Carers NSW
AUSTRALIA

22 July 2015

Advocacy and Access Team
Department of Social Services
disabilityadvocacy@dss.gov.au

Re: Review of the National Disability Advocacy Framework

Dear Sir/Madam,

Carers NSW welcomes the opportunity to provide a submission in relation to the Discussion Paper for the Review of the National Disability Advocacy Framework. Our submission focuses on the recognition and inclusion of family members and friends (carers) who support people with disability.

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 providers systemic advocacy but not individual advocacy. 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,

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

Background

The Discussion Paper for the Review of the National Disability Advocacy Framework (the Framework) defines advocacy as 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.[1] Formal advocacy services play a key role in achieving these outcomes. However, in many cases advocacy is performed 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, 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.[2] 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
Total no. people receiving informal assistance with at least one activity	*721,100*
Total no. people with disability needing assistance with at least one activity	*774,000*

Source: Australian Bureau of Statistics[3]

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.[4]

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.[5] 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.[6]

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

The inclusion of Family Advocacy and Parent Advocacy in the current Framework acknowledges the importance of supporting carers to advocate with and for people with disability. Carers are mentioned in two further contexts. The first notes that the role of families and carers will be taken into consideration, but the needs and aspirations of the person with disability are paramount.[7] The second reference occurs in relation to person centred service delivery, which is defined as meaning:

> "that people with a disability and their families drive service planning, have control over important decisions which affect their lives and are able to access responsive, flexible service options that capitalise on their strengths and respond to their changing needs." [8]

These principles closely align with the approach of the National Disability Insurance Scheme (NDIS), which recognises the important support roles played by carers. However, Carers NSW is concerned that the concept of "people with disability *and* their families" driving planning and decision making is not consistently upheld in the current Framework. In order to address this, the language used by the Framework needs to be more inclusive of carers. Examples are noted in subsequent sections of this submission.

Family and Parent Advocacy also needs to be addressed throughout the framework along with individual advocacy, rather than simply being listed in the glossary. Family and Parent Advocacy need to be a priority as the NDIS rolls out, because 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 list[9] that they provide family advocacy. Some carers have reported to Carers NSW that local advocacy services in the trial site appear stretched. Carers NSW has 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.

2. Are the principles of the Framework appropriate for guiding the delivery of advocacy for people with disability

Overall, Carers NSW believes that the new Framework needs to use more inclusive language addressing the families and carers of people with disability, where appropriate. Specifically, we would recommend referring to families and/or carers in *Principles b, d, g* and *h.*

Principle d

In many cases, building the capacity of informal carers can be just as important as building the capacity of people with disability. Additionally, carers often play a key role in facilitating capacity building for the person they care for. Carers should therefore be provided with information and training opportunities that strengthen them in these roles.

Principle g

Carer diversity should be taken into account. Some groups of carers face particular barriers to accessing services, which may also impact the people they care for. For example, if a carer has difficulties communicating in English, has limited literacy skills, or has a disability themselves they will find it difficult to support access to advocacy services for the person they care for. All information should be available in multiple modes: online, in print form, over the phone and in person. Language should be clear and free of jargon, with any translated material written at an appropriate level of language for the intended audience.

Principle i

Greater clarity as to the meaning of the “strategic alliances” is required including what these are in relation to the NDIS and whether they involve carer networks and carers’ organisations.

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

Carers NSW supports the outcomes in the current Framework, however some clarification is required as to how these outcomes will be achieved in the NDIS environment. For example, independence, addressed in *Outcome e*, will be critical to ensure that people with disability and carers receive appropriate advocacy support in the NDIS. Consistent with the recommendations of the Productivity Commission in its 2011 report,[10] Carers NSW believes that advocacy services should be funded and provided separately from the NDIS to prevent conflict of interest.

Carers NSW also recommends that *Outcome g* be more inclusive of carers in its language and application, as carers who are involved in supporting people with disability are also service users and offer valuable information pertaining to the development, delivery and evaluation of services.

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

Carers NSW supports the outputs in the current Framework, however, as Family and Parent Advocacy are types of Individual Advocacy, *Outcome a* should refer to these services meeting the individual needs of people with disability “and their families and carers”.

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

The current Framework does not identify two components of disability advocacy that will be critical as the NDIS rolls out: the availability of advocates to attend planning sessions, and the availability of advocacy services to people who do not have access to NDIS packages. The importance of independent advocates being available to attend planning sessions was addressed earlier in this submission.

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 very important, as not all people with disability will be eligible for an NDIS package.[11] 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. 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.[12]

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

Carers NSW has long been advocating 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.[13] 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 carers[14]. 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.[15]

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.

Carers NSW also notes that the recent reduction in funding to several disability-specific peak bodies[16] is of concern to many families, as these organisations hold valuable specialist knowledge and networks that inform their advocacy. The voices of systemic advocacy need to be diverse to represent the diversity of people with disability and their carers, and provide accurate feedback about the impact of the NDIS on diverse groups. While Carers NSW understands the Government’s desire to streamline the system, we are concerned that these changes will reduce the ability of such organisations to positively inform and influence the development of the NDIS, to the detriment of the people they represent.

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[1] Department of Social Services (2015), *Discussion paper: Review of the National Disability Advocacy Framework*, June 2015, Australian Government, p. 2.

[2] 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.

[3] Ibid.

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

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

[6] *Carer Recognition Act 2010* (Cwth)

[7] Disability Policy & Research Working Group (2008), *National Disability Advocacy Framework*, Community and Disability Services Ministers' Advisory Council, Australian Government, p. 1.

[8] Ibid, p. 7.

[9] 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.

[10] Productivity Commission (2011), *Disability Care and Support*, *Productivity Commission Inquiry Report, Volume 1,* Commonwealth of Australia, Canberra.

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

[12] Ibid.

[13] Ibid.

[14] 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.

[15] *Carer Recognition Act 2010* (Cwth)

[16] Macey, J. (2015), 'NDIS: Advocates argue funding cut will make scheme participation difficult for those with intellectual disabilities', *ABC News*, 25 February 2015, http://www.abc.net.au/news/2015-02-25/ndis-participation-made-difficult-by-funding-cut-advocates-say/6262116; Woodley, N. (2014) 'Disability advocates warn Government cuts to social services grants could affect NDIS rollout', *ABC News*, 24 December 2014, http://www.abc.net.au/news/2014-12-24/disability-advocates-fear-social-services-cuts-will-affect-ndis/5986528.