Carers Australia

Carers Australia submission

PRE-BUDGET 2020

August 2020

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AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

ABOUT CARERS AUSTRALIA

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness
- or who are frail aged

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.

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.

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Carers Australia

2020 BUDGET ASKS- SUMMARY

RECOMMENDATION 1: DEVELOP A NATIONAL CARER STRATEGY TO DEMONSTRATE A REAL COMMITMENT TO THE CRUCIAL ROLE OF CARERS

RECOMMENDATION 2: A CROSS PORTFOLIO MINISTERIAL COUNCIL FOR CARERS

RECOMMENDATION 3: ADDITIONAL STIMULUS PAYMENTS ARE PROVIDED TO ALL CARERS RECEIVING CARER PAYMENTS ACROSS AUSTRALIA

RECOMMENDATION 4: ENHANCED SUPPORT FOR EDUCATION & TRAINING ACTIVITIES

RECOMMENDATION 5: INVESTMENT IN WORKPLACE SUPPORT INITIATIVES

RECOMMENDATION 6: INVESTMENT TO REDUCE THE DIGITAL DIVIDE FOR CARERS

RECOMMENDATION 7: FUNDING TO DELIVER A ANNUAL NATIONAL CARERS CONFERENCE

INTRODUCTION

First and foremost, this pre-budget submission seeks to work in partnership with the Australian government to build a better future for all carers by recognising and investing in Australia's estimated 2.65 million carers. In 2020 this 'invisible army' have played a crucial role during the COVID-19 pandemic.

It is important that the valuable contribution of all carers is recognised by governments at all levels and across portfolios, as well as the wider community. This includes carers:

Who is a carer?

A carer is any individual who provides unpaid 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 come from all walks of life, cultural backgrounds and age groups.

Carers assist the people they care for with daily living tasks and support them to more fully participate in society.

- 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).

Carers Australia is cognisant of the significant investment made by the Australian Government in response to COVID-19 and the need to balance prudent financial management with continued support of the economy. The pre-budget submission focuses on supporting carers to continue productively in their unpaid caring roles and/or to engage in the workforce, both of which will have a resultant economic and social benefit.

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 socially isolating experience, where carers have among the lowest levels of wellbeing of any group of Australians, even before the impact of COVID-19. COVID-19 added another level of complexity for carers as they were required to isolate with the person(s) they care for in addition to:

- Reduced social support activities and formal and informal respite options, due to service cessation, reduction or postponement, and increased digital delivery methods
- An increased risk of violence and abuse within the home, due to the stress associated with household changes and uncertainties regarding the health and financial impacts and/or challenging behaviours among the people they cared for
- Contingency planning as many of the people cared for are in a high-risk health or age category for COVID-19, and many carers are also in high-risk categories themselves
- The challenges of balancing caring roles, employment and home learning, often in crowded households
- Reduced employment and income, especially young carers and women in lower paid, casualised sectors, exacerbated by increased basic living expenses and difficulty accessing essential items through isolation processes, lack of respite and reduced transport options, and
- An increased and sudden reliance on technology for social connection, medical appointments, therapies, and to undertake work and study commitments, including the costs associated with acquiring and setting up various IT equipment and maintaining an adequate internet connection and levels of data.

A recent Carer Network review of evidence highlights the main challenges experienced by carers during COVID-19 across health and wellbeing, service access, caring role, education and employment, finances, and technology. As a result, Carers Australia calls on the Australian Government to provide funding in the 2020-21 Budget that addresses essential support and services are provided to ensure carers:

- Engage in education, employment and community
- Are heathy and well
- Are recognised, acknowledged and respected in their caring role
- Can access respite and other supports they require when needed
- Improve their digital literacy and access to technology
- Have less financial stress

THE PROFILE OF CARERS IN AUSTRALIA

Carers Australia commissioned Deloitte Access Economics to estimate the economic value of Australia's informal (unpaid) carers in 2020[i].

The total estimated hours of care nationally is 2.2 billion in 2020 – this equates to a total national replacement of all informal care of $77,910.7 billion.

