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Committee Secretary
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Carers NSW welcomes the opportunity to provide a submission to the Community Affairs Legislation Committee (the Committee) in response to the Aged Care Bill 2024 [Provisions] (the Bill). Carers NSW commends the Australian Government on the development and introduction of the new Bill and associated aged care reforms that aim to improve the quality and safety of aged care services for all Australians who are ageing and their carers. This submission will reinforce Carers NSW feedback to the Department of Health and Aged Care (DoHAC) in response to the exposure draft of the Bill, focusing on the need to embed and strengthen carer recognition, inclusion and support throughout the new Bill to ensure the sustainability of informal care arrangements into the future.

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.

Yours sincerely,

Elena Katrakis
CEO
Carers NSW

Introduction

Carers NSW thanks the Committee for the opportunity to provide feedback on the Aged Care Bill 2024 [Provisions] (the Bill). Carers NSW welcomes this landmark opportunity to strengthen the rights and safety of people accessing aged care services. A new Aged Care Act also provides an opportunity to improve recognition and supports for family and friend carers. Carers are vital in assisting, supporting and advocating for people who are ageing and are often active participants in the aged care system themselves. However, Carers NSW is concerned that they continue to receive limited recognition and inclusions within the new Bill.

Carers NSW believes in the importance of autonomy and self-determination for people who are ageing and is supportive of policy and practice that facilitates their independence and meaningful participation in community life. Carers NSW recognises that not all people who are ageing receive informal support or would identify as having a 'carer'. However, the 2022 Survey of Disability, Ageing and Carers (SDAC) found that of the approximate 1.7 million people who are ageing who require assistance with at least one everyday activity, 71.6% (approximately 1.2 million) reported receiving some assistance with everyday activities from informal supports, most commonly their spouse who is often ageing themselves.¹

While Carers NSW is pleased to see the inclusion of the Commonwealth (Cth) *Carer Recognition Act 2010* within the new Bill, Carers NSW is disappointed that recognition of rights for and reference to carers is limited throughout the new Bill despite the recommendations made in the recent Royal Commission into Aged Care Quality and Safety (the Royal Commission). The Royal Commission identified the need for improved supports for carers as the aged care system currently provides 'reactive' and 'inadequate' support that comes only when carers have reached crisis point.² Their Final Report included a number of recommendations focusing on embedding recognition and improving support for carers under a new Aged Care Act.³ Carers NSW believes that there remains a number of opportunities to build on the current Bill to achieve the Royal Commission's vision.

Improving consultation processes

Carers NSW welcomes the opportunity to participate in this consultation. However, Carers NSW has concerns about the consultation timeline for the Bill. While Carers NSW commends the Government on conducting a Committee inquiry into the Bill, Carers NSW has concerns that participation in the consultation may be limited due to the short timeline to review and respond to an approximately 500-page piece of legislation. This is not conducive to diverse participation, especially given that many carers are balancing multiple responsibilities and have limited time available.

Carers NSW commends DoHAC for holding extensive consultation on the exposure draft of the new Aged Care Act, however, feels that consultation on the final Bill should also be extended to include more diverse experiences and perspectives given the number of aged care users across Australia. Furthermore, given some elements of the Bill such as fees and financial contributions were not consulted on in the exposure draft, Carers NSW believes that additional time must be provided to ensure that all elements of the Bill, especially newer elements, can be considered and responded to by the community.

¹ Australian Bureau of Statistics (ABS) (2024), *Disability, Ageing and Carers, Australia: Summary of findings, 2022*, New South Wales Tables, Canberra.

² Royal Commission into Aged Care Quality and Safety (2022), *Final Report – Care, Dignity and Respect: Volume 1*, 2021. Canberra.

³ Ibid.

Embedding carer recognition

Defining ‘carer’ within the Act

Carers NSW supports the inclusion of a carer definition within the *Definitions and key concepts* of the Bill.⁴ Carers NSW believes that explicitly including the Cth *Carer Recognition Act 2010* as the point of reference for the definition of a carer under the new Aged Care Act is likely to strengthen the definition, providing a clear legislative origin that can be referred to for additional detail and to better integrate the two Acts.

Recognising carers in their own right

Carers NSW was pleased to see carers recognised through reference to the Cth *Carer Recognition Act 2010* within the *Aged care principles* of the new Bill under ‘*An aged care system that values workers and carers*’. However, Carers NSW is concerned that carer recognition is included within the same section as recognition for aged care workers. While Carers NSW commends the formal recognition of aged care workers, the grouping of carers with the paid aged care workforce may exacerbate confusion about the roles and responsibilities of family and friend carers, who have unique and distinct experiences and needs within the aged care system. Carer awareness and identification is essential to accurate, timely referral of carers to support services. Furthermore, nuanced understanding of the role of family and friend carers – in comparison to paid care workers – is essential for improving carer recognition and inclusion in the delivery of aged care services, and subsequently supporting better wellbeing and health outcomes for carers.⁵

Recognition and inclusion of carers in high quality care

Carers NSW welcomes the outline of high quality care within the new Bill, however Carers NSW also has concerns that there is no mention of recognition, inclusion or respect for carers, or other identified supporters of people who are ageing under the definition of high quality care. Given the important roles of carers within the aged care system and their frequent contact with aged care services and supports, Carers NSW believes that recognition and inclusion of carers and respect for the relationships of people who are ageing and their carers, must be embedded within the legislative definition of high quality care.

