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National Disability Strategy Governance and Engagement Section
Department of Social Services
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Carers NSW welcomes the opportunity to respond to the Department of Social Services NDS and NDIS Outcomes Framework Introductory Paper. Carers NSW previously responded to the Department's National Disability Strategy Position Paper on behalf of the National Carer Network. This submission will continue to highlight the need for greater carer recognition and inclusion within the outcomes framework to ensure the success of the National Disability Strategy and National Disability Insurance Scheme for people living with disability.

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, Policy Officer at melissad@carersnsw.org.au or on (02) 9280 4744.

Yours sincerely,



Elena Katrakis
CEO
Carers NSW

Introduction

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 independence and meaningful participation in community life. The review of the National Disability Strategy (the Strategy) and National Disability Insurance Scheme (NDIS) Outcomes Framework represents a valuable opportunity for Carers NSW to highlight the crucial role of family and friend carers in the lives of people with disability and ensure carers' interests and outcomes are adequately reflected.

As noted in our previous submission, Carers NSW recognises that not all people with disability receive informal support or would identify with having a 'carer'. However, many Australians with a reported 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 Furthermore, many primary carers also have a reported disability themselves, at more than twice the rate of non-carers.²

According to the Australian Bureau of Statistics there are approximately 2.65 million carers across Australia, including 861,600 primary carers.³ For many, caring is a 24 hour-a-day job with emotional, physical and financial impacts that can also affect their health and wellbeing as well as participation in employment and community activities. It has been estimated that value of informal care provided by family and friend carers has risen to \$72 billion each year,⁴ with Deloitte Access Economics projecting it would cost the Australian Government just under \$1.5 billion per week to replace.

Recognising and supporting the important role of carers in the lives of people with disability and in facilitating the inclusion of people with disability will be critical to the ongoing success of the Strategy and the NDIS. Therefore, Carers NSW would again like to encourage the inclusion of carers in the intent and measurement of the effectiveness of the Strategy as well as in the measurement of the effectiveness on the NDIS.

Carer recognition and inclusion

Carers NSW commends the Department on its acknowledgement and recognition of carers in some of the outcomes within the Framework⁵. However, Carers NSW is concerned that family members and carers of people with disability are only identified and acknowledged in the outcomes of two of the six proposed domains. Furthermore, we are concerned that the limited inclusion of carers in sub-outcomes and in carer focused example indicators will result in limited consideration of carers in data collection and reporting. We believe more attention needs to be paid to the integration of carer recognition throughout the Framework. It is particularly important that carers not only be included in principle, but also in practice, with genuine efforts to promote carer recognition and support being reflected across key areas.

Carers NSW in our submission in response to the Position Paper on behalf of the National Carer Network⁶ highlighted the need for a Strategy that recognises and addresses carers' needs, enabling carers to have an enhanced quality of life and participate as valued members of the community, as per the objective outlined in the NDA. While there has previously been a National Carer Strategy, the lack

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

² Ibid.

³ Australian Bureau of Statistics (2019) *Disability, Ageing and Carers, Australia: Summary of findings, 2018*, New South Wales Tables, Canberra.

⁴ Carers NSW analysis based on national findings from Deloitte Access Economics (2020) *The economic value of informal care in Australia in 2020*.

⁵ Department of Social Services (2020a) *Improving outcomes for people with disability under the National Disability Strategy and the National Disability Insurance Scheme*, available online at <https://engage.dss.gov.au/wp-content/uploads/2020/10/nds-outcomes-framework-accessible-pdf-final.pdf>

⁶ Carers NSW (2020) *Carers NSW submission on behalf of the National Carer Network in response to the National Disability Strategy Position Paper*

of a current national strategy for carers has resulted in reduced emphasis on the importance of a whole-of-government and whole-of-society commitment to supporting carers' interests, even amid the major reforms to the carer support sector occurring during this period. Regardless of whether or not a new National Carer Strategy proceeds, Carers NSW believes that the Disability Strategy and associated NDS and NDIS Outcomes Framework should explicitly support the inclusion of carers of people with disability in its objectives and implementation.

As highlighted in our previous submission,⁷ a key step to improving carer inclusion in the Strategy would be referring to carers in the vision statement, and Carers NSW believes that this should also be reflected in the Outcomes Framework. Furthermore, the Framework must increase inclusion of carers by creating greater provisions, responsibilities and obligations regarding supports for carers, as well as look to identify and address the service gaps that are currently being filled by carers. Reducing strain on carers and providing adequate carer supports will ensure that carer health and wellbeing is maintained and that carers can continue to provide care and support more sustainably to people with disability.

It is also important that the Framework align with and complement any future National Carer Strategy, the Commonwealth *Carer Recognition Act 2010* and equivalent carer strategies and carer recognition legislation at state and territory level, in order to strengthen existing carer policy coordination and clarify which level of government has which responsibilities, enabling optimal outcomes for carers and the people with disability they care for.

