



Response to the Home Care Hearing Draft Propositions

31 August - 4 September 2020

Royal Commission into Aged Care Quality and Safety

11 September 2020

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

About Carers Australia

Carers Australia is the national peak body representing Australia's unpaid carers, advocating on their behalf to influence policies and services at a national level. Our vision is an Australia that values and supports the contribution that carers make both to the people they care for and to the community as a whole.

Carers Australia advocates and lobbies on a wide range of issues that affect carers, and manage the delivery of national programs, support and services for carers across Australia. We work in collaboration with carers, Carers Associations, government and peak bodies to develop policy, advocacy, programs and events to improve the lives of Australia's 2.65 million carers.

Contact details:

Liz Callaghan
Chief Executive Officer | Carers Australia
Unit 1, 16 Napier Close DEAKIN ACT 2600
T: 02 6122 9910 | E: ceo@carersaustralia.com.au
www.carersaustralia.com.au

Introduction

Carers Australia are providing this response to the Royal Commission into Aged Care Quality and Safety (Royal Commission) Home Care Hearing Draft Propositions¹ (Propositions) per the Direction dated 2 September 2020. This follows other [submissions](#) by Carers Australia to the Royal Commission (see “Carers need a place to call home within aged care, submitted 30 July 2020).

This response has been developed in collaboration with the Carers Australia Network – Carers Australia’s member organisations who are the carer organisations in each state and territory. Collectively we believe all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians. They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

The Carers Australia Network have provided comments are on the Propositions that impact on carers explicitly, and where in reading this response we highlight the following:

It is important to understand who ‘carers’ are

During our lifetime many of us will provide care to a family member or friend, or will need care ourselves. Carers are people who provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue, or who are frail aged.

This includes carers:

- Who have their own care needs
- Who are in multiple care relationships
- Who have employment and/or education commitments
- Aged under 25 years (young carers)
- Aged over 65 years, including ‘grandparent carers
- From culturally and linguistically diverse backgrounds
- Who identify as Aboriginal and Torres Strait Islander
- Who identify as lesbian, gay, bisexual, transgender, intersex (LGBTI+)
- Who are living in rural and remote Australia, and
- That are no longer in a caring role (former carers).

It is often the carers role to uphold the rights of the people they care for

The role and valuable contribution of carers is not widely known or understood and should matter to our whole community. Carers have rights regarding involvement in decisions that affect them and the person they care for, and to receive services they need in their own right to sustain their caring role.

Carers need:

- choice about their caring role and the level of care they are willing or able to provide
- to have access to training and aids to support their caring role
- to be included as a partner in care by health professionals and aged care providers, and

¹ RCD.9999.0459.0001

- increased engagement in strategic policy and service design that impacts on them and the person they care for.

The Carer Recognition Act stipulates what government funded aged care providers should do

The [Carer Recognition Act 2010](#) (the Act) is a guide for government agencies and funded organisations, with the objective to increase recognition and awareness of carers, and to acknowledge the valuable contribution they make to society.

Per the Act, aged care providers funded by government have to:

- Ensure employees and agents have an awareness and understanding of the Statement for Australia’s Carers
- Take action to reflect the principles of the Statement for Australia’s Carers in developing, implementing, providing or evaluating care supports

Carers are an integral part of Australia’s health system. They are the foundation of our aged, disability, palliative and community care systems, and need to be supported to prepare for and celebrate their caring role.

Impact of COVID19 on unpaid carers

The Covid-19 pandemic has revealed weaknesses across aged care, across the world. A recent policy brief on this issue released by the [World Health Organisation](#) points to a series of recommendations to support unpaid carers. The report notes:

- Family caregivers provide an important share of care, but support such as respite care, training or care leave schemes remain limited and without compensation
- The provision of intense levels of care has generally been associated with lower income and ultimately higher poverty rates, as well as poor mental health
- The discontinuation of residential care options has left many family caregivers with increased responsibilities and without their usual support structures
- Caregivers need to be able to get to the person with care needs, have access to information, PPE and testing, and be supported in developing contingency plans
- Changes in care needs and violence or abuse towards the caregiver

The Home Care Hearing Draft Propositions

At the Home Care hearing, the Commissioners examined some of the key design issues for a new home care system and how to transition to a new system.