Establishing rights for carers

Carers NSW commends the inclusion of the Cth *Carer Recognition Act 2010* in the *Aged care principles* of the new Bill. However, Carers NSW is concerned that carers are not conferred any rights or entitlements to support under the *Statement of Rights* in the new Bill. The consultation paper on the exposure draft of the new Aged Care Act stated that a decision was made not to establish rights for carers under the new Act, as carers are conferred rights through other legislation, such as the Cth *Carer Recognition Act 2010*.⁶ However, the rights of carers under Commonwealth carer recognition legislation are non-enforceable and therefore provide carers with very little protection in their interactions with the aged care system. This is a critical oversight considering the integral role of carers as central users, advocates and navigators of the aged care system, and as partners in care with the ageing family member or friend they support.

Carers are highly involved in the planning and organisation of aged care services with or on behalf of the person that they care for. The Carers NSW 2022 National Carer Survey⁷ found that, of respondents caring for someone receiving aged care services, 85.1% provide assistance with coordinating support services or care workers, 89.7% provide support with cognitive and emotional tasks such as decision making and 92.5% provide administrative support to the person they care for. In addition, carers are

⁴ *Carer Recognition Act 2010* (Cth), Schedule 1 The Statement for Australia’s Carers.

⁵ Carers NSW (2022), *2022 National Carer Survey, Unpublished data*.

⁶ *Carer Recognition Act 2010* (Cth), Schedule 1 The Statement for Australia’s Carers.

⁷ Carers NSW (2022).

often also service users of the aged care system themselves, accessing respite services to support them to maintain their caring role.⁸ As such, Carers NSW believes that as supporters and service users within the aged care system, it is vital that carers have access to their own enforceable rights embedded within the Bill to protect them and ensure positive, safe service experiences.

Right to assessment

Carers NSW believes that carers should be conferred rights in the new aged care legislation, in addition to policies and processes that are relevant to their caring role. One key example of this is the right to assessment of a carer's own needs within the aged care system. While Carers NSW understands that the new Independent Assessment Tool (IAT) captures information about the care of a person who is ageing, this information is limited in regard to the needs of the carer and is captured in the presence of the older person, which may result in the minimisation of a carer's experience or needs due to fear of causing emotional discomfort or distress for the older person they care for.

The exclusion of carers from aged care assessment processes, or the inability of a carer to access an assessment in their own right, can significantly impact the longevity of the caring role and adversely affect the care of the person they care for, as a carer's needs cannot be effectively met if they are not well understood. Furthermore, Carers NSW believes there should not be a reliance on a consumer to inform understanding of informal care arrangements and carer needs as this may not be an accurate reflection of the sustainability of arrangements or carer needs. Carers NSW believes that there must be opportunities for carers to be asked about their own perspectives and needs, as distinctive from the person they care for, to ensure that an accurate assessment of the current circumstances is obtained.

To ensure that carers' needs can be understood and addressed, Carers NSW believes that the new Act must establish a right to assessment for carers. This assessment may be conducted within the aged care system, or through referral to Carer Gateway for further assessment, however Carers NSW believes that there should be a legislative requirement to ensure that a carer is referred for assessment on identification to ensure that carers are proactively supported, or can enforce their right to assessment where this is not actioned proactively.

Right to respite

Carers NSW believes that the new Bill should also establish a right to respite for both the person who is ageing and the carer. Providing opportunities for older people and carers to take breaks from informal caring arrangements, both together and separately, is key to the sustainability of informal caring arrangements.

Existing aged care legislation including the *Aged Care Act 1997*⁹ and the associated *Aged Care (Transitional Provisions) Principles 2014*¹⁰ create provisions for service providers to access up to 63 days of funding for the provision of respite. While this has not established a right for older people or carers to access respite, Carers NSW has significant concerns that there is limited mention of access to or provision of respite within the new Bill beyond identification of respite as a service type. While Carers NSW understands there will be development of further legislation that will provide the legislative framework for the new Support at Home Program which may be inclusive of provisions regarding respite, Carers NSW believes that access to respite should be a fundamental right for older people and carers within the new Bill. How this is implemented through service delivery can then be outlined through the Support at Home legislation, as well as aged care rules and guidelines.