Further:

- Of the estimated 2.8 million informal carers in Australia,
    - Around 906,000 are 'primary carers' - someone over 15 years of age who provides most care
    - a further 1.9 million are 'non-primary carers'
    - This is a 5.5% increase in the number of carers since 2018
- The demand for informal carers will grow from around 1.25 million in 2020 to 1.54 million in 2030 representing a 23% total increase.
- Primary carers are estimated to spend an average of 35.2 hours per week providing care compared with 5 hours of weekly care for non-primary carers
    - 28% of primary carers spend more than 60 hours per week in their caring role
- The majority of unpaid carers are aged 45-64 years old
- Women account for 57% (or 1.6M) of all carers and 72% of primary carers
- Male carers over 75 years of age outnumber women carers in the same age group, and
- 22% of primary carers are employed full-time versus 43% for the general population.

A WHOLE OF GOVERNMENT NATIONAL CARER STRATEGY

Carers are an essential part of our community, providing unpaid care for family and friends, and deserve a whole-of-government National Carer Strategy which delivers a clear vision and strategy for all people in care relationships, now and into the future.

The role of the carer and need for increased support has been highlighted numerous times during the Royal Commission into Aged Care Quality and Safety and the Disability Royal Commission. While the *Carer Recognition Act 2010* (The Act) formally acknowledges the valuable social and economic contribution of carers in Australia, however the National Carers Strategy 2011, Action Plan 2011-2014 and companion Implementation Plan are long out of date, and not aligned with jurisdictions or the current reform agenda.

Current data gaps and a lack of research into carers and their role in health, aged care, disability care and broader social capital of our communities has a substantial impact on the development of evidence-based policy, service planning and provision, and policy and initiatives. A new National Carer Strategy is essential to acknowledge and 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[ii].

A new Carers Strategy would underpin the Primary Health Care 10-Year Plan (under development) and new National Disability Strategy. In addition, it needs to examine existing relevant policy that emphasise but do not address the essential role of the carer, including the National Palliative Care Strategy, Fifth National Mental Health and Suicide Prevention Plan, National Aboriginal and Torres Strait Islander Health Plan 2013–2023, National Framework for Action on Dementia 2015-2019, National Drug Strategy 2017-2026 and the National Alcohol Strategy 2019-2028.

RECOMMENDATION 1: DEVELOP A NATIONAL CARER STRATEGY TO DEMONSTRATE A REAL COMMITMENT TO THE CRUCIAL ROLE OF CARERS

This National Strategy must:

- Include supported community consultation and extensive engagement with stakeholders during planning, development and implementation
- Be for all people with a caring role
- Outline how to address carers' rights and needs, together with and separately from the people they care for
- Apply across portfolios and governments, including health, aged care, disability care, employment, education and broader social services
- Consider the data gaps and limited research on carers and the resultant impact this has on the development of evidence-based health, aged-care disability-care and social policy and service planning, and
- Take a long-term view and specify how it will be funded for implementation, monitoring and evaluation, in collaboration with carers, the private sector, non-government organisations and government.

MINISTERIAL FOCUS ON CARERS

Issues relating to carers in their own right have been subsumed by the overall disability reform agenda. Recognition of informal carers in providing support and care is crucial in the post-COVID world, and must focus on carer reform across ministerial portfolios including education, employment, health, aged care, disability care, and digital literacy.

Formation of a National Disability and Carers Advisory Council (the Council) was a Federal Government election commitment from 2014 in recognition of the complexity and diversity of the disability sector, and convened to enable the Government's regulatory reform agenda to be progressed through coordinated advice to the Minister and the Assistant Minister. The necessary focus of the Council at the time was on driving the implementation of the overarching National Disability Strategy 2010-2020, including the National Disability Insurance Scheme (NDIS) and proposed reforms to disability employment, as well as the Integrated Plan for Carer Support Services. However, there is now an independent National Disability Advisory Council to government.

