

8 March 2024

Department of Health and Aged Care
GPO Box 9848
Sirius Building, Level 9 South
Canberra ACT 2601 Australia
AgedCareLegislativeReform@Health.gov.au

Carers NSW welcomes the opportunity to provide a submission on the exposure draft of the Bill for the new Aged Care Act (the new Act). Carers NSW commends the Australian Government on the development of the new Act 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 highlight the need to embed and strengthen carer recognition, inclusion and support throughout the new Act 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. For further information, please contact Ada Lester, Policy and Research Officer, at adal@carersnsw.org.au or by calling (02) 9280 4744.

Yours sincerely,



Elena Katrakis
CEO
Carers NSW

Introduction

Carers NSW thanks the Department of Health and Aged Care (DoHAC) for the opportunity to provide feedback on the exposure draft of the new Aged Care Act (the Act). The Act seeks to strengthen the rights and safety of people accessing aged care services. A new Act also provides an opportunity to improve supports for family and friend carers. Carers are vital to assisting, supporting and advocating for people who are ageing and are therefore active participants in the aged care system. However, Carers NSW is concerned that they continue to receive limited recognition within the new Act.

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 2018 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, 70% (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 Act, Carers NSW is disappointed that recognition of rights for and reference to carers is limited throughout the new Act 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 the new Act.³ Carers NSW believes that there remains a number of opportunities to build on the exposure draft 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 exposure draft of the new Act. While Carers NSW commends the DoHAC on extending the consultation period, Carers NSW has concerns that participation in the consultation may be reduced as much of the consultation took place over the holiday period when carers and consumers had limited time to participate and many relevant organisations had reduced capability due to periods of leave. Carers NSW has also found that many of the workshops and in-person consultation opportunities were scarcely promoted with tight turnarounds between when they were advertised and when they were due to take place. This is not conducive to diverse attendance, especially among carers who often require enough notice to organise alternative care arrangements for the person they care for.

Carers NSW commends DoHAC for having 2,000 participants in the consultation on the Foundations of the new Act, however feels this could be extended to represent more diverse experiences and perspectives given the number of aged care users across Australia. Carers NSW also supports embedding a legislated review of the new Act in five years. This review will be important for evaluating the effectiveness of the new Act and enabling continuous improvement.

Embedding carer recognition

¹ Australian Bureau of Statistics (ABS) (2019), *Disability, Ageing and Carers, Australia: Summary of findings, 2018*, 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.

Defining 'carer' within the Act

Carers NSW supports the inclusion of a carer definition within the *Definitions and key concepts* of the new Aged Care Act.⁴ However, Carers NSW recommends that the definition be expanded to include caring on the basis of disability, mental illness and chronic illness as not all people accessing aged care services or receiving formal supports are doing so as a result of age-related frailty or on the grounds of being an older persons. Additionally, Carers NSW believes that explicitly including the *Carer Recognition Act 2010* as the point of reference for the definition of a carer under the new Aged Care Act is also 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 Act 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 Act, however Carers NSW 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 Act. However, Carers NSW is concerned that carers are not conferred any rights under the *Statement of Rights* in the new Act. The consultation paper for the new Act states 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 that they care for. In addition, carers

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).

are 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 Act 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 for a carer to access an assessment in their own right, can significantly impact on the longevity of the caring role and adversely affect the care of the person they care for, as if a carer's needs are not well understood they subsequently cannot be effectively met. 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 Act 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 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 no mention of access to or provision of respite within the new Act beyond identification of respite as a service type. While Carers NSW understands that there will be development of further legislation that will provide the legislative framework for the new Support at Home Program that may be inclusive of provisions regarding respite, Carers NSW believes that access to respite should be a fundamental right within the new Act. 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).

Right to remain connected

Carers NSW also commends the inclusion of the right for people who are ageing to maintain relationships and connections with their carer – as well as family, friends, and pets. However, Carers NSW is concerned that carers are not protected in their own right. This is a detrimental oversight for both the carer and the person they care for. While carers can be perpetrators and victims of abuse, they are most often critical safeguards against violence and neglect for the person who is ageing.

