

Submission to the Inquiry into the Recognition of Unpaid Carers, August 2023

Setting the scene

Some key facts about unpaid carers

The role carers play is essential to the health, wellbeing of livelihood of the person (or people) they care for, whether a child, partner, parent, sibling, other family member or friend. Their range of responsibilities often include personal care, healthcare, transport, advocacy, communication, cognitive and/or emotional support, household tasks and behaviour support. Approximately 30% of carers provide care to more than one person, and time spent providing care can be well over and above the requirements of a full-time job.

These caring responsibilities will often have an impact on their capacity to maintain work hours, sustain paid employment and/or participate in recruitment processes. This is reflