

1 June 2016

Disability and Carers Group
Department of Social Services
disabilityadvocacy@dss.gov.au

Re: Review of the National Disability Advocacy Program

Dear Sir/Madam,

Carers NSW welcomes the opportunity to respond to the *Review of the National Disability Advocacy Program Discussion Paper*. Our submission focuses on the recognition and inclusion of family members and friends (carers) who support people with disability in New South Wales (NSW).

Carers NSW is an organisation for people who provide informal care and support to a family member or friend who has a disability, mental illness, drug or alcohol dependency, chronic condition, terminal illness, or who is frail. Carers NSW supports and advocates for carers in NSW and is the only state-wide organisation that has all carers as its primary focus. Carers NSW is also part of the National Network of Carers Associations, which works collaboratively to lead change and action for carers.

Thank you for accepting our submission. For further information, please contact Sarah Judd, Policy and Development Officer, on (02) 9290 4744 or email sarahj@carersnsw.org.au.

Yours sincerely,



Elena Katrakis
CEO
Carers NSW

Carers NSW submission to the Review of the National Disability Advocacy Program

Background

The Review of the National Disability Advocacy Program (NDAP) Discussion Paper describes effective disability advocacy as promoting, protecting and ensuring full and equal enjoyment by people with disability of all human rights, enabling full community participation. Formal advocacy services such as those funded by the NDAP play a key role in pursuing and achieving these objectives. However, in many cases advocacy is performed largely by family members and friends (carers). Many carers also support the people with disability they care for to self-advocate and to access formal advocacy services, or access services on their behalf.

While not all people with disability identify as having a carer, data from the 2012 Survey of Disability, Ageing and Carers indicates that most people with disability in New South Wales (NSW) require assistance with at least one activity, and the majority of these people receive at least some support from carers.¹ Every caring role is different, but some of the key supports carers provide are listed in the table below.

Table 1: People with a reported disability receiving assistance from informal providers (carers), New South Wales 2012

Activities for which assistance is received	People receiving assistance
Mobility	288,800
Transport	253,700
Property maintenance	241,100
Household chores	233,800
Cognitive or emotional tasks	220,600
Health care	212,300
Self-care	174,500
Reading or writing tasks	112,200
Meal preparation	108,800
Communication	81,300
<i>Total no. people receiving informal assistance with at least one activity</i>	<i>721,100</i>
<i>Total no. people with disability needing assistance with at least one activity</i>	<i>774,000</i>

Source: Australian Bureau of Statistics²

Many of the supports listed in Table 1 could be critical in enabling people with disability to self-advocate or to access formal advocacy services. For example, a carer may need to assist a person with disability to express their wishes or to physically access an advocacy service. In some cases, a carer may even act on behalf of a person with disability, accessing advocacy services to deal with issues they have identified that the person they care for is facing.

Carers NSW engages with many carers who are seasoned advocates, usually without any particular training or formal recognition. For many carers, advocacy is a normal part of life. Whether or not they use the term, advocacy is often something they have been doing for years or even decades. Carers advocate because they have to in order to improve the support and inclusion of the person they care for.³

However, performing the role of advocate can come at a cost for carers, who have to balance advocacy with their often demanding caring role, not to mention other responsibilities such as working or raising a family. The cost is usually the carer's own wellbeing. Many carers report that they are simply too busy or exhausted to advocate effectively. Others lack the skills and confidence required to do so.⁴ Carers need support if they are to advocate effectively for the people with disability they care for, help them to access formal advocacy services and empower them to self-advocate.

Acknowledging the role of carers and including them in service provision are key principles enshrined in the Statement for Australia's Carers, part of the Commonwealth *Carer Recognition Act 2010*:

- 6 The relationship between carers and the persons for whom they care should be recognised and respected.
- 7 Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.⁵

Transition to the NDIS

The inclusion of Family Advocacy and Parent Advocacy in the current NDAP acknowledges the importance of supporting carers to advocate with and for people with disability. Family and Parent Advocacy needs to be a priority as the National Disability Insurance Scheme (NDIS) rolls out, as carers will play a key role in supporting many people with disability to prepare for and access the NDIS. Many carers will support participants with the planning process, and many will assist participants with managing and implementing their plan. Some carers will naturally take an advocacy role, but others may require the support of a friend, service provider representative or advocacy service.

Information and resources need to be readily available to carers to help them advocate effectively. Adequate advocacy services also need to be on offer for carers who do not feel confident advocating themselves. However, of the 28 NDAP providers in NSW, only two currently specify in the online provider list⁶ that they provide family advocacy. Some carers have reported to Carers NSW that local advocacy services in the Hunter trial site have appeared stretched in the area's transition to NDIS.

Carers NSW has also heard that some service providers are offering support with pre-planning and attending planning sessions with existing clients, even though they are not funded to perform this function. While their prime motivation is to facilitate a smooth transition, it raises concerns about conflict of interest and service quality, and indicates that alternative advocacy support may not be adequate.

If disability advocacy services were better resourced and more intentional about building the capacity of carers, advocacy support would be more equitable and independent. People with disability and their carers need informed, trained advocates available to sit down with them as they prepare for the NDIS, engage in the planning process and implement their plan. Carers who are not equipped to self-advocate, or who lack informal networks to assist, also need access to independent, professional advocates to attend planning sessions with them.

Although additional funding has been provided through the NDAP to address advocacy needs particular to the NDIS context, the current Framework does not identify two areas in which advocacy will be critical as the NDIS rolls out: the availability of advocates to attend planning sessions, and access to advocacy services for people who are not eligible for NDIS packages.

Ongoing block funding for disability advocacy that extends to people with disability and their carers who do not have access to an NDIS package is also very important, as not all people with disability will be eligible for an NDIS package.⁷ While the soon to be finalised Information, Linkages and Capacity Building (Tier 2) component of the NDIS will go some way towards meeting the advocacy needs of this group, it is not a dedicated advocacy program, and will not be independent of the NDIA. Therefore, Carers NSW believes that the Department of Social Services needs to ensure that there are no advocacy service gaps created by the transition to the NDIS for people with disability and their carers.⁸

Carer advocacy

Carers NSW has long advocated for the inclusion of carer advocacy in the NDAP. This will become even more important as the NDIS rolls out, given the limited entitlements of carers in the NDIS policy framework.⁹ Carers NSW believes that under the NDIS carers should be able to have a voice, receive support and challenge decisions in their own right. Shortcomings in the participant's plan and funded supports may negatively impact on the carer as well as the person with a disability. For example a carer may be unhappy with the level and nature of the caring responsibilities they are providing under the plan, or the level of support they are offered in their caring role. If not addressed, such circumstances could negatively impact on a carer's wellbeing, and ultimately on their capacity to care.

The "pressing need" for carer advocacy services was recognised by the House of Representative Standing Committee on Family, Community, Housing and Youth report into the inquiry into better support for carers¹⁰. Carers NSW believes that carers need their own advocacy services primarily because they are service users in their own right. This is supported by Principle 5 in the Statement for Australia's Carers:

- 5 Carers should be acknowledged as individuals with their own needs within and beyond the caring role.¹¹

While the Department of Social Services (DSS) is currently designing an Integrated Carer Support Service, carer advocacy has not been identified as a key component of future funded carer support. The Information, Linkages and Capacity Building (ILC) component of the NDIS was also touted to bring capacity building opportunities to carers, but as it has been refined, the ILC has demonstrated a decreasing focus on carer specific support. Carers NSW argues that all carers must be entitled to advocacy in their own right, either through the carer support sector or, for carers of people with disability, through the NDIS or NDAP.

Conclusion

Carers NSW supports the continuation and review of the NDAP, bringing it into line with the evolving sector as it transitions to the NDIS. However, we strongly believe that carer support and carer advocacy need to be a greater focus at this critical time.

¹ Australian Bureau of Statistics (2014) 'Disability, Ageing and Carers, New South Wales', *Disability, Ageing and Carers, Australia: Summary of Findings, 2012*, Catalogue no. 4430.0, Australian Bureau of Statistics, Canberra.

² Ibid.

³ Carers Victoria (2011), *Discussion paper on individual advocacy and caring families*, October 2011, Carers Victoria.

⁴ Ibid; ARAFEMI Victoria (2011), *ARAFEMI Victoria Carer Advocate Program Research Report*, ARAFEMI Victoria, Melbourne.

⁵ *Carer Recognition Act 2010* (Cwth)

⁶ Department of Social Services (2015), 'Provider list', *National Disability Advocacy Program Provider Search*, <http://finder.dss.gov.au/disability/ndap/providerlist.aspx?service=NDAP>, accessed 21 July 2015.

⁷ Carers NSW (2014) *The NDIS one year in: Experiences of carers in the Hunter trial site*, Carers NSW, Sydney.

⁸ Ibid.

⁹ Ibid.

¹⁰ House of Representatives Standing Committee on Family, Community, Housing and Youth (2009) *Who cares...? Report on the inquiry into better support for carers*, Parliament of the Commonwealth of Australia, Canberra.

¹¹ *Carer Recognition Act 2010* (Cwth)