

13 March 2025

Department of Health and Aged Care
GPO Box 9848
Sirius Building, Level 9 South
Canberra ACT 2601 Australia

Carers NSW welcomes the opportunity to provide a submission to the Department of Health and Aged Care (the Department) on the Stage 3 release of the new Aged Care Rules (the proposed Rules) relating to provider obligations. Carers NSW supports greater regulation and clarity around provider obligations that aim to improve the quality and safety of aged care services for people who are ageing and their carers. This submission will reinforce Carers NSW feedback to the Department in response to the Aged Care Bill, Revised Aged Care Quality Standards (the Quality Standards) and previous releases of the proposed Rules, focusing on the need to strengthen provider obligations to recognise, include and support carers.

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 lives with 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.

Yours sincerely,

Elena Katrakis
CEO
Carers NSW

Introduction

Carers NSW thanks the Department for the opportunity to provide feedback on the Stage 3 release of the proposed Rules. Carers NSW supports strengthening provider obligations that aim to promote and uphold the rights and safety of people accessing aged care services. The proposed Rules also present a critical opportunity to improve recognition and support 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 carers will continue to receive limited recognition, inclusion and support within the proposed Rules and subsequent implementation.

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 Carers provide a range of supports to help the person they care for remain living at home and in the community. This care can include practical care and support, support with navigating and coordinating aged care services, emotional and social support, as well as advocacy.

Carers NSW believes that as supporters, advocates and service users within the aged care system, it is vital that the proposed Rules include obligations and requirements for providers to recognise, include and support carers. Principle 7 of the *Statement for Australia's Carers* states that "carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers."² Carers NSW proposes that recognition of this Principle, and the *Carer Recognition Act 2010* (Cwlth) more broadly, is foundational to the delivery of high-quality care and safety for both people receiving aged care services and their carers.

While Carers NSW welcomes the opportunity to participate in this consultation, Carers NSW notes that some aspects of the proposed Rules have not yet been drafted, such as *Part 8 – Supporters*. Carers NSW encourages further consultation to inform the development and implementation of supporter arrangements which is likely to impact family and friend carers who play a significant role in the lives of people who are ageing and accessing or seeking access to funded aged care services.

Strengthen obligations to recognise, include and support carers

The care provided by family members and friends plays a critical role in supporting the independence and wellbeing of older people. Many 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 2024 National Carer Survey found that more than half of carers of someone receiving aged care services in the home and community provided assistance with administration and coordinating support services (84.3%), managing finances (82.8%), cognitive support including making decisions (76.2%) and advocacy (67.4%). Carers often play a vital role in supporting decision-making for the people they care for, particularly as they age or experience cognitive decline, whether this is through informal substitute or supported decision making arrangements or through formalised substitute decision

¹ Australian Bureau of Statistics (2022) *Survey of Disability, Ageing and Carers, Carer Tables*. Australian Government, Canberra. Available online at: www.abs.gov.au.

² *Carer Recognition Act 2010* (Cwlth) s1.

making arrangements such Enduring Power of Attorney (EPOA). Many Survey respondents caring for someone receiving in-home and community aged care services reported having legal arrangements in place, including Powers of Attorney (45.4%), EPOAs (59.4%), guardianship orders (9.6%), Enduring Guardianship (23.1%), Advanced Care Plans (39.2%), Supportive Guardian or Administrator roles (4.7%) and other legal arrangements (6.7%).

While carers play a vital role in supporting the person they care for in communicating information and making decisions, there is often little guidance provided to carers on how to ensure a person's preferences and needs are adequately captured and conveyed. Carers often report to Carers NSW wanting to make the 'right' decision that would align with the will and preference of the person they care for, however in some instances this may not be clear to them. Others have also expressed difficulty understanding and navigating supported and substitute decision making approaches or systems, as they are unable to access carer-focused information.

Carers NSW is pleased to see the inclusion of provider obligations to recognise and include registered supporters, which may include carers, in key areas where informal support is often needed such as assessment, planning and delivery of funded aged care services. However, it is important to recognise that not all carers may be formalised or nominated supporters due to their own preferences or the preferences of the person they care for. Despite this, it is important to ensure that carers, as partners in care are still recognised and included in the planning and delivery of services where appropriate.