⁸ Carers NSW (2022).

⁹ *Aged Care Act 1997* (Cth).

¹⁰ *Aged Care (Transitional Provisions) Principles 2014* (Cth).

Supporters and representatives

Carers NSW commends the changes to the supporter and representative arrangements within the Bill and believes that these changes will improve cohesion between aged care supporter arrangements and existing state and territory supported and substitute decision making arrangements.

However, Carers NSW would like to stress the need for effective oversight and mechanisms for review where carers are denied supporter status or challenged on their supporter status due to concerns about their inability to comply with duties or a perceived breach of their duties. While Carers NSW is supportive of arrangements that promote autonomy and independence and ensure the safety and wellbeing of people who are ageing, it is important that a measured, supportive approach is taken in instances where there is consideration of denying or revoking supporter status. This should include thorough investigation of perceptions or concerns about inability to perform the role, or circumstances that may have caused an inability to comply with duties, and exploration of options for support, education or remediation in the first instance. Research suggests that incidences of abuse and neglect perpetrated by carers are often the result of systemic circumstances, including stress related to providing care and inability to access services or supports that aim to enable carers to sustain their caring role. In these circumstances, there must be appropriate pathways to provide further education, support and remediation, as opposed to punitive approaches. For example, the NSW Ageing and Disability Commission acknowledges the complexities and nuances of caring arrangements in their responses to alleged abuse, and as such has worked closely with Carers NSW to enable a supportive approach where reports are made against carers. Carers NSW recommends that a similar approach is taken regarding concerns about misuse or breaches of the duties of representatives by carers, and that this approach is outlined within the new Act.

Furthermore, where carers are perceived or identified to be making decisions on behalf of the person they care for that do not reflect the older person's will and preference, this may also be the result of insufficient training in the implementation of supported decision making approaches. It is important that carers are encouraged and assisted to improve their supported decision making skills through appropriate and accessible resources, rather than simply being denied supporter status where concerns arise. While the Bill requires representatives to implement supported decision making, Carers NSW is concerned that there is no substantive, consistent definition of supported decision making in practice. Although the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability made similar recommendations regarding supported decision making, there remains no agreed upon or nationally consistent framework or process that guides supported decision making in practice. Carers NSW believes that in order to progress the implementation of supported decision making approaches as intended within aged care, in line with the recommendations of the ALRC,¹¹ a supported decision making framework must first be established to guide how this will look in practice and how it can be effectively applied by carers acting as representatives.

While Carers NSW ultimately supports a shift to supported decision making approaches, we also have concerns that, if not implemented well, new legislation regarding the appointment and duties of supporters may result in additional administrative tasks and psychological distress for carers who are acting in good faith to support the person they care for to make decisions. Carers NSW believes that these changes must be developed and implemented in consultation with carers navigating these changes with or on behalf of the person they care for. It is particularly important that carers receive education and support on how to transition and implement supported decision making for the person they care for, however this is established through the Bill. There must also be ongoing education and support to effectively enable carers to identify and respond to conflicts of interest, especially those where a representative is balancing their own needs and preferences against those of the person they

¹¹ Australian Law Reform Commission (2014) Towards supported decision-making in Australia, available online at: alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/1-executive-summary-2/towards-supported-decision-making-in-australia/, viewed 15 December 2022.

care for. Taking a supportive approach to enabling carers to effectively implement supported decision making principles is likely to result in the best outcomes for older people and their carers.

Additionally, Carers NSW believes that there is a need to establish a clear framework for resolving conflicts of interest or disputes not only between a person who is ageing and their representative, but also where a person who is ageing has elected multiple representatives who may have different perceptions of their will and preference or how their care should be delivered. These disputes are commonplace in families – for example, regarding whether the person who is ageing should be in residential care or remain in the community – and they require a nuanced and considered approach that does not result in unfairly revoking supporter status or unnecessary legal action. While elder mediation services such as ‘Let’s Talk’ Elder Support and Mediation Service, funded by the NSW Government and facilitated by Relationships Australia NSW, may be well placed to resolve these types of family conflicts where a legal resolution is required, this may not always be suitable. Carers NSW has concerns that limited guidance within the Bill regarding how these conflicts will be addressed may result in delays initiating services, or breakdowns in family and informal caring arrangements.

Conclusion

Carers NSW commends the Department for providing an opportunity to provide feedback on the Aged Care Bill 2024 [Provisions]. New aged care legislation provides a key opportunity to strengthen the rights and safety of people who are ageing when accessing aged care services, as well as providing an opportunity to improve supports for family and friend carers. Carers NSW believes that establishing enforceable rights for carers, as well as ensuring support and protections for carers are embedded within the Bill is likely to be the most effective in ensuring the success of the new aged care system and ultimately, optimal outcomes for people who are ageing and their carers.