

Response by Siblings Australia to the Review of the National Disability Advocacy Framework

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Introduction

[Siblings Australia](#) is pleased to respond to this Review. It is understood that the National Disability Advocacy Framework focuses on People with Disability (PWD) but advocacy for and by PWD, especially those with severe intellectual disability, cannot and should not be considered in isolation from their families.

This submission will first respond to some preliminary statements on the Review website, including previous work that informed the development of the Framework, before addressing the key questions posed by the Review. It will also explore why siblings and their relationship with a brother or sister with disability are important, and why they should be considered in current disability advocacy and broader NDIS/disability policy and approaches in the future. Finally, some recommendations will be included to improve the gaps that exist now regarding sibling acknowledgement.

Previous work

The Review website states: *Recent public consultation on the NDIS Quality and Safeguarding Framework and the NDIS Information, Linkages and Capacity-Building Framework, has already facilitated discussion and ideas on advocacy supports in the NDIS. Feedback from these consultations will be used to inform development of the new Framework.* I urge this current review to also consider the submissions previously provided by Siblings Australia to these two consultations i.e. with respect to the [ILC Framework](#) and NDIS [Quality and Safeguards](#).

The website also states: *The Australian Government funded National Disability Advocacy Program (NDAP), will continue to ensure people have access to advocacy support. The NDAP is also being reviewed in consultation with advocacy agencies.* If certain stakeholders do not have recognised advocacy agencies then it is less likely that their views will be considered. The program should be reviewed to include input from a range of stakeholders, not just from recognised advocacy agencies.

The website also states that the Framework's implementation is *'guided by the principles and priorities of Commonwealth, State and Territory Disability Services legislation, the United Nations Convention on the Rights of Persons with Disabilities, the National Disability Agreement and the National Disability Strategy.'*

The National Disability Agreement had the following joint reform priority: Enhancing **Family** (emphasis added) and Carer Capacity.

The National Disability Strategy set out a national policy framework for improving life for Australians with disability, their **families** (emphasis added) and carers. The NDS was the result of a large nationwide public consultation process, involving more than 2,500 people and reported in *Shut Out: The Experience of People with Disabilities and their Families in Australia*, which was formally endorsed by COAG on 13 February 2011. It should be noted that whilst this report includes 'families' in its title, the focus was on PWD and parents and, regrettably, siblings were not considered in any meaningful way.

The Strategy assured a number of outcomes related to families and carers:

*People with disability, their **families** and carers have access to a range of supports to assist them to live independently and actively engage in their communities.*

*The role of **families** and carers is acknowledged and supported.*

*Governments will work collaboratively with people with disability, **families** and carers, in developing policies, programs and systems.*

*Areas for action include (4.8): Promote and sustain community support networks which provide information and support to **families** and carers. (emphases added)*

These statements recognising the need to support families of a PWD have not been translated into 'outcomes' in the form of specific strategy or actions in the case of siblings of people with disability. Siblings have not been acknowledged or included in the discussions around the policies and programs that affect them, and there are no policies or programs related to siblings specifically. None of the input from Siblings Australia, through various submissions on behalf of siblings, over many years has been acknowledged or followed up. This lack of acknowledgement is a significant gap in family and disability policy and particularly alarming as, in most cases, siblings will have the longest relationship of any with the person with disability, long after parents, disability workers, special educators etc. It is hard to imagine that interest in the needs of and advocacy of/for people with disability can occur without a concurrent interest in their longest family relationships.

The section on 'advocacy' in the National Disability Strategy is also very weak in terms of persons with intellectual disability (PWID) having the opportunity to participate in decisions that affect their lives. It does not respect the enormous role that families play in advocacy in relation to the PWID, nor does it identify the need of different family members to have their own advocacy processes.

The other guiding document in the development of the Framework, the UN Convention on the Rights of People with Disability is one of the enablers of good disability practice in this country. The Convention certainly acknowledges the importance of family, when it states that *persons with disabilities **and their family members** should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities*

Article 23 goes on to say: *States Parties shall ensure that children with disabilities have equal rights with respect to family life.....States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their **families*** (emphasis added).