Furthermore, given changes to supporter and representative arrangements under the new Aged Care Act, Carers NSW recommends the Department strengthen existing and new provider obligations, including the Aged Care Quality Standards (Quality Standards) and Statement of Principles, to ensure carers receive adequate information from providers about supporter nomination and registration in case they are not aware of these options. This includes information about the process of appointment, the rights and responsibilities of supporters, and how these new arrangements operate within existing legal decision-making frameworks. Carers NSW also recommends the proposed Rules clearly define and distinguish between the various formal roles of 'representatives,' 'supporters,' 'restrictive practices nominees,' and 'restrictive practices substitute decision-makers', and ensures providers obligations to recognise and include carers are appropriately applied to each role. Carers NSW believes greater clarity and guidance around these arrangements is paramount, not only for the benefit of carers, but also to ensure effective support of older people to make and communicate their own decisions about their care.

To ensure older people receive the right support to make and communicate their own decisions, it is also essential that carers are also provided with adequate information and support to fulfil formal supporter roles and that they are treated with dignity and respect in these roles. This includes supporting 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 care for and implementing supported decision-making approaches that enable older people as active participants in decision making.

In addition to opportunities to strengthen provider obligations to carers and supporters, Carers NSW notes some limitations as to how carers are framed in the proposed Rules and associated Quality Standards. While Carers NSW supports the alignment between the Quality Standards, the new Act and the proposed Rules, Carers NSW cautions preferencing the term 'supporter/s' over the term 'carer/s' or conflating the terms. Carers NSW is concerned that this approach may limit recognition of diverse caring roles and exclude carers who are not appointed as formal supporters, relying on

provider awareness and understanding of the important roles and expertise of carers in supporting older people.

Carers NSW recommends the Department clearly defines the terms 'supporters' and 'carers'. As highlighted in Carers NSW submission in response to the new Aged Care Bill Exposure Draft, definition of 'carer' should align with the *Carer Recognition Act 2010* (Cwlth) and explicitly reference this legislation. When specifically referring to people who are registered supporters, the term 'supporter/s' is recommended and the term 'carer/s' is recommended when referring to people who provide informal care and support to a family member or friend who may or may not be appointed as supporters, as stipulated in the *Carer Recognition Act 2010* (Cwlth).

Carers NSW further encourages the Department to use the principles of the *Carer Recognition Act 2010* (Cwlth) and associated Statement of Australia's Carers to strengthen and guide provider obligations to recognise, include and support carers. Carers NSW recommends the obligations and requirements of public service care agencies and associated providers stipulated in the Act are reflected in the proposed Rules, irrespective of supporter registration. Section 7(3) of the *Carer Recognition Act 2010* (Cwlth) outlines obligations of public service care agencies and associated providers take measures to ensure awareness and understanding of the Statement for Australia's Carers within the agency and reflect the principles of the Statement in developing, implementing, providing or evaluating care supports.³ Accordingly, Carers NSW has identified the following requirements and obligations that could be included in the proposed Rules:

- Require register providers to engage in meaningful and active partnerships with the person receiving care and their carers and supporters.
- Require registered providers to demonstrate the capability for, and commitment to, building carer awareness and inclusion in the delivery of high-quality care.
- Require registered providers to develop and implement policies that outline processes for identifying family and friend carers, including 'hidden' and diverse carer cohorts such as young carers.
- Require registered providers to allow and facilitate supporters or carers of the person receiving care to access to the person, at any time requested, or consented to, by the person.
- Require registered providers to provide people accessing or seeking access to funded aged care services, and their carers and supporters with timely and accessible information regarding:
 - The rights of older people and their own rights as carers.
 - The aged care services provided to the person receiving care, where appropriate.
 - The information collected about the person receiving care and their carers and supporters, where appropriate.
 - Policies and procedures that affect them such as disaster planning, reporting and incident management, and feedback and complaints.
 - Available services and supports for carers.

³ *Carer Recognition Act 2010* (Cwlth) s7.

- Require registered providers to encourage and support the person receiving care and their carers to make complaints and provide feedback on the delivery of services without reprisal.
- Require training for registered providers and paid aged care workers to identify, include, and engage with carers as partners in care.

Conclusion

Carers NSW again thanks the Department for the opportunity to provide feedback on the proposed Aged Care Act Rules. Carers NSW strongly encourages the Department to strengthen existing and new provider obligations by aligning them with the *Carer Recognition Act 2010* (Cwlth) and associated the Statement for Australia's Carers. Recognition, inclusion and support for family and friend carers of people accessing or seeking access to funded care services is essential in ensuring greater quality and safety of care, and in turn, better outcomes for people who are ageing and their carers.