***

*Local Area Coordination (LAC) is the development of relationships between the NDIS, PWD, their families & carers, & the local community (including informal networks, community groups, disability and mainstream services). This role is delivered through working with people with disability, their families & carers to consider their immediate & future goals & how these might be best achieved.*

If LAC is going to work meaningfully with PWD, their families and carers to consider goals and how they might be best achieved then local area co-ordinators need to have greater awareness of the needs of siblings, have siblings included in their brief and be expected to develop KPIs against those activities. For example, consideration needs to be given to the impact of the disability on the siblings and how those impacts might be managed more effectively within the family but also with support from outside the family.

### *The proposed outcomes for ILC and the best ways to measure them*

- *Do you agree with the nine outcomes outlined in the Consultation Draft? Is there anything else the Agency should consider?*

The nine outcomes would seem to be fair but again there is little emphasis on the whole family. I have made the following suggestions for additional words underlined for outcomes numbered 1, 6, 8 and 9.

1. *People with disability and their families have capacity to exercise choice and control in pursuit of goals.*
6. *People with disability and their families have appropriate support during their lifetime, including early intervention.*
8. *Increased community/mainstream awareness of how to support people with disability and their families.*
9. *Interests of people with disability and their families are faithfully represented in policy/infrastructure design.*

Also, in particular, for outcome 3 (Informal support and care arrangements are upheld and nurtured) to be meaningful, and able to be measured, there needs to be far greater understanding of how these informal arrangements can be nurtured most effectively. Who plays these roles and what are the barriers and enhancers for people to take on these arrangements? The agency should support research into the roles that siblings play and what helps and hinders that, especially when there is intellectual disability. We already know much about the roles of parents but little about siblings.

- *Do the nine outcomes cover everything you would expect to see in ILC?*

Again, if the NDIS wants to strengthen informal supports it needs to consider the needs of siblings over their lifetime. If this is not possible then the agency needs to be ensuring that this recognition of siblings comes from another area of government.

- *How should we measure each of the nine outcomes?*

It is difficult to have input into this until there is recognition of the whole family in outcomes. Most importantly, if there is recognition of the whole family there needs to be a strong focus on ensuring 'best practice' approaches, as well as 'sib to sib' ones.

- *How can people with disability, their families and carers and the broader community stay involved in measuring outcomes as ILC rolls out?*

First, siblings need to be given a 'voice'. One way for siblings to be involved would be through Siblings Australia, if the organisation was officially recognised.

- *Is there anything we should consider in setting up our data collection processes?*

Siblings should be included in case notes, or similar, in the same way that parents are. Also Participant Plans should include information on siblings and their involvement. There is a current gap in information about the numbers of siblings involved and their different roles.

- *Is there anything else you would like to tell us?*

Thank you for this opportunity. Siblings cannot continue to be overlooked within the disability sector and beyond. It is a huge gap. In order to strengthen the whole family there need to be meaningful support approaches for the whole family. If this is not possible via NDIS or ILC there needs to be some advocacy targeted at other levels of government to ensure there is recognition of siblings elsewhere.