

23 October 2019

NSW Ageing and Disability Commissioner  
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Carers NSW wishes to thank the NSW Ageing and Disability Commissioner for the opportunity to provide a submission to the NSW Disability Advocacy Review. This submission is informed by the experiences of carers of older people and people with disability in New South Wales (NSW), as expressed by carers in the Carers NSW 2018 Carer Survey and relayed to Carers NSW staff.

A carer is any individual who provides care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Carers NSW is the peak non-government organisation for carers in New South Wales (NSW). Our vision is an Australia that values and supports all carers, and our goals are to:

- Be a leading carer organisation in which carers have confidence
- Actively promote carer recognition and support
- Actively support carers to navigate a changing service landscape that will be characterised by ongoing policy reform
- Promote connected community experiences and opportunities for carers that are inclusive of diverse carer groups
- Lead and advocate for carer-specific and carer-inclusive policy making, research and service delivery
- Continue to be a quality-driven, responsive and carer-focused organisation.

Carers NSW would like to commend the NSW Government on the establishment of the NSW Ageing and Disability Commissioner, an important initiative to address and prevent instances of abuse, neglect and exploitation among vulnerable adults in the community. Having advocated in past Pre Budget Submissions to have State disability advocacy funding continue following the closure of Ageing, Disability and Home Care (ADHC) in 2018, Carers NSW is pleased that this funding has continued until now and that the sector is currently open to review. Carers NSW believes State funding to support disability advocacy remains a joint responsibility of the NSW and Commonwealth governments.

### The role of carers in disability advocacy

In 2015, approximately 80% of people with disability in Australia who needed assistance received it from informal supports.<sup>1</sup> Almost 90% of people who received informal support reported receiving assistance with communication, and over 87% reported receiving assistance with reading or writing tasks.<sup>2</sup> In many cases, it is carers who provide this informal support.

In NSW, approximately 48% of households with a reported disability contained one or more primary carers.<sup>3</sup> Additionally, approximately 31% of carers in NSW have a disability themselves.<sup>4</sup> Carers are often active in supporting people with disability to understand, access, plan, organise and administer both mainstream and formal supports. This means, that when there are barriers to access, or issues arise with the quality or safety of services, carers are often highly involved in supporting people with a disability to address and overcome these barriers.

### The growing need for disability advocacy in NSW

With the rollout of the National Disability Insurance Scheme (NDIS) in NSW, people with disability and their carers are not only facing complex new systems with a reduction in certain types of support; many are also dealing with multiple other mainstream service systems which they require support to navigate effectively including, but not limited to, health, education, justice, accommodation and employment. The reduction in case management support across the sector and the intended withdrawal of State disability advocacy funding will increase the urgent need many carers have for one-to-one, intensive support.

*“Applied for a [NDIS] review twice. Currently using a disability advocate to fight for our core funding with the Ombudsman so that we can access our funding we applied for to cover his support worker and therapy needs.”*

- Carer NSW 2018 Carer Survey respondent

The Carers NSW 2018 Carer Survey found that since the rollout of the NDIS in 2016, over two thirds (68%) of respondents caring for an NDIS participant and almost half (48%) of respondents caring for a person under the age of 65 who was not accessing the NDIS had experienced an increase in time spent organising supports for their care recipient.<sup>5</sup> Many carers have reported to Carers NSW that the additional strain associated with navigating

disability reforms has placed immense strain on their health and wellbeing, in some cases to such an extent that it has disrupted caring arrangements.

<sup>1</sup> Australian Bureau of Statistics (ABS). (2016). ABS Survey of Disability, Ageing and Carers: 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2015. Available online at: <https://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features12015?opendocument&tabname=Summary&prodno=4430.0&issue=2015&num=&view=>, last accessed 12 September 2019.

<sup>2</sup> Ibid

<sup>3</sup> Ibid

<sup>4</sup> Ibid

<sup>5</sup> Carers NSW (2018), *Carers NSW 2018 Carer Survey: Unpublished data*.

Additionally, with the transition to more person-centred disability services, carers' needs are increasingly being addressed indirectly through the supports that their care recipient receives. One such example of this is respite; opportunities to take breaks from the caring role. While respite for carers is not named as a service type in the NDIS Price Guide, participants can be funded for services that have the potential to provide carers with a break, such as support to undertake activities and participate in the community. However, despite recent Administrative Appeals Tribunal (AAT) decisions which have enforced the importance of supports that give carers an opportunity to take a break from caring,<sup>6</sup> carers are still reporting significant difficulty accessing these supports through NDIS participant plans.

*"Had difficulty with NDIS responding to authorising purchase of motorised scooter even though it was included in participant's first plan, and spent another 18 months for it to be approved... Eventually resolved because I accessed advocacy service to negotiate with the NDIS on their behalf"*

- Carer NSW 2018 Carer Survey respondent

In these situations, where carers are required to submit appeals or negotiate with the NDIS, in the absence of carer advocacy services, carers have reported that they have had to engage disability advocates with specialised knowledge of the NDIS to support them to access the vital respite that enables them to continue to provide care to their care recipient. This increased demand for disability advocacy has placed additional strain on disability advocacy services, which are already struggling to meet the growing demand.

### **The impact of reduced disability advocacy funding on carers**

Many carers inform us that they rely on specialist disability peak and advocacy organisations across NSW for reliable information about the condition of the person they care for and support in accessing services. There are concerns that these needs will not be adequately covered under the NDIS Information, Linkages and Capacity Building (ILC) grants or National Disability Advocacy Program (NDAP), especially in regards to State funded mainstream specific services.

