

June 2016

Siblings Australia is pleased to have the opportunity to contribute to this discussion. A previous submission to the NDAP was provided in August 2015 and can be viewed here:

<http://siblingsaustralia.org.au/assets/submissions/review-of-the-national-disability-advocacy-framework-1.pdf>

This current submission will cover the following themes:

1. Background
2. Problems with current advocacy models
3. Sibling advocacy
4. Recommendations

Background

This submission will be influenced by a variety of experiences – as a sister and lifetime advocate for my sister who had cerebral palsy with both physical and intellectual disability; as the founder and Director of Siblings Australia, where I have been an advocate for siblings for 17 years; and again, through that work (which involves training, counselling, developing resources and services, research etc.), I have a broad understanding of the issues faced by families in the old and emerging disability sector.

Siblings Australia believes very strongly that family is a crucial part of the whole advocacy puzzle especially in relation to those people with disability who cannot advocate for themselves. We believe that siblings will likely have the longest relationship of any with the person with disability (PWD) and so it is crucial to nurture and sustain that relationship as much as possible from an early age. At the moment siblings are nowhere in government policy or programs – this is a huge gap.

In relation to the NDAP, the objective of this program is to ensure people with disability are provided access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights, enabling full community participation. NDAP agencies receive funding under the Disability Services Act 1986, so they can provide disability advocacy support using a disability advocacy support model. Disability advocacy support models are focused on individual advocacy, systemic advocacy, citizen advocacy, family advocacy, self-advocacy and legal advocacy. This submission focuses on systemic and family advocacy.

Problems with current advocacy funding models

1. Systemic disability advocacy

Current disability advocacy models fund systemic advocacy groups which tend to promote their own ideology at the expense of certain individual needs. They largely speak for people with physical or only mild ID, those who are more able to make choices of their own. Families are often disparaged by such groups as are their attempts over many years to provide dignified options for their family member. Certain groups seem to want to rid our community of ADEs, for example, when there are many people for whom this model works well. It is certainly important to make sure these agencies provide choices and that people who can access open employment are trained and supported to do so, but many people would be lost without ADEs. Many love their work and are supported to carry out tasks that, while fairly mundane, give purpose, social contact and, most of all, dignity. A person may have no idea how much money is earned or what can be bought with such but there can still be joy in getting that weekly pay packet, no matter the amount. There is a big danger that if this type of advocacy continues the ‘baby will be thrown out with the bathwater’.

It is the same with small group homes. Of course many group homes are badly run and need massive improvement. And of course there should be ongoing attempts to ensure people with high needs

are able to be involved in the community, but for many people this model also works well, especially if they are given privacy and choices.

This cohort of vulnerable people with ID (PWID) are largely unrepresented in disability advocacy services. Their families are often their only voice protecting them from a system that does not understand them. And there are many problems in families having that voice.

2. Family advocacy

As mentioned it can be difficult for parents and siblings to have a voice within 'disability advocacy'. It can also be difficult for family members to have a voice in 'family advocacy'. There is a lot of confusion and uncertainty around formal roles such as current Guardianship, 'person responsible', Power of Attorney. Families are told different things by different people and the rules are different in each state of Australia. Some parents, after years of devoted care, are denied Guardianship when a person reaches 18 years of age, for no real reason. There are stories of parents not even being consulted on medical issues, at huge detriment to the PWD and the family. Where the person has intellectual disability this is a particular concern, as family members are likely to have the greatest understanding of the PWD, especially if there are difficult behaviours. Sometimes the ideologies of 'choice and control' are seen as being more important than the welfare of the individual. Certain Disability Advocacy agencies only advocate for what they believe a person with an intellectual disability SHOULD want. And, in some cases, they actually lobby government and its agencies against the family having a voice or any say at all. Of course we need to safeguard PWID from family members who do not have the best interests of the person in mind, but they are few and far between and can be assessed during any Guardianship proposal.

Sibling advocacy

Sibling advocacy is very tied up with family advocacy but with some extra complexity. Many families work together to ensure a 'good life' for their family member with disability, especially when that family member has an intellectual disability and/or communication difficulties.

There are two particular themes related to sibling advocacy: advocacy for siblings themselves to manage the challenges they face; and assisting siblings to be advocates for a brother or sister with disability, especially intellectual disability.

1. Advocacy for siblings. Whilst many parents would say that 'carer' agencies are inadequate and out of touch, there ARE national organisations that advocate for the needs of parent carers. There are current policies and programs related to parent carer wellbeing. There are no such policies or programs related to siblings, even though siblings often experience very similar stresses to parents. And siblings are usually dealing with those stresses from childhood, without the maturity to cope. Research shows that many siblings develop their own mental and physical health problems as a result. As they become older, some siblings have a very close relationship with their brother or sister and take an active role in their life. Some are given little choice in terms of the roles they play – some are forced to give up their own life goals to support a brother or sister. As soon as possible, some move away from their family. We know so little about what the barriers and enhancers are with respect a sibling remaining involved in the life of the PWD.

We also know that many people with disability become isolated. If we are genuinely concerned about a PWD we must be concerned about the person who will likely have the longest relationship of any with them. We should be doing all we can to strengthen and nurture that relationship – as brothers and sisters, NOT necessarily carers. Siblings are affected regardless of any caring role they may or may not play. They also have the potential of adding much to the social and emotional wellbeing of the PWD, again regardless of any caring role they may play. Siblings Australia has been the only voice for siblings at a national level for over 17 years but, in spite of a national and international reputation, cannot get any funding for this important work. For further discussion about issues related to siblings and 'carers' see our [submission](#) to the discussion paper on the new Integrated Carer Support Services.

2. Siblings as advocates for a PWD. Many siblings, as mentioned, do remain closely involved with their brother or sister with disability and enjoy a very mutually satisfying relationship. The sibling might take an active role in the life of the PWD and advocate on their behalf – even from a very young age. As they become older, and parents become less able, many take on a bigger role in terms of advocacy and overseeing the needs of the PWD, especially those with ID. For some this is a gradual process, for others it happens suddenly when a parent dies or develops a serious illness. Some are totally unprepared for this and they often struggle with understanding the system and what roles they can play (formal and informal) within that system to support their brother or sister. Many find that services do not want or know how to include siblings in a meaningful way. Sometimes there is suspicion about their motives, but most times it is just ignorance of the sibling experience and their needs. Do they need Guardianship? Should they take out Administration orders (financial management role)? Some are told to get Power of Attorney but this is very misleading as people with an ID who do not understand legal documents cannot appoint a P of A. Some siblings have been told by particular Guardianship boards that they will never appoint siblings as a Guardian, without even considering the options. Some have been told that Guardianship is not necessary. However, when siblings try to advocate on behalf of the PWID in a particular disability service they are often dismissed as not having a legitimate role. Being seen as the ‘responsible person’ is not enough for many siblings to be able to engage effectively with disability agencies. For example, they may need to access medical files to be informed about medical issues. However, privacy laws might prevent this from happening without a more formal role in place. Sometimes siblings will become stronger advocates for their brother or sister as their parents age or are no longer able. After years of fighting with the system and caring for their ‘child’, parents can be ‘burned out’. Siblings are often able to come in with new energy to advocate for better services and options. Of course, some siblings are also in the ‘burned out’ category if they have been the main person responsible over many years, having forgone their own life goals to ensure the wellbeing of their brother or sister. Some of the information provided through carer agencies may be relevant to some siblings who are taking on more of a ‘carer’ role, but some is not always relevant or appropriate. Siblings need their own support – by siblings for siblings – through counselling, advocacy, information, peer support. Siblings Australia provides some of this but should be resourced to expand this work. Ultimately, support for siblings ensures they get what they need in terms of information and tools to better advocate for and with their brother or sister, especially those with ID.

Recommendations

In order to improve current advocacy approaches through the Disability Advocacy Program the following needs to be implemented:

- A national peak advocacy organisation for siblings of all ages (separate to disability and parent carer advocacy) so that they can receive the support they need to ensure a ‘good life’ for themselves and their brother or sister with disability over a lifetime
- A national unified system of formalised roles that families need to advocate most effectively for and with their family member with disability, with clear guidelines as to need/suitability
- Greater representation of people with intellectual disability, especially those who cannot speak for themselves, in systemic advocacy, through representation by family members (parents and/or siblings)

Contact details

Kate Strohm

PH: 0408720558

E: kate@siblingsaustralia.org.au