Many carers report to Carers NSW that they experience significant distress when the person they care for is receiving substandard care and many feel a heightened sense of responsibility to assist with personal tasks in place of, or in addition to, paid care workers. In these instances, it is particularly important that carers have a right to maintain a relationship with the person who is ageing, especially in crises such as pandemics where under resourcing may impact on quality of care. Furthermore, anecdotally, Carers NSW has heard scenarios where service providers attempt to ostracise or exclude carers who raise concerns about the quality or safety of care on behalf of the person they care for. Carers NSW believes that in these instances, a right to maintain contact with the person they care for is vital for ensuring that carers can fulfil their role as an advocate.

There are also instances where the person who is ageing may require support from their carer but have conflicting sentiments towards them. An example of this may be where a person who is ageing is also living with dementia and this has impacted memories related to their relationship with their carer. The person living with dementia may also experience a change in their ability to communicate their wants and needs. This may put the older person at higher risk of abuse, neglect or violence. This is particularly complex in situations where the carer may also be a guardian or representative and requires contact with the person who is ageing to successfully enact their duties. While there are instances where this right could be revoked, carers who are also representatives or supporters require their own enforceable right to maintain connection as this role confers them with significant responsibilities that require an ongoing relationship to, and understanding of, the person they care for.

Supporters and representatives

Carers NSW commends the changes to the supporter and representative arrangements within the exposure draft of the new Aged Care Act. The ability to have multiple representatives more accurately reflects the caring arrangements that are commonplace among many families, where multiple family members or friends may be involved in the care and support of a person who is ageing. This also better aligns with Enduring Powers of Attorney (EPOA) arrangements where multiple people may be appointed as EPOA for a person who is ageing.

Carers NSW is also supportive of the acknowledgement of existing guardianship arrangements within the Act and encourages the establishment of streamlined pathways for guardians to be appointed representatives without additional administrative burden. However, Carers NSW has some concerns regarding the implementation of these proposed arrangements, including their potential to overlap with or contradict existing state-based substitute decision making legislation and processes. For example, where two family members are made representatives in relation to aged care services however only one has formal substitute decision making powers under state-based arrangements. Carers NSW believes that there is a need to acknowledge this intersection and ensure that there is clear guidance within the Act on how it will be managed in practice.

Carers NSW is also concerned that people accessing My Aged Care will only be able to have either supporter/s or representative/s under the new Act and will not be able to have people appointed to both roles. In many caring arrangements, while one or more people may be responsible for decision making or enacting the decisions of a person who is ageing (i.e. the representative), they may also have other family members or friends, or independent advocates, who support their participation and engagement with the aged care system (i.e. the supporters). Ensuring that these supporters are also provided with

key updates or relevant information regarding the older person's aged care services and supports will enable them better able to support the older person to effectively access and utilise these services and supports. As such, Carers NSW believes that the new Act should be amended to enable individuals to appoint representatives and supporters concurrently as they see fit.

Carers NSW would also like to ensure that there is effective oversight and mechanisms for review where carers are denied representative status or challenged on their representative 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 representative 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 that do not reflect the older persons 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 representative status where concerns arise. While it is noted in the consultation paper that the Act will require representatives to implement supported decision making, Carers NSW is concerned that there is no substantive definition of supported decision making within the exposure draft of the new Aged Care Act or more broadly. 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 and representatives 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 new Act. 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

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.

those of the person they 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 representative 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 Act regarding how these conflicts will be addressed may result in delays initiating services, or breakdowns in family and informal caring arrangements.

Ensuring safe and high quality aged care services

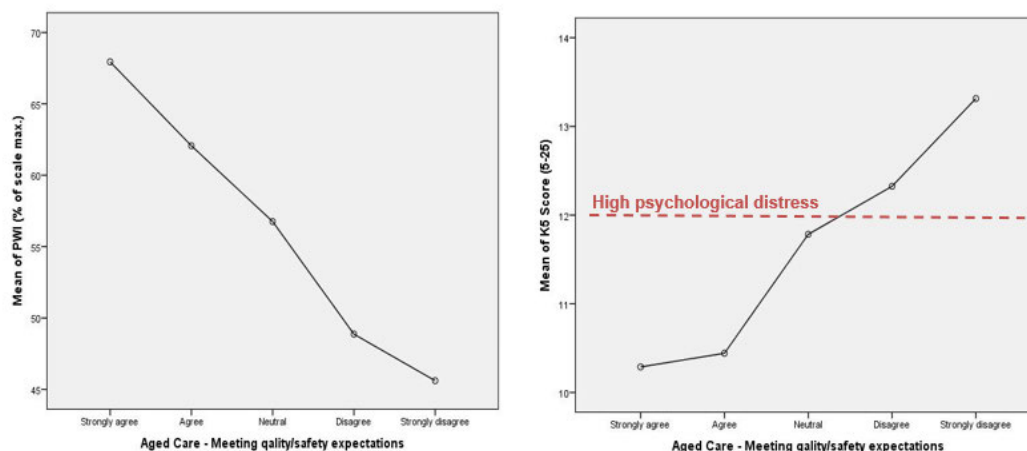
Carers NSW commends the Government on their ongoing work to implement the recommendations of the Royal Commission to improve the quality and safety of aged care services and supports. The Royal Commission highlighted the significant impact of unsafe or poor quality services on carers, with many carers sharing the long-standing emotional effects of witnessing and responding to the abuse or neglect of the person they care for.