It is Carers Australia's firm view that there is a lack of recognition of the complexity of interface issues faced by unpaid carers and those for whom they care for, particularly outside of the disability sector, noting that without unpaid carers both the aged care system and NDIS are completely unaffordable. This has been documented recently by the Aged Care Royal Commission and the Productivity Commission.

The lack of accountability in government for carer well-being, including employment support and access to education must be addressed, particularly given the estimated $77.9 billion it would cost to replace the informal care provided in 2020 alone.[iii] This significant contribution is even more valuable to government in the context of the ongoing COVID-19 response, where it is essential to ensure current services appropriately assist carers to meet the needs of the people that they care for, and themselves.

RECOMMENDATION 2: A CROSS PORTFOLIO MINISTERIAL COUNCIL FOR CARERS

A Ministerial Advisory Council on Carers be established to provide a voice for the 2.65 million unpaid carers, and at a minimum:

- Oversee development of a National Carers Strategy
- Champion continued carer reform across portfolios
- Increased awareness and greater accountability of the national recognition legislation
- Map the provision of respite across sectors in order to identify gaps, improve efficiencies and direct investment
- Ensure that approaches to policy are responsive to the needs of carers and care recipients alike
- Support the sustainability of unpaid care to benefit the health and wellbeing of Australians in need of support and assistance, and the boarder Australian economy
- Examine interface issues between Commonwealth and jurisdictional systems and funding, and
- Embed appropriate accountability processes and measures.

ADDITIONAL COVID-19 CARER PAYMENTS

Carers continue to experience negative financial impacts as a result of COVID-19. Additional carer payments are required to assist in providing the support carers need to continue caring during the ongoing uncertainty that COVID-19 brings.

While Carers Australia acknowledge the payments provided to-date, further stimulus payments to all carers receiving carer payments across Australia are needed, also noting that pension payments would not rise in September 2020 as a result of the indexation formula going down.

Many carers have reduced employment and income, especially young carers and women in lower paid, casualised sectors. This is exacerbated by increased basic living expenses and difficulty accessing essential items through isolation processes, lack of respite and reduced transport options, as well as an increased reliance on technology for social connection, services, and to undertake work and study commitments, including the costs associated with acquiring and setting up various IT equipment and maintaining an adequate internet connection and levels of data.

RECOMMENDATION 3: ADDITIONAL STIMULUS PAYMENTS ARE PROVIDED TO ALL CARERS RECEIVING CARER PAYMENTS ACROSS AUSTRALIA

In addition, ongoing carer payment needs are factored into COVID-19 Recovery considerations.

EMPLOYMENT SUPPORT FOR CARERS

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[iv]. 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.

The costs incurred when carers disengage from the workforce are both personal and economic. Long periods out of the workforce can result in the scarring effects of 'labour market detachment' such as reduced quality of life and financial hardship. The peak age for caring is 45 to 65 years, where those who leave the workforce at this point are often at the peak of their careers, and are at particular risk of detachment and financial hardship that extends into their retirement years[v]. Losing effective employees results in significant costs in the longer-term. These costs could be reduced if organisations are willing to support working carers, where there is evidence that this can[vi] improve employee retention, lower absence rates, facilitate recruitment and improve business outcomes.

COVID-19 has shown all Australians that there is a need to promote carer-friendly working environments, supplemented by the broader availability of carer support services in the community, to assist carers to combine work and care. National recognition of carers in the workplace can mean:

- Improvement of support for staff balancing work and care
- Management of the growing impact of caring on the workforce, especially with the impact of COVID-19
- Strengthening diversity and inclusion initiatives, and
- Gaining formal recognition as an employer of choice for carers.

