

8 July 2022

Disability Advocacy Policy
GPO Box 9820
Department of Social Services
Canberra ACT 2601

Carers NSW wishes to thank The Department of Social Services (the Department) for the opportunity to provide a submission for the draft National Disability Advocacy Framework 2022-2025 (the Framework). This submission will highlight the important role of family and friend carers in relation to disability advocacy and the need to consider and include them in the Framework as such. The submission will also highlight the need to create clear, measurable outcomes as well as establish accountability to ensure equitable access to disability advocacy and support the success of the Framework.

Carers NSW is the peak non-government organisation for carers in New South Wales (NSW). 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 part of the National Carer Network and a member of Carers Australia. 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.

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

Yours sincerely,



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CEO
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Introduction

Carers NSW thanks the Department of Social Services for the opportunity to provide feedback on the National Disability Advocacy Framework 2022-2025 (the Framework). Carers NSW supports reforms that aim to improve the quality and accessibility of disability advocacy for people living with disability and their carers.

Carers NSW believes in the importance of autonomy and self-determination for people with disability and is supportive of policy and practice that facilitates their meaningful participation in community life. While we recognise that not all people with disability receive informal support or would identify as having a carer or carers, family members and friends are important in the lives of all Australians, and the Australian Bureau of Statistics (ABS) reports that the majority of Australians with disability who need assistance receive at least some of that assistance from a family member or friend; in many cases, on a daily basis.¹

Many carers also report living with disability themselves. More than one in three (37.4%) primary carers report living with disability, higher than the incidence of disability reported in the broader Australian population.² People with caring responsibilities and disability experience additional barriers accessing meaningful work and education, participating in the community and achieving optimal health outcomes, as they navigate and balance their own needs and self-determination with those of the person they care for.

Carers NSW welcomes the development of a new Framework, which is likely to result in improved access to disability advocacy. However, Carers NSW has concerns that the current draft of the Framework does not adequately consider or include carers. Furthermore, there are concerns that the Framework is broad and has limited mechanisms that enable measurement of outcomes, are enforceable or that establish accountability. Carers NSW believes that for the Framework to be most effective, it must be carer inclusive and establish clear accountability across all levels of government.

Carer recognition and inclusion

Recognising the important role of carers in the Framework

Carers NSW has significant concerns that there is no mention of family and friend carers throughout the entirety of the Framework. While Carers NSW respects that the Framework is person-centred and rights based, carers often play a significant role in the lives of people with disability, including providing assistance with advocacy, often in lieu of adequate formal advocacy services.

The important role of carers in representing the interests and rights of the person they support is highlighted in Australia's Disability Strategy 2021-2031,³ within the *Policy Priority 3: The role of informal support is acknowledged and supported of Outcome Area: Personal and Community Support*. It was also supported by the Review into Disability Advocacy in NSW: A report by the NSW Ageing and Disability Commissioner (the Review),⁴ which identified the important role of carers in disability advocacy as well as the positive outcomes for carers that can be achieved through disability advocacy. The Review also highlighted the need for targeted systemic advocacy within the disability

¹ Australian Bureau of Statistics (ABS) (2019) *Survey of Ageing, Disability and Carers 2018*, TableBuilder Dataset, available online at: www.abs.gov.au

² Ibid.

³ Commonwealth of Australia (Department of Social Services) (2021), *Australia's Disability Strategy 2021-2031*, available online at: <https://www.disabilitygateway.gov.au/sites/default/files/documents/2021-11/1786-australias-disability.pdf>, viewed 07 July 2022.

⁴ NSW Ageing and Disability Commission (NSW ADC) (2019), *Review into Disability Advocacy in NSW: A report by the NSW Ageing and Disability Commissioner*, available online at: https://www.ageingdisabilitycommission.nsw.gov.au/__data/assets/pdf_file/0008/765530/Review-into-Disability-Advocacy-in-NSW.pdf, viewed 07 July 2022.

advocacy context that focuses on the rights and needs of families and carers of people with disability, as supporters and users of both mainstream and disability services and supports.

Carers NSW believes that in line with the Policy Priority 3 within the Strategy and the Commonwealth *Carers Recognition Act 2010*, that carers be considered and where appropriate, identified and included within the Framework as supporters and users of disability advocacy. Carers NSW has concerns that failure to include carers throughout the Framework is likely to result in subsequent disability advocacy programs and policies that do not recognise the key role of carers and are therefore not carer-inclusive.