The 2020 National Carer Survey found that approximately 1 in 6 (16.4%) disagreed that community-based care met the needs of the person they were caring for and almost 1 in 5 (18.9%) disagreed that residential care met the needs of the person they care for.¹² Further analysis of Survey findings found that there is a strong, statistically significant connection between whether a carer’s expectations of quality and safety are met (measured with a 5-level Likert item), and both carer wellbeing (measured through the Personal Wellbeing Index) and carer psychological distress (measured through the Kessler 5-item Psychological Distress Scale) (Figure 1).¹³ There was a large effect of perceived quality and safety of care on wellbeing and a medium effect on psychological distress.

¹² Carers NSW (2020) *2020 National Carer Survey*, unpublished data.

¹³ Ibid.

Figure 1. Connection between perceived quality of services, wellbeing and psychological distress



While many carers choose to take on a caring role, caring can have significant negative impacts on health and wellbeing, social connectedness and finances, especially where they may be hesitant to engage with formal care services due to concerns about quality and safety. Where carers do engage with aged care services and supports with or on behalf of the person that they care for, Carers NSW believes that it is vital that carers are supported and protected to identify and report concerns about quality and safety of care to ensure the health and wellbeing of the person they care for. Additionally, Carers NSW believes that it is also important to ensure that carers have pathways for reporting and redress where they themselves are physically or psychologically harmed in the delivery of aged care services to the person they care for.

Regulatory mechanisms

Carers NSW commends ongoing initiatives aimed at improving the powers, oversight and accountability of the Aged Care Quality and Safety Commission (the Commission). The Commission is a crucial safeguarding mechanism for people who are ageing and their carers. Carers NSW commends the extensive breadth of work undertaken by the Commission to maintain quality and safety in the aged care sector and acknowledges that such a task is logistically difficult and can be hampered by limited resourcing. However, Carers NSW believes there must be clear guidance within the new Act around the scope, roles, responsibilities and intersections of the Commission, as well as the new quality and safety bodies and regulators being introduced, including Inspector General of Aged Care, the Aged Care Quality and Safety Advisory Council, and the Complaints Commissioner. Duplication or confusion regarding responsibilities between the many federal and state quality and safety bodies is likely to cause confusion for carers seeking to raise concerns or complaints about the quality of aged care services and supports, and may disrupt pathways for redress.

Additionally, Carers NSW supports the inclusion of education as a responsibility and role of the Aged Care Quality and Safety Commission, including for supporters, representatives and other people assisting those accessing aged care. Carers NSW has previously expressed concerns that much of the external communication coming from the Commission, as well as education opportunities and relevant resources, are targeted to a service provider audience. While Carers NSW acknowledges the important role of the Commission in supporting and regulating providers to deliver safe and high quality aged care services, there is an equally important role of the Commission in supporting people who are ageing and their carers to understand the safety and quality of services they can confidently expect to receive, including how to respond when this level of safety or quality is not met.

Furthermore, limited digital literacy among some people who are ageing, as well as their carers, continues to be a barrier to accessing information regarding the Aged Care Quality and Safety Commission. While the Commission's website is an important resource for reporting abuse, Carers NSW believes that in order to achieve high quality and safe services, the Commission must ensure that resources about reporting abuse and neglect are accessible and widely distributed off-line. Ongoing distribution of relevant resources, as well as education, will be especially pertinent throughout the upcoming reforms resulting from the new Act.