However, a 'rights-based' approach in relation to PWD cannot be viewed in isolation from the rights of families. Dr Kirsty Muir and Beth Goldblatt¹, argue that the different Rights Conventions (eg Rights of Persons with Disabilities, and Rights of the Child) should 'work together to ensure that young people with disabilities and challenging behavior and their parents and siblings all have equal rights'. They add that 'service system deficits mean that this is not always the case', and that governments 'need to provide a whole of family and community support approach to ensure the human rights of all family members are met'. They conclude that 'this is a complex ethical, moral and human rights issue that needs addressing by disability scholars and the disability community'.

Current review of National Disability Advocacy Framework

1. Do you believe the current Framework encompasses your **vision of advocacy** in the NDIS environment? If not, what changes are required?

Disability Advocacy means supporting people with disability: to stand up for their rights and choices; take part in their community; find employment and training; feel valued and respected; achieve their goals; and have their say.

There are two core propositions advanced in this submission: 1) that the Framework, whilst commendably seeking to address "*the support needs of people with disability, their families and carers*",

¹ K Muir and B Goldblatt 'Complementing or conflicting human rights conventions? Realizing an inclusive approach to families with a young person with a disability and challenging behaviour' (2011) Disability and Society (Volume 26, Number 5, August 2011, 629-642).

adopts a too general approach that fails to acknowledge the particular needs of people with disability (PWD) who are not able, or find it difficult, to have their own voice, in particular those with a severe intellectual disability (PWID). There needs to be a different advocacy approach when considering PWID and their families. Throughout this paper the term PWID will be used to refer to people who have a disability or injury that prevents or hinders them from taking part in self-advocacy, without support.

2) The Framework fails to acknowledge the important role and subsequent needs of families of PWD. Families and, in particular, siblings are missing from the framework and this is an unfortunate oversight. All PWD must be supported in having a voice and choice, but for many this is very difficult. Of course there are some families who do not promote the best interests of the PWD, but for the vast majority of PWD, in particular, their families are their strongest advocates.

The NDIS environment talks about the importance of 'informal supports'. We know that many people with disability (especially those with intellectual disability) face isolation in the community. And yet there is still little or no interest in finding out more about the important sibling relationship, the longest of any that the PWD is likely to have. There is no acknowledgement of siblings in policy or practice, in spite of siblings often being the most outspoken 'defenders' of the rights of their brother or sister with disability. Siblings often take over a caring role as they become older and parents are less able, but they are rarely asked to contribute to policy-making that might affect their lives and the lives of their brother or sister. Even if they do not take on a direct caring role, they can still contribute enormously to the wellbeing of the PWD, but again, unless they identify as 'carers,' there is no interest in them from a policy perspective. See 'Why siblings are important' below for further discussion on this.

Also generalised references to 'family' throughout government policy and programs, and within such Frameworks as this one, do not recognise that different members of the family have quite distinguishable needs that require specific attention and support if the person with disability (PWD) within the family is also to be fully supported. The roles and needs of parents are generally understood, and there is some attempt to provide advocacy for parent carers through carer organisations. However, many would argue that this does not provide adequate advocacy for parents of children/adults with intellectual disability, whose needs can be quite different to other groups of carers.

The roles and needs of siblings are much less understood and there is no effort at a national level to support advocacy for this group. Siblings of PWD are in need of their own advocacy mechanisms; not only to more effectively advocate for the needs of their brother or sister with disability in a changing environment, but also to advocate for their own needs. Siblings also need a voice and they need to be able to make choices. Unfortunately, often, siblings themselves are not good self-advocates, as they feel some disloyalty if they pursue their own interests and guilt for raising their own needs when those of a brother or sister seem so much more critical. If the new Framework cannot include families then the Framework needs to identify where and how families and in particular siblings might be given a voice.

Carers Australia plays an advocacy role in relation to 'Young Carers', but this policy area is only relevant for some siblings. It is Siblings Australia's belief that young siblings should not be included under this policy for a number of reasons and that they need their own advocacy organisation. See Addendum 1 for further discussion on this issue.

In conclusion, siblings are often the first advocates for a brother or sister with disability. As they become older, navigating the current disability service sector and also the NDIS as it rolls out, they often need help in developing the tools that are necessary to help ensure a good life for their brother or sister and themselves. The Framework needs to devote much greater, and more specific, attention to this particular perspective.

2. Are the **principles** of the Framework appropriate for guiding the delivery of advocacy for people with disability in a changing disability environment, including in the context of the NDIS? If not, what changes are required?