Additionally, Carers NSW believes that it must be clear within the Framework that disability advocacy must take a supportive and inclusive approach towards carers, with carers' expertise, rights and preferences acknowledged and respected, in balance with those of the person with disability that they care for. Where a carer is present and tensions exist between the rights and preferences of a person with disability and their carer, Carers NSW believes that the Framework should encourage a supportive approach, aimed at finding solutions that best uphold the rights and preferences of both parties. This is likely to be the most effective approach for supporting positive, sustainable caring arrangements.

Acknowledging the intersectionality between caring and disability

Carers living with disability face compounding barriers to social and economic participation. Carers NSW believes that this intersection must be acknowledged to ensure that carers living with disability themselves also have access to disability advocacy as needed, and that their unique experiences and needs as a carer living with disability are acknowledged and considered in the planning and delivery of disability advocacy. Carers NSW believes that within the Principles of the Framework, caring responsibilities should be explicitly identified within 'Respect for Intersectionality and Diversity' as a diversity characteristic that can result in forms of discrimination and disadvantage.

Carers NSW advocates for the Framework to specify the relevant stakeholder groups who are compliant to it, including services, businesses, independent traders and government. Stating the stakeholder groups within the Framework will ground the responsibility for achieving these outcomes onto the stakeholder, reducing a perception that it is the individual who must advocate for these rights for advocacy.

Ensuring the effectiveness of the Framework

Clear guidelines for disability advocacy programs

The draft Framework states that in agreeing to the Framework, the Commonwealth, state and territory governments commit to sharing the responsibility for disability advocacy in their jurisdictions. However, it also states that how each advocacy program is developed, funded and managed is at the discretion and responsibility of the funding government. Carers NSW is concerned that limited guidance on minimal funding levels or service requirements may result in a lack of consistency or inequitable access to disability advocacy across Australia, with carers often left to fill service gaps where advocacy services are not available locally or in a timely manner.

Carers NSW recognises the need for disability advocacy programs to be flexible and responsive to local need. The Disability Advocacy Futures Program (DAFP)⁵ in NSW is one such disability advocacy program developed based on findings from a review of disability advocacy services, experiences and

⁵ NSW Government (2019), *NSW Disability Advocacy Futures Program: Improving the disability advocacy system for people with disability in NSW*, available online at: https://www.ageingdisabilitycommission.nsw.gov.au/__data/assets/pdf_file/0008/765863/Disability-Advocacy-Summary.pdf, viewed 7 July 2022.

needs within the NSW jurisdiction.⁶ However, Carers NSW has concerns that without specifying minimum funding, service provision, and service access standards such as timeliness, there will be ongoing inequitable access to disability advocacy between states and territories. Furthermore, some states and territories, including NSW, may develop or continue disability advocacy programs that are not adequate to meet demand.

Carers NSW acknowledges that the Framework will also be accompanied by a work plan to drive the implementation and its objective, principles and outcomes, and this document may include more detailed information in regards to clear, measurable guidelines for disability advocacy programs. However, it is challenging to assess the strength and usefulness of the Framework without being able to review the work plan in tandem.

Carers NSW recommends that the associated work plan be developed and released alongside with the Framework for review, and that the outcome of these documents include minimum requirements for funding, service distribution, and program expectations and inclusions for each state. This action will enable a proper assessment of the capacity and usefulness of the Framework to be responsive to the needs of people with disability and their carers.

Establishing accountability and redress pathways

The Department is commended for grounding the Framework in international and national human rights tools and mechanisms. However, Carers NSW has concerns that the intangible nature of the Framework may make it challenging for people with disability and their carers to advocate for their rights as outlined in the Framework, and to seek recourse where disability advocacy policy, programs and services do not align with the Framework.

Carers NSW advocates for the specification within the Framework of the government bodies or agencies who will be responsible for oversight of the Framework and its implementation. Establishing and outlining clear accountability for the Framework will ensure that people with disability and their carers are able to take tangible steps to seek recourse or redress where the Framework is not implemented in its intent or adequately upheld.

Conclusion

Carers NSW again thanks the Department for the opportunity to provide feedback on the Framework. Carers NSW believes that ensuring that the framework is carer inclusive, measurable and creates clear accountability is key for ensuring its success and improving outcomes for people with disability and their carers.

⁶ NSW ADC (2019).