Some of the propositions look to remove decision making, dignity of risk and choice for older Australians in favour of all decision-making being undertaken by aged care providers.

It is critical that carers of older Australians remain at the centre of the support assessment, planning and delivery processes, informing paid support workers appropriately, and advocating for older Australians rights as required. Carers must be adequately resourced and supported to carry out these roles, including having access to flexible respite services.

The following table outlines the Carers Australia Network response to relevant draft Propositions.

The Carers Australia Network response to the home care hearing draft propositions

Proposition	Carers Australia Network Response
Proposition HC2. More funding for care at home to meet assessed needs – QUALIFIED SUPPORT	
<p>To support the transition to an integrated program of care at home, the Australian Government should implement a new model of funding for an integrated program of care at home (combining the CHSP and the HCPP). This should involve separate funding for categories of:</p> <ul style="list-style-type: none"> • social support (including social support, meals and transport) • enabling care (including short term enabling plans, home modifications and assistive technology) • respite care (including at home, in the community and in facilities) • care at home (including care management, living support (domestic assistance and home maintenance) and personal, clinical and therapeutic care, and end-of-life and palliative care). <p>The new model should provide personalised funding for ‘care at home’.</p> <p>An independent assessment should lead to the allocation of an entitlement to a person. That person will be able to choose or change providers. The assessor should also specify the domains of support and care that the individual can receive, and set a plan and budget based on the individual’s assessed needs. The assessor should set a budget in light of the standard schedule of fees for the relevant area. The plan should set the hours of care per year to be used across the major domains of:</p> <ul style="list-style-type: none"> • care management • living supports • personal, clinical, enabling and therapeutic care 	<p>Carers Australia Network provide heavily qualified support to this proposition, noting especially the reference to separate funding for respite care (including at home, in the community and in residential aged care facilities).</p> <p>Carers Australia Network however are concerned that there are over 100,000 people waiting for home care packages that are being supported through CHSP. This equates to thousands of people whose care is being supplemented by CHSP. If funding for both programs are combined wait lists will not be reduced. As a result, it is possible that care could be removed from those whose needs do not yet meet the requirements for a package, and there could be a reduction in care for those who require a level 4 package but receive funding at a level 2.</p> <p>Removing core block funding to the in-home aged care sector will likely have significant consequences. For example, the ability to react and adapt due to COVID 19 was largely due to organisations having access to core funding. The differences between the CHSP sector and NDIS sector demonstrates the need for block funding to support consumer directed funding. Removal of block funding will destroy the market place and potentially allow for greater exploitation.</p> <p>Carers Australia advocate for increased funding for packages (both collectively and individual packages). Taking the CHSP funds and allocating to ‘care at home’ will not see an increase in funding.</p> <p>With respect to the reference to independent assessment, we note that carers needs should be subject to separate assessment rather than be treated as a by-product of the assessment of the consumer.</p> <p>Currently carer needs are assessed, but this assessment does not influence decision making. The assessor is only paid for the assessment on the person who is frail aged and</p>

Proposition	Carers Australia Network Response
Proposition HC2. More funding for care at home to meet assessed needs – QUALIFIED SUPPORT	
<ul style="list-style-type: none"> • palliative and end-of-life care. <p>The assessment should also identify when a person is no longer safe at home even if they receive the maximum care available under the program.</p>	<p>has nothing to offer the carer, nor are their needs considered in the plan and therefore there is no incentive to complete the carer assessment.</p> <p>The proposed independent assessment should be used to develop a plan according to an individual’s agreed needs, and should include assessment of carers needs in order to support the person they are caring for. The plan would also contain their goals for wellness reablement where appropriate. People should then have a choice of providers, services and supports.</p> <p>The Terms of Reference for the Royal Commission identified the need to ensure that aged care services are person-centred, including through allowing people to exercise greater choice, control and independence in relation to their care, and improving engagement with families and carers on care-related matters.</p> <p>There is loss of dignity of risk and cultural inclusivity in this proposition, particularly with respect to safety in the home. The proposition is premised on risk adversity. The automatic removal of an older person to a facility contradicts the principles of Consumer Directed Care and assumes end-of life care should only happen outside of the home. This principle is not practical in rural and remote Australia.</p> <p>Unless the carer or carers are integral to assessment, the lack of flexibility in use of budget may not support Consumer Directed Care Principles which identify the care recipients as having the following rights:</p> <ol style="list-style-type: none"> a) to be supported by the approved provider: <ol style="list-style-type: none"> (i) to set goals in relation to the outcomes he or she seeks from home care; and (ii) to determine the level of ongoing involvement and control that he or she wishes to have in the provision of the home care; and (iii) to make decisions relating to his or her own care; and (iv) to maintain his or her independence as far as possible;