Overall the principles are appropriate. However, there needs to be greater consideration given to those people with disability that are unable or less able to voice their own needs. It is easier to promote the inclusion of certain people with disability in the community but for those with ID it is much more complex and again the family is one of the key drivers of their inclusion. Families, being part of the 'informal supports' recognised in the NDIS, also need support if they are going to be able to contribute in this way on behalf of PWID, in particular. In order for disability advocacy to ensure that the views that are being represented meet the individual preferences, goals and needs of people with disability, there needs to be special consideration given to PWID and their families. Disability advocacy MUST recognise and respect the diversity of people with disability in meaningful ways.

In order for disability advocacy to be able to foster effective strategic alliances to develop capacity to identify and respond to the needs of people with disability, it must engage with families and, in particular, with siblings who will be involved over a lifetime. This includes a deep analysis of what roles the different family members play and their ongoing needs.

3. Are the **outcomes** of the Framework still relevant or should different ones be included? If so, what should be included?

As in the discussion of principles above, the focus in the Framework with respect to outcomes is on community inclusion and developing a good life. However when reference is made to people with disability being able to make decisions, the section on being supported to make decisions is too simplistic. It needs to include more focused attention on who can support such decision making. Is it family members, is it providers, or a combination of both? Current practice does not include any active promotion of the involvement of families, and siblings in particular, in such decisions. Siblings are often overlooked - both as an important store of knowledge concerning the person with disability but also in terms of their own needs in order to be more effective in that involvement.

The last principle says that 'people with disability are actively involved in all aspects of the development, delivery and evaluation of disability and broader government policies, programs and services that impact them'. Again what of PWID who may have limited ability to contribute in meaningful ways to this discourse? Surely family members, including siblings, should be involved in this activity.

4. Are the **outputs** of the Framework still relevant or should different outputs be included?

One of the outputs states, 'Disability advocacy that is informed by an evidence base and is provided in an accountable and transparent manner'. The current evidence base is very sparse in terms of family involvement and therefore presents a challenge in terms of the achievement of this particular outcome. Again, we suggest that families are the foundation of advocacy for PWD, especially PWID, but they are largely overlooked. If a sound evidence base were to be developed with respect to families, there should be more questions asked about the involvement of families. There is certainly some data about parent carers – numbers, roles etc. However, in the case of adult siblings of PWD, there is scant evidence of the numbers of siblings involved in support and advocacy for their brother or sister, what roles they play, why some play these roles and why others move away from the family. There is little evidence either of what are the barriers and enhancers for siblings to be actively involved in support and advocacy for their brother or sister. These are all crucial questions if the NDIS is going to understand and develop 'informal supports' for PWD.

5. Does the Framework identify what is needed in the current and future disability environment? If not, what changes are required?

The Framework does not give adequate consideration to the role and needs of families of PWD, not only in relation to their caring role but also in terms of their contribution as 'informal supports' for the PWD. In order for these 'informal supports' to be better understood and maximised, the Framework must identify the need for family involvement in advocacy. Siblings need to be supported in their role as advocates for the PWD but also they need a peak advocacy body to ensure their own lifelong needs are

recognised and respected. This would ensure better outcomes for themselves but also better outcomes for the PWD over a lifetime.

If we recognise that PWD and, in particular, PWID often become isolated, especially as they age, surely it makes good sense to give some consideration to the longest relationship they are likely to have? Siblings Australia, the only national organisation to focus on siblings, has never been asked to contribute to discussions around advocacy or other disability policy directions, in spite of siblings having an intimate knowledge of disability. Whenever submissions have been provided to various consultations, these have largely been overlooked.

6. Do you have any other comments, thoughts or ideas about the Framework?

The aim of any advocacy framework, alongside the NDIS, is to *'provide better outcomes for people with disability, their families and carers.'* Siblings Australia would welcome the opportunity to be part of ongoing discussions about the Framework.

Why siblings are important

Relationship with PWD

Siblings are likely to have the longest relationship of any with the PWD. They have the potential to add much to the emotional and social wellbeing of the PWD, regardless of any 'carer' role they may or may not play, and such relationships can be mutually satisfying and supportive over a lifetime.

Many of the adult siblings that contact Siblings Australia, either directly or via its online forums, are wanting to ensure a good life for their brother or sister. They have a deep concern for their brother or sister's wellbeing, and are often ardent advocates. However, they may struggle with what role to play, how they might understand the service system and, in some cases, how to engage with parents on planning for the future. They talk of their role not being respected by many service providers and of not having any support to manage the challenges which would enable them to be a better support to a brother or sister.