Jenny\* cares for her son Adam\* who has Down Syndrome. She said: *"I have found the support of the Down Syndrome Association of NSW, IDEAS and NSW Council for Intellectual Disability invaluable, as with Family Advocacy. They have been a source of practical information and a way to connect with the wider community. Also they provide inspiration and ideas through lots of positive stories. Lastly they are an important voice for us all."*

\*Names changed

<sup>6</sup> Carers Australia (2018), Review of NDIS respite care decisions by the Administrative Appeals Tribunal – A resource for carers. Available online at: <https://www.carersaustralia.com.au/files/download/?id=1919>, last accessed 12 September 2019.

The impending cessation of this funding scheduled for 30 June 2020 is causing many carers distress, as it is evident that much specialist knowledge and familiar, grassroots support will be lost to families at the time they need it most. Furthermore, any reduction in disability advocacy funding is likely to place further strain on carers, with the expectation that they will pick up additional informal advocacy responsibilities, even though many do not have the time, skills and resources to do so.

The Productivity Commission's 2011 *Disability Care and Support* report raised concerns that the funding of disability advocacy through the NDIS would create a conflict of interest, whereby disability advocacy services would at times be forced to directly challenge their funding body, potentially impacting on their ability to represent their client or client group to the best of their ability for fear of having their funding cut.<sup>7</sup> However, carers have identified a further conflict of interest faced by disability advocacy services due to ongoing reductions in State funding, where providers have been forced to seek other sources of income, often through the direct provision of NDIS services, jeopardising their ability to provide and focus on independent disability advocacy.

Susan\* cares for her son with a disability. Susan reported that since the condition specific advocacy organisation she has accessed lost its State advocacy funding, it is now operating both under a commercial model with receipt of NDIS funding and as a fundraising charity. Susan reported that since this transition, she and other carers have not been able to get the information or support they have been asking for and are feeling increasingly unrepresented and alienated.

\* Name changed

### Future directions for disability advocacy in NSW

Carers NSW acknowledges that the Commonwealth has made a commitment to the funding the NDAP, NDIS Appeal Support program and Disability Representative Organisations,<sup>8</sup> however, these commitments alone are not equivalent to the previous funding levels received by disability advocacy services in NSW. Furthermore, many of the service systems in which people with disability and their carers need assistance with advocacy fall within State and Territory responsibility. In a complex service environment with ongoing change and jurisdictional complexity, the funding shortfall for disability advocacy in NSW will continue to grow with any reduction of NSW Government disability advocacy funding.

The Productivity Commission's 2017 *NDIS Costs* report recommended that states and territories that had reduced or ceased disability advocacy funding should restore it and increase data collection and evaluation, citing the ongoing importance of independent

<sup>7</sup> Productivity Commission. (2011). *Disability Care and Support: Inquiry report*. Available online at: <https://www.pc.gov.au/inquiries/completed/disability-support/report>, last accessed 13 September 2019.

<sup>8</sup> Parliament of Australia (2019). Joint Standing Committee on the National Disability Insurance Scheme: Progress report, March 2019. Available online at: [https://www.aph.gov.au/Parliamentary\\_Business/Committees/Joint/National\\_Disability\\_Insurance\\_Scheme/General\\_NDIS/~/\\_media/Committees/ndis\\_ctte/General\\_NDIS/report.pdf](https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/General_NDIS/~/_media/Committees/ndis_ctte/General_NDIS/report.pdf), last accessed 15 October 2019.

disability advocacy.<sup>9</sup> The Joint Standing Committee on the NDIS has further highlighted the importance of disability advocacy, noting that all levels of government have a responsibility to support disability advocacy.<sup>10</sup> The Commonwealth Government has in turn recommended ongoing investment in disability advocacy from the states and territories to ensure that people with disability and their carers can resolve issues within state-run service systems.<sup>11</sup>

Carers NSW urges the NSW Government to continue to fund disability advocacy at both individual and systemic levels whilst gathering further data, beyond this report, that explores the met and unmet need for disability advocacy in NSW. Ongoing and increased investment in disability advocacy in NSW will ensure that all people with disability in NSW have fair and equitable access to services and supports and can be supported against potential injustices, whilst reducing strain on carers who would otherwise be required to fill this advocacy gap.

Thank you for accepting our submission. For further information, please contact Melissa Docker, Policy and Development Officer, on (02) 9280 4744 or [melissad@carersnsw.org.au](mailto:melissad@carersnsw.org.au).

Yours sincerely,



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<sup>9</sup> Productivity Commission 2017, *National Disability Insurance Scheme (NDIS) Costs*, Study Report, Canberra. Available online at: <https://www.pc.gov.au/inquiries/completed/ndis-costs/report/ndis-costs-overview.pdf>.

<sup>10</sup> Parliament of Australia (2019). Joint Standing Committee on the National Disability Insurance Scheme: Progress report, March 2019. Available online at: [https://www.aph.gov.au/Parliamentary\\_Business/Committees/Joint/National\\_Disability\\_Insurance\\_Scheme/General\\_NDIS/~/\\_media/Committees/ndis\\_ctte/General\\_NDIS/report.pdf](https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/General_NDIS/~/_media/Committees/ndis_ctte/General_NDIS/report.pdf), last accessed 15 October 2019.

<sup>11</sup> Ibid.