Proposition	Carers Australia Network Response
Proposition HC2. More funding for care at home to meet assessed needs – QUALIFIED SUPPORT	
	<ul style="list-style-type: none"> b) to choose the care and services that best meet his or her goals and assessed needs and preferences, within the limits of the resources available; c) to have choice and flexibility in the way the care and services are provided at home; d) to participate in making decisions that affect him or her; e) to have his or her representative participate in decisions relating to his or her care if he or she requests it or if he or she does not have capacity. <p>This proposition also proposes the introduction of a standard set of scheduled fees. The Carer Australia Network have experienced first hand how this type of approach by the NDIS negatively impacts the marketplace and quality of service delivery. For example, there is no choice if there are no services and there is no choice if the service is not able to set the price and the quality. If the price is too high people will not buy. Because of this first-hand experience, Carers Australia do not support this element of the proposition.</p> <p>The current approach, whereby there is an assessment, an allocation of a plan with a set funding level and the consumer can then spend on what they want and from whom is supported. The current issue however are the fees the administrators set for coordinating and exiting. Providers set their fees and people choose what they want. Often consumers do not know their rights or are afraid to exercise their rights. Carer Network experience is that consumers are scared that if they question a provider they will lose the services they have.</p> <p>In addition, the proposition proposes that the plan should set the hours of care per year to be used. Carers Australia would query how this number would be derived, is it based on number of hours the unpaid carer can provide? If this approach were to be modelled on the current NDIS approach then the number of hours of care in the plan would be based on the ability of the carer to say they will not provide that care.</p>

Proposition	Carers Australia Network Response
Proposition HC3. Changes to consumer directed care – NOT SUPPORTED	
<p>While the ‘care at home’ category in Proposition HC2 is built around personalised funding, the model will involve changes to consumer directed care. Under the ‘care at home’ category:</p> <ul style="list-style-type: none"> • People will have choice over how the hours of care per year are used, and providers should work in partnership with the older person to make decisions about how care is provided. • People will no longer be able to use the funding on non-aged care related needs or items. <p>There will be a shift from self-management to shared management where the focus will be around delivering care to meet assessed needs.</p>	<p>Carers Australia Network do not support this proposition.</p> <p>The reference to “a shift from self-management to shared management where the focus will be around delivering care to meet assessed needs” requires considerable unpacking to be in any way clear or explanatory. The concept of shared management raises concerns regarding the agency of the individual around the care that they receive.</p> <p>Self-management under Consumer Directed Care is a right under the legislation. It could be argued that shared management should be offered as a choice to those who prefer it or choose increased assistance rather than taking rights away from care recipients and their carers.</p> <p>The introduction of shared management, as opposed to self-management may mean carers, who most often are the ones providing decision making supports, will be excluded from supporting the rights of those they care for.</p> <p>People who are frail aged and their carer are competent humans and until they are not competent, as assessed by a court, then they and their family should manage their affairs, with the right safeguards in place to prevent elder abuse, without taking away their rights.</p> <p>An assumption that ‘care at home’ in HC2 is built around ‘personalised’ funding is incorrect. It is Carers Australia view that that it is built around the determination of an assessor in the first instance, and then a price guide thereafter.</p> <p>Carers Australia Network also notes a level of inconsistency within this proposition whereby it states that the hours will be allocated against categories, and also saying people will have choice over how the hours of care per year are used. An assumption could be made that here is no choice over how the hours are used unless it corresponds to the category.</p>

Proposition	Carers Australia Network Response
Proposition HC3. Changes to consumer directed care – NOT SUPPORTED	
	Case managers have a role in coordinating supports and problem solving, not decision-making. Carers Australia Network report that many of our aged carers and carers of aged talk about wanting a case manager to help them navigate, choose services, access supports, organise things. They don't talk about them making decisions but rather helping them to make the decisions.