Some siblings come to play an active role in supporting the PWD later in their lives, when parents are no longer able to play this role. They may have had no experience in navigating the disability (or NDIS) sector, and may find it difficult to find services that are right for them and right for their brother or sister with disability. It can be difficult managing the needs of their ageing parents, their brother or sister with disability and their own family, including children. They have often been referred to the 'club sandwich' generation. It can be difficult to pursue their own goals surrounding career and family.

Of course any sibling relationship can be complex and ever-changing. When one sibling has a disability, there can be even greater complexity and, in many cases, there is a breakdown of the sibling bonds. Sadly, many people with disability become socially isolated, which may have been prevented if family relationships were strengthened earlier.

Whilst intervention early is the best approach, if it comes later it can still have benefits for both the sibling and the person with disability. For example, one adult sibling who became involved in Siblings Australia's online support had not had contact with her brother (who had intellectual disability) for many years. She had felt enormous panic being with him as he had often abused her when they were younger. With the online support of peers, alongside reading stories from other siblings and therapy, she was able to eventually renew contact with her brother and they now enjoy a full relationship,

especially important as both parents have died. However, it is regrettable that this support could not have come earlier, in childhood.

Impact on sibling's life

Siblings are also important in their own right. Whilst this issue does not fit well into the National Disability Advocacy Framework, the impacts on family cannot be ignored. Whilst some can be enriched by their experiences of growing up with a brother or sister with disability, others face a situation of major stress without the maturity to cope. This can have immediate and longer term impacts on their mental, emotional and social and physical health. Siblings Australia has heard from many parents who are worried about the impact on other children in the family; some have noted that the sibling has become more of a worry than the child with disability. Some siblings are physically abused by a brother or sister with disability. As mentioned earlier, the rights of a PWD cannot be considered without also considering the rights of a sibling to safety. This is a child protection issue. Siblings Australia has written a [report](#) on a small research project it carried out in 2012 on the impact of difficult/aggressive behavior on siblings. The work of Kirsty Muir and Beth Goldblatt, referenced earlier, reinforces the importance of considering the rights of the whole family.

An Australian Institute for Family Studies report from 2008² showed that siblings have higher rates of depression regardless of any caring role they may or may not play. An Adult Sibling Project carried out by Siblings Australia in 2009 showed that many siblings struggle into adulthood and turn to unhealthy coping strategies. Regrettably, many siblings move away from their family due to significant stresses and a lack of support during childhood and into adulthood to manage those stresses.

Siblings and the NDIS

The NDIS, as part of its proposed “effective, integrative response to disability”, may provide some opportunities to recognise the importance of siblings, and progress from the policy documents discussed earlier, but current responses from government and the NDIS are not overly encouraging. When Siblings Australia asked the current government about specific support for the advocacy needs of siblings we were told that 5 disability advocacy organisations (PDA, CDA, FPDN, NEDA, and WDA) had been funded as the National Cross-Disability Alliance to give PWD a voice. Are these organisations now supposed to cater for the needs of siblings? I think not. Particular questions about siblings, sent to the National Carer Gateway Advisory Group, were totally ignored and the response that was received showed no understanding of the issues for siblings and parent carers who might be concerned about them. It also indicated that this \$33million project for carers was interested in siblings only when ‘adult siblings are carers’. This is such a narrow view and totally ignores the important contribution siblings can make to a PWD’s social and emotional wellbeing from childhood and beyond, even if the sibling is providing no direct care. Siblings Australia is continually told by government that ‘siblings should access mainstream services’, and that the organisation just needs to look out for relevant grants. These and other responses are totally inadequate and do not indicate any change in approach regarding the value of siblings and the importance of giving them a voice. In spite of strong [advocacy](#) by Siblings Australia and other agencies e.g. the Royal Australian and NZ College of Psychiatrists, siblings are still very much overlooked.