Protections for carers

Carers NSW commends protections for whistleblowers within the new Act. Whistleblowers have been essential to raising understanding and awareness of abuse and neglect occurring within the aged care system, as well as illuminating systemic issues that have been a catalyst for the Royal Commission into Aged Care Quality and Safety. While carers may be perpetrators of abuse or neglect in some instances, they are more commonly advocates on behalf of the person they care for and are well placed to recognise signs of elder abuse that often go unnoticed such as weight loss, confusion, poor hygiene, increased hospitalisations and low self-esteem. Many reports of elder abuse in the Royal Commission were provided by carers.¹⁴

Furthermore, Carers NSW supports the statutory duties placed on aged care providers and responsible persons, which ensure they are taking reasonable steps to avoid actions that adversely affect the safety and health of persons in their care. Carers NSW also supports the inclusion of civil penalties for significant failures or systemic patterns of conduct. This includes requirements for such organisations to pay compensation towards individuals within the aged care system who have experienced serious injury or illness as a result of their behaviour. However, Carers NSW believes that this duty and associated compensation should also be extended to carers where carers themselves are physically and/or emotionally harmed in their interactions with aged care services, recognising carers as a key cohort engaged and interacting with the aged care system.

Ensuring timely access to aged care services

In line with the movement to a more person-centred model of care, Carers NSW understands the shift of allocation of permanent residential care to people who are ageing, rather than allocating places to residential care providers. This aims to enable people who are ageing and their carers greater choice in determining a suitable residential aged care facility that is likely to best meet their needs. This market model may enable larger innovative providers to expand and offer services in a greater range of locations, as well as support smaller providers to offer and develop tailored services that meet the needs of consumers and carers. However, Carers NSW has previously raised concerns with the Department about the potential impacts on financial sustainability on residential care facilities with fewer individuals accessing a larger range of services, reducing effectiveness of economies of scale that support the delivery of high cost services such as residential care.

Furthermore, Carers NSW has concerns about the proposed prioritisation of residential care funding within the new Act. Carers NSW understands that currently supply exceeds demand in relation to funding available for residential care beds. However, there are concerns that with an ageing population, significant workforce shortages and reduced access to informal care, that over time, if there is a shift in supply or demand, prioritisation of residential care funding may have significant impacts on timely access to residential care. Disruptions to the availability of residential services will place additional strain on carers who will be required to provide further high-level care, jeopardising the sustainability of ongoing caring arrangements and leading to a potential increase in hospital and premature permanent residential care admissions. Carers NSW believes that it is important to ensure that assessment of

¹⁴ Royal Commission into Aged Care Quality and Safety (2021) *Final Report*. Available online at: <https://www.royalcommission.gov.au/aged-care/final-report>, accessed 1 February 2024.

urgency should not limit or inhibit a consumer's access to residential care where they are perceived as a 'lower priority'.

Additionally, Carers NSW believes that preferences around caring arrangements should be taken into consideration in assessment of urgency. There is a risk that delayed transition to residential care as a means of prevention of deterioration of the older person, as well as of caring relationships, may be undermined by a misinterpretation of 'urgency' by an assessor. Furthermore, Carers NSW has some concerns that any changes made to the way in which residential aged care places are allocated, without appropriate safeguards, may impact the availability and accessibility of permanent and temporary (respite) residential care.

Fees

Carers NSW acknowledges that the report from the Aged Care Taskforce on funding arrangements that will inform aged care fees and costs has been provided to Government. However, with the report not publicly available, it is difficult to comment on the proposed approach to fees within the new Act.

As it stands, Carers NSW has some concerns regarding equity in access to aged care, as those who most often require services are least able to meet the associated costs. This may become cyclical for carers. Where services are required to support carers to sustain their caring role or enable them to work in paid employment, but these services are unaffordable, they are likely to need longer, more intensive services. This is especially the case for residential respite, with many carers reporting that they are unable to afford co-payments for residential or cottage respite of \$800 or more. However, residential respite is key to supporting ongoing informal care in the community.

Carers NSW believes that there should be further opportunities to respond to fee arrangements within the new Act once these are finalised to ensure that aged care funding and requirements for co-payments ensure equitable access to aged care services and supports.

Computer generated decision making

Carers NSW welcomes increased efficiencies within service systems that reduce delays accessing aged care services and supports. While Carers NSW understands that computer programs can support the processing of large amounts of information and enable consistency in decision making, Carers NSW has concerns about overreliance on automated decision making where there may be minimal or no human oversight in individual decisions. Many carers have previously been adversely affected by automated decision making, including through Centrelink's Compliance Program (Robodebt). The automated decision making algorithm employed by the program resulted in the miscalculation of debts for a number of people receiving or formerly receiving Commonwealth income support payments, including carers and the people they care for, who are more likely to rely on income support payments.