Proposition	Carers Australia Network Response
Proposition HC5. Responsibility for coordination of care in the new program - SUPPORT	
<p>The Australian Government should fund a care management domain in personalised care at home, matched to the complexity of the older person's needs. All older people with an entitlement to care at home will have care management. The hours per year of care management that a person is entitled to will be in their personalised budget.</p> <p>As part of care management, a provider should assign a care manager and undertake:</p> <ul style="list-style-type: none"> • early discussions with the person and, if applicable, their carer on the persons strengths, capabilities, aspirations and goals • consultation with the person and, if applicable, their carer, to develop a holistic care plan, including activities to promote various aspects of health and wellbeing and to enhance their ability to live and participate in the community • care plan implementation • regular monitoring and review of the person's progress and situation, with adjustments to goals and service delivery as appropriate 	<p>The role of the carer in assessment and the development of the care plan is important and should be recognised and supported.</p> <p>Independent carer assessment should be undertaken at the same time to assess the extent to which the carer is able to support and contribute to the health and wellbeing of the person being cared for.</p> <p>If the carer is to specifically have a role in the coordination of the care in the proposed new program then carer supports to undertake this role must be defined, resourced and delivered to carers by services that work specifically to support carers.</p> <p>There are lessons that can be learnt from the NDIS in relation to this recommendation. Case management and coordination is something carers ask for all the time. Carers Australia Network advocates for choice to be provided, for the choice of care manager, that the care manager is independent of the assessor, that the care manager acts in the best interest of the person and their carer, and that they are funded at an appropriate level with appropriate allocation of time.</p>

Proposition	Carers Australia Network Response
Proposition HC5. Responsibility for coordination of care in the new program - SUPPORT	
<ul style="list-style-type: none"> • consideration of current service use and determination of additional services needed, in line with the personalised budget • use of technology to meet and exchange information with representatives of the older person if requested. <p>The care manager, the older person and, if applicable, their carer should develop a care plan. This plan should include strategies to achieve the person’s goals and detail services to be provided by aged care and other programs or providers. Services should then be planned and delivered in a manner that reflects the priorities and preferences of the person and carer.</p> <p>The effectiveness of the care plan should be monitored through the care manager’s communication with the person, carer and other providers. The care plan should be reviewed and updated biannually. The care manager must meet the hours of care management set out in the personalised budget.</p> <p>The care manager must support the older person to access re-assessment as their care needs change.</p> <p>The care manager must have relevant qualifications or experience, matched to the complexity of needs of the older person. This may include qualifications and experience as a registered nurse, allied health professional or experienced personal care workers.</p>	

Proposition	Carers Australia Network Response
Proposition HC6(e) Systemic indicators of health and well-being	
<p>The Australian Government should:</p> <ul style="list-style-type: none"> • establish, as soon and efficiently as possible, objective and measurable indicators of outcomes for the home care population at a system level • implement a comprehensive Quality of Life assessment tool • assign responsibility for the maintenance, update, amendment, introduction and removal of quality indicators to [an entity within the institutional architecture], including: <ul style="list-style-type: none"> - promoting [in cooperation with the NHMRC] ongoing research into the use and evidence basis for quality indicators - publishing guidance for and educating providers and the industry more broadly on how to use indicator data to identify risks and publish guidance on evidence-based risk management. • establish the following reporting, benchmarking and performance measures in relation to quality indicators: <ul style="list-style-type: none"> - targeted and easily digestible reports for different stakeholders, including services and consumers, on the basis of raw data - benchmarking of services, where appropriate, on the basis of classes of services/case-mix - tracking of sector performance and considering improvement targets, where relevant and appropriate 	<p>It is widely understood that providing care to family members or friends often comes at personal cost. It can be a rewarding yet demanding and a socially isolating experience, where carers have among the lowest levels of wellbeing of any group of Australians,</p> <p>It is the Carer Australia Network view that Australia needs to prepare for the growth in demand for informal carers - from around 1.25 million in 2020 to 1.54 million in 2030, representing a 23% total increase.</p>