RECOMMENDATION 4: ENHANCED SUPPORT FOR EDUCATION & TRAINING ACTIVITIES

- Develop an awareness campaign aimed at carers to assist in identifying what opportunities and avenues for support are available to facilitate education and training
- Fund programs that specifically enable carers wanting and/or needing to return to the workforce and/or undertake additional education or training
    - For example, expanding the Your Caring Way Program operating in Queensland, Tasmania and South Australia

RECOMMENDATION 5: INVESTMENT IN WORKPLACE SUPPORT INITIATIVES

- Increase workforce capacity and capability to support carers through an awareness campaign related to the benefits of a carer-friendly workplace
- Identify carers as defined in the *Carer Recognition Act (2010)* within workplaces
- Funding for employment programs that support best practice standards for supporting staff with caring responsibilities
    - For example, the Carers + Employers program in NSW, and work toward accreditation benefit by retaining talent and supporting employees with caring responsibilities.

IMPROVE DIGITAL INCLUSION FOR CARERS

Use of technology has a vital role to play in supporting carers in their caring responsibilities and they must be enabled and empowered to work, care and access information and services digitally.

Digital inclusion is whether a person can access, afford and have the digital ability to connect and use online technologies effectively[vii]. With Government services and supports increasingly moving to online only options, the need to improve carer digital inclusion is essential or risk increasing the 'digital divide' which will impact on carers ability to not only undertake their caring responsibilities, but also manage their own health and wellbeing, access education, finance services and support, as well as connection with friends, family, and peer support.

Households are now spending more money on internet services to account for more usage, where expenditure on these services has increased faster than increases in household income. This has led to an increase in household expenditure on internet services at a rate faster than the growth of household income. For those with low household incomes, affordability not only remains a critical issue, but the gap has widened over the period 2014-2019[viii].

COVID-19 has exacerbated this, where an increased and sudden reliance on technology for social connection, medical appointments, services, and to undertake work and study commitments has occurred. Carers Australia also highlight the importance of continued offline service delivery options for those who cannot, or do not want to for various reasons, engage in an online environment.

RECOMMENDATION 6: INVESTMENT TO REDUCE THE DIGITAL DIVIDE FOR CARERS

- Increase awareness of the availability of services and supports available online
- Improve navigation of online information in order to select the most appropriate options, and support informed choice and decision-making, and to effectively engage with government, and
- Consider options to support carers to maintain an online presence, through subsidised internet connections and availability of devices.

ANNUAL NATIONAL CARER CONFERENCE

Unpaid care arrangements are evolving, as are the delivery of carer support services- this year has seen the introduction of the Carer Gateway and all the associated changes in the service delivery arena. The Department of Social Services are planning the development of an online Disability Gateway and MyAgedCare, an aged care gateway, delivered by the Department of Health -and also utilised by carers- has been in existence for a few years now.

These 'gateways' serve to support carers, participants and clients of these three different, but intersecting service systems. There is a need to ensure that learnings from service delivery meet the needs of individuals and of families and communities; and caring must be possible alongside paid work and must be able to connect with health services.

Understanding the changing dynamics of families, changed economic and policy contexts is important in delivering wellbeing for carers.

Carers Australia is calling for a way to connect carers, services and systems as part of knowledge translation and ultimately engagement in co-design for the wellbeing of carers. This connection could potentially provide a space for critical analysis, debate and reform thinking- for carers, researchers, service providers and policy-makers.

RECOMMENDATION 7: FUNDING TO DELIVER AN ANNUAL NATIONAL CARERS CONFERENCE

[i] Deloitte Access Economics (2020) 'The value of informal care in 2020' for Carers Australia [accessed online]
[ii] Ibid
[iii] Ibid
[iv] 2015 ABS Survey of Disability, Ageing and Carers (SDAC) - for persons aged 15 to 64
[v] Carers UK. (2013). "Supporting Working Carers: The Benefits to Families, Business and the Economy". Final Report of the Carers in Employment Task and Finish Group.
[vi] Peters, I. & Wilson, K. (2017). "The business case for employers supporting carers: reflecting on a UK model" *Int. J Care and Caring*, Vol.1(3):415-20.
[vii] 2019, Measuring Australia's Digital Divide: The Australian Digital Inclusion Index 2019, RMIT University and Swinburne University of Technology, Melbourne, for Telstra [accessed online].
[viii] Ibid