With decision making becoming increasingly automated, Carers NSW believes that there must be additional safeguards in place to protect those who are most vulnerable, including carers and people who are ageing. Carers NSW supports the introduction of an external, new independent body for the review, approval, monitoring and auditing of automated decision making. Carers NSW believes that this body should also provide information and referrals to individuals, including carers and people who are ageing, to enable them to understand automated decision making outcomes and to assist them to access the appropriate advocacy or legal services to challenge automated decisions.

Furthermore, Carers NSW believes that where an automated decision making process has occurred under the new Act, there should be an onus on the decision making body – in this instance, the Department – to review and investigate the accuracy and appropriateness of decisions before they are applied. Where the onus is placed on the person the decision is made against, carers and people who

are ageing may be disadvantaged, feeling unable to challenge decisions due to time constraints, financial constraints or a lack of adequate information or education.

Review processes

Carers NSW supports the expansion of reviewable decisions through the new Act, including decisions made by the System Governor as well as the Commissioner. Increased consistency in review processes and the creation of a new federal administrative body to replace the Administrative Appeals Tribunal will likely support better outcomes for people who are ageing and their carers. However, Carers NSW believes that it is important to ensure that there is not an over-reliance on the Administrative Appeals Tribunal (AAT) or the new body to review decisions, resulting in review processes becoming legalistic, costly, long and highly complex, as seen in the National Disability Insurance Scheme (NDIS).

Carers NSW recommends considering a similar approach to that recently piloted by the National Disability Insurance Agency (NDIA), the Independent Expert Review (IER) Program. This program enables participants to resolve matters, such as reviews of decisions, without going to AAT. The process involves initiating a non-binding and confidential review by an Independent Expert to resolve the matter prior to a tribunal hearing.¹⁵ Participants not satisfied with the outcome through the IER can then escalate the matter to the AAT if they choose to. Carers NSW believes that ensuring these mechanisms are established and processes are embedded in the new Act will ensure optimal outcomes throughout the transition period and into the future.

Readiness support

Carers NSW acknowledges the important change that this proposed legislation seeks to enact. While this submission has already discussed the necessity for targeted education in regard to particular proposals – such as introducing supporters and representatives – Carers NSW also believes the Government must invest in general readiness supports specifically for carers to support them to effectively navigate aged care reforms with or on behalf of the person they care for.

The Royal Commission consistently referred to the important role of carers in supporting those who are ageing.¹⁶ To minimise additional stress and administrative burden as carers adapt to the new system, it is essential that there are supports such as carer-focused webinars, online learning modules, short videos, and other resources. While some state and territory carer organisations receive funding through the CHSP Sector Support and Development program, which 25% of can be used to support capacity building of consumers and carers, this program predominantly focuses on provider readiness. As such, Carers NSW recommends additional investment in carer-focused education and support, similar to those funded during the roll out of the National Disability and Insurance Scheme, to enable carers to navigate changes to aged care services with minimal disruptions or gaps in services. This is likely to ensure the best outcomes for not only carers, but also the older persons that they care for.

Conclusion

Carers NSW commends the Department for providing an opportunity to provide feedback on the exposure draft of the new Aged Care Act. The new Act seeks to strengthen the rights and safety of people who are ageing when accessing aged care services, while providing an opportunity to improve supports for family and friend carers. Carers are vital to assisting, supporting and advocating for people who are ageing and are therefore active participants in the aged care system. However, Carers NSW is concerned that they continue to receive limited recognition within the new Act. Carers NSW believes

¹⁵ National Disability Insurance Scheme (2024) *Legal Matters*, available online at: <https://www.ndis.gov.au/about-us/legal-matters/improved-approach-dispute-resolution>. Accessed 8 February 2024.

¹⁶ Royal Commission into Aged Care Quality and Safety (2021) *Final Report*. Available online at: <https://www.royalcommission.gov.au/aged-care/final-report>, accessed 1 February 2024.

that establishing enforceable rights for carers, as well as ensuring support and protections for carers are embedded within the Act is likely to be the most effective in ensuring the success of the new aged care system. Furthermore, ensuring carer-focused readiness support and information is available will enable a more streamlined transition that is likely to minimise the impact on people who are ageing and their carers.