Measuring outcomes and reporting

Many people with disability are supported to increase or optimise their participation in the community by their carer or carers. A well-rounded Framework should acknowledge carers in this role and look to create accountability for governments to adequately support carers as this also supports the outcomes of the people with disability that they care for. Carers NSW believes that including carers in the outcomes, outcome indicators and outcome measures in the Framework is essential to ensuring that carers are also a focus of the Framework and that governments and non-government organisations are held accountable for improving the inclusion and participation of carers. However, Carers NSW has concerns that current data sources may not be thorough or frequent enough to capture adequate information on people with disability, their family and carers, to enable regular and accurate outcome reporting.

Current national surveys that collect data on people with disability and their carers are infrequent and limited in their depth of information. As highlighted in our previous submission,⁸ The Survey of Disability, Ageing and Carers (SDAC) and the NDIS Participant and Family and Carer outcome measures do not capture adequate data to report on against the proposed Framework. Furthermore, limited data sharing between levels of government and different government agencies creates additional difficulties in identifying and monitoring intersectional and cross-jurisdictional issues.

Carers NSW raised concerns in our previous submission⁹ about comments made by the Hon. Stuart Robert MP¹⁰ in regards to the limited collection or coordination of state and territory disability information at a Federal level during COVID-19. Carers NSW is concerned that these comments are indicative of the limited availability of nationally collected and consistent data on people with disability, especially those who are not eligible for the NDIS. Carers NSW believes that in order to report on the Outcomes Framework, overall collection, sharing, monitoring and reporting on data must be improved and

⁷ Ibid

⁸ Ibid.

⁹ Carers NSW (2020) *Carers NSW submission on behalf of the National Carer Network in response to the National Disability Strategy Position Paper*.

¹⁰ Commonwealth of Australia. House of Representatives (2020) *Questions without notice, COVID-19: Disability* (Official Hansard), available online at: https://parlinfo.aph.gov.au/parlInfo/genpdf/chamber/hansardr/b8197f17-5287-4edd-8f7f-5577701ad7c3/0157/hansard_frag.pdf;fileType=application%2Fpdf

increased. We also believe that this should also include improved collection and reporting of carer data to enable more regular and accurate reporting on the Strategy against the Outcomes Framework.

Carers NSW contends that as users, co-users or significant stakeholders impacted by the development and delivery of disability-specific and mainstream services and supports, carers should be represented and considered in data collection. The Framework should encourage the collection of carer data in all relevant data sets across Australia (including those held by the Department of Social Services, National Disability Insurance Agency, Services Australia and state and territory departments responsible for overseeing disability policy and services) as best practice to increase the depth of carer data available. Without better understanding of the number, diversity and experiences of carers, it is not possible to monitor the effectiveness of the Strategy in optimising outcomes for carers, and subsequently, the people they care for.

Further considerations

Inclusive emergency preparedness and response

The 2019-20 bushfires and ongoing COVID-19 pandemic have highlighted the inadequate level of preparedness the broader community and mainstream services have had in supporting people with disability and carers to prepare for and respond to such crises. Carers NSW has heard from many carers who have found information and support limited in meeting their own needs and the needs of the person they care for. Appropriate accommodation, access to assistive technology or life-saving equipment, personal protective equipment (PPE) and essential food or medication have been identified by carers as being particularly difficult to obtain, often resulting in significant distress for both carers and the people they care for.

Carers NSW believes that the Framework should create clear responsibility and accountability for the increased inclusion of people with disability and their carers in planning and preparing for emergencies. In addition to this, the Framework should place an onus on governments to ensure that people with disability and their carers are considered and included and receive targeted support where appropriate in COVID-19 recovery measures.

Ongoing disability reform

With ongoing reform of disability policies and programs likely to result from the Tune Review, the Disability Royal Commission, and ongoing inquiries of the Joint Standing Committee on the National Disability Insurance Scheme, the Framework must be comprehensive while creating space for the Strategy to develop over time based on the recommendations that arise from these ongoing proceedings. Carers NSW believes that the Framework should align with emerging findings and recommendations from current reviews and create greater accountability for governments to act on these recommendations to ensure that inquiries, reviews and commissions are effective and result in improved outcomes for people with disability and their carers.

Conclusion

The development of a new National Disability Strategy and associated Outcomes Framework provides an important opportunity to ensure a clear, whole of government plan for increased inclusion and participation of people with disability and their carers. Carers NSW believes that a key to the success of the Strategy and Framework will be the inclusion of carers, as the key supporters of people with disability, throughout all areas. A dual focus on the overlapping and unique needs of people with disability and their carers will ensure optimal inclusion and participation of both groups.