Proposition	Carers Australia Network Response
Proposition HC8. Carers Leave - QUALIFIED SUPPORT	
<p>The National Employment Standards under Part 2-2 of the Fair Work Act 2009 (Cth) should be amended to provide an:</p> <ul style="list-style-type: none"> entitlement of up to two years unpaid leave to care for on older person, for long term permanent and casual employees with a return to work guarantee entitlement to flexible work arrangements for the purpose of caring for an elderly person (as opposed to the right to request them). 	<p>While carers play an invaluable role in providing help and support to the people in their care, as a result of these responsibilities they face a number of barriers to finding and keeping paid employment. Primary carers in Australia experience considerably poorer employment outcomes, with a 52.2% employment to population ratio compared to 75.9% for people without caring responsibilities. Carers Australia believes that supporting carers to participate in employment and/or ongoing education and training is pivotal to enabling their social and financial inclusion and greater social and economic outcomes for community and government.</p> <p>Carers Australia Network agree that leave entitlements for carers in Australia is far from generous (especially since that leave is taken out of their personal leave), and understand that this proposition reflects best practice in some European countries. The issue of flexible working conditions goes far beyond carers of the aged and would need to be approached from a wider employment rights perspective. Carers Australia are of the opinion that far more analysis, thought and consultation needs to go into this matter, especially as it requires changes to the Fair Work Act which would impact on all carers, not just carers of the aged.</p> <p>There is a strong case for carer leave entitlements which are equivalent to parental leave. Carers Australia advocates for choice that allows a carer to decide to take leave for a length of time, up to 2 years with a return to the position. It should be a choice that a carer can make.</p> <p>In addition, Carers Australia Network recognises that there are situations where the nature of employment is such that it cannot accommodate flexibility. Covid 19 has demonstrated that there are many more options available to carers such as working from home, job sharing, requesting lower level work to accommodate caring, and flexible working hours.</p> <p>The current Fair Work Act, which only requires that an employer who does not want to agree to an employees' request for flexibility respond with some sort of reason, is very weak. Mechanisms for right of appeal should be considered.</p>

Proposition	Carers Australia Network Response
Proposition HC10. An enablement approach to care in the home and community - QUALIFIED SUPPORT	
<p>The assessment process for older people to receive home care should identify the care and services (including allied health services) that they need to restore their physical and mental health to the highest level possible (and maintain it at that level) to maximise their independence and autonomy.</p> <p>Providers of home care services are responsible for:</p> <ul style="list-style-type: none"> • ensuring the delivery of these services; and • monitoring the status of people receiving care and adjusting the nature and intensity of the care provided within available funding; and • referring people for re-assessment if additional funding is required. 	<p>It is Carers Australia view that the agency of the individual, where able, is most important in collaboration with carer and care providers.</p> <p>Carers also have a role in ‘monitoring the status of people receiving care and adjusting the nature and intensity of the care provided within available funding’</p> <p>Older Australians and their carers must still retain the capacity to make decisions about their own lives, including access to their own preferred allied and health providers outside of aged care.</p>

Appendix 1 – The Statement for Australia’s Carers

Per the *Carer Recognition Act 2010*

1. All carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality.
2. Children and young people who are carers should have the same rights as all children and young people and should be supported to reach their full potential.
3. The valuable social and economic contribution that carers make to society should be recognised and supported.
4. Carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life.
5. Carers should be acknowledged as individuals with their own needs within and beyond the caring role.
6. The relationship between carers and the persons for whom they care should be recognised and respected.
7. Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.
8. Carers should be treated with dignity and respect.
9. Carers should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education.
10. Support for carers should be timely, responsive, appropriate and accessible.