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*

Recommendations

1. Siblings are recognised as an important part of the lifelong social support and advocacy system for people with disability regardless of whether they are playing a direct caring role or not
2. Research is carried out to better understand the role that siblings play in both advocacy and support for their brothers and sisters, especially when the person with disability has limited capacity for self-advocacy. This should also include better data about the numbers of siblings and the roles they play, as well as research into the barriers and enhancers that influence the level of sibling engagement.
3. Within the new advocacy framework and within the NDIS in general there is consultation on how best to support siblings (including the voices of siblings), both for their own benefit but also for the benefit of their brother or sister with disability.
4. Siblings Australia is recognised within the new advocacy framework and within the NDIS as a valuable resource for both families and providers, and as an important peak advocacy organisation for siblings, which ultimately will be of benefit to PWD.

If these recommendations cannot be included in some way within the National Disability Advocacy Framework then this Review should at least acknowledge this gap in relation to siblings of people with disability in broader policy and programs. Advocacy for people with disability cannot be considered in isolation from their families, who are often the one constant in their lives.

Kate Strohm, August 2015

Addendum 1

Siblings or young carers/carers

This addendum to the submission to the Review of the National Advocacy Framework will address some of the issues that come up about using the term 'young carers' or 'carer' in relation to siblings of children and adults with disability. This is important to understand in terms of whether this group is being adequately recognised or not, both in terms of their own needs and, more importantly for this review, whether they are being supported adequately in their role as potential advocates for PWD.

Let me say at the beginning that there are Young Carer programs that do an excellent job of supporting young people who have caring responsibilities. My belief is that it is wonderful if siblings can gain support through any avenue. Certainly for some siblings the term 'young carer' gives validity to the role they play in supporting their brother or sister with disability. Some young people wear this role with pride.

However, for the majority of siblings, this is not a sound policy direction. It is preferable to use a family approach to disability and to acknowledge that all members of a family are affected, regardless of any caring role, when one member has a disability and that all members can contribute different things to a person with disability.

Initially, Young Carers were identified as children who had caring responsibility for a parent – usually a single parent family where there was not another adult to provide the care. It was a hidden problem and it was encouraging that people started to recognise these young people who were playing a primary carer role and who had much too much responsibility. My first question though is why these children were allowed to continue performing these roles. Certainly all children in a family should be expected to contribute to the family – performing household tasks, helping each other out etc.

However, caring for a parent and needing to provide intimate daily living activities for them e.g. showering, toileting, but also things like cooking, cleaning and washing, should not be the responsibility of children but, instead, social services. And if a child is missing school due to their caring responsibilities then, again, government should be providing these supports, given the Australian government is a signatory to the Convention on the Rights of the Child. However, the focus for Siblings Australia is on siblings and, therefore, this issue needs to be left for others to consider.

Slowly, siblings have been included under the policy umbrella of ‘young carers’, and on the surface this could seem to be a good thing. However there are three main reasons why Siblings Australia has concerns about this.

1. If we go down the ‘young carer’ path, we will miss many siblings.

A little four year old with an older brother with a disability that involves difficult, even aggressive behaviour may not provide any care but is certainly in need of support. A ‘carer’ model overlooks many family members – it is focused on the carer role, and in order to be eligible for such support, a family member needs to satisfy certain requirements. I have known of some siblings who have not been able to access ‘young carer’ programs because they are not the primary carer (most families with a child with disability have at least one parent who takes on the primary carer role) or, in one case, only one sibling out of two was allowed to attend the program. The education bursaries that are offered to young carers would only rarely be available to siblings as they would not meet the criteria. Some ‘young carer’ services are more flexible, allowing siblings to access support, but some have stricter guidelines, based on the amount of caring they provide. Of course, some siblings *are* performing significant caring roles, but many others do not play any extra caring role beyond the usual helping out that happens in all families. Even if siblings are not playing a significant caring role, they can still contribute much in terms of emotional and social support to a child/adult with disability, and this should be recognised too.

We know that siblings can be at risk regardless of any caring role, and that many of the concerns of siblings are not related to a caring role. In fact, if siblings do provide care, that may be one of the more beneficial aspects of their experience. There is money put into ‘young carer’ programs by the Australian government, but none to specific sibling programs. If we continue with this model, over time, many siblings will continue to miss out on support.

So whilst young carer programs are providing a very useful service for many young people, siblings should have their own policy and programs that are geared to their particular needs. In this case, one size does not fit all. Siblings should not be included under this policy umbrella.

2. The differences in sibling and ‘young carer’ experiences

Some siblings certainly do play a ‘carer’ role for their brother or sister with disability. And for many this caring role may be the most positive part of their experience. They may love and care about their brother or sister and do all they can to make his or her life easier. But, for many others, the responsibility and other challenges involved can cause stress and anxiety. Providing care to a parent and growing up next to a brother or sister with significant additional needs can be quite different. A sibling might be quite confused by what is happening around them, especially if there are significant medical or behavioural issues. Their identity might be affected, and they may grow up feeling less important than the child with disability - which can have huge impacts on their self-worth. There can be enormous grief and guilt about their brother or sister, when growing up next to them, and in realising that the child with disability is not able to do many of the things a sibling can do – a kind of ‘survivor guilt’. There may

be a lot of stress at home which can lead to anxiety, and embarrassment when out in public. Other people's reactions can add to the stress. Many siblings take on a lot of responsibility for a brother or sister, and can worry about the future in terms of what might happen if mum and/or dad is no longer able to provide care. This sense of responsibility can carry over a lifetime, and affect the sibling's own life decisions e.g. should they move away to pursue career options, will they find a partner to share the responsibility, should they have children themselves?

Children who provide care to a parent may have some of the same issues but many will be quite different. There may be more practical issues for these children. They may need more support to manage their education and stay involved in the community. Of course, siblings can also require support for these more practical issues, but it is often the psychological issues that predominate. Siblings Australia's ongoing [research](#) has explored further these lifelong and complex challenges and impacts for siblings.

3. Identity issues

There are identity issues related to a 'carer' or 'young carer' model. Even parents don't always like being referred to as 'carers' – they want first to be parents. Such terms can add to the sense of difference that many families with disability feel. For siblings, such a label can add to their sometimes unhealthy sense of responsibility. Many siblings grow up as the 'good child', the 'helper', or 'giver', which can lead to a number of problems, including with relationships as adults. The book *Burdened Children* addresses this in the chapter, *The Parentification of Siblings of Children with Disability or Chronic Disease* (Lamorey, 1999). Certainly, siblings can gain much from contributing to the family in a number of ways, but I question the increasing use of the label 'young carer' for children who may have increased responsibility. It can add to their narrow view of themselves as a helper or carer for others, subjugating their own needs in the process. Such approaches go against the principles included in the International Convention on the Rights of the Child, to which Australia is a signatory.

Within various consultations by Siblings Australia, adult siblings say they would prefer to access support via sibling support services (by siblings for siblings) rather than 'carer' services, but acknowledged that there was little, if any, available.

It is a complex issue that cannot be explored in depth here, but suffice to say using such a definitive label for siblings can add to the responsibility they feel. Of course, they might add to the care and support of the child with disability but they should be brothers and sisters first.

4. Role of siblings in the future

As mentioned, many adult siblings play a crucial role in the emotional and social wellbeing of their brother or sister with disability. The relationship can be mutually satisfying; much like the sibling relationships of those without disability. Other siblings do not remain involved. For some, the expectation of being a primary 'carer' becomes too much and they move away from their family.

At one Siblings Australia workshop, a father who had attended a consultation with other parents of an adult child with disability, relayed that all 17 parents who attended had other adult children (siblings) who had moved interstate. Of course, there could be a number of reasons why this was so, but it seemed a high percentage.

There is a need for research on why these family relationships may be strained but, from talking with families, two main reasons emerge. First, many siblings have had no support and subsequently may

struggle into adulthood, and therefore feel a need to distance themselves from family issues. And second, many siblings become concerned that they may be left with the responsibility of full-time caring if anything happens to their ageing parents. Some believe that governments are trying to include siblings under the 'carer' model so that families, governments and the community can expect that siblings take responsibility when parents are no longer able to.

In Australia, there is now discussion about 'ageing carers' and the implications of this. If we were to listen to siblings and provide what they need over a lifetime (ie, support regardless of any caring role they may play), outcomes might be very different, both for them and for their brother or sister with disability.

5. Dignity and stigma issues

Finally, it is important to consider the impact of a 'carer' model with regard siblings on those with disability. This model sets up a power differential and does not consider dignity issues for people with disability. What 16-year-old boy wants his 14-year-old sister to be known as his 'carer'? The use of this term isolates him further from other young people in the community and can add to the sense of being a 'burden'. Families of children with disability want to take part in the community, just like other families. What is needed is a 'family support' model that is more enabling and inclusive, not more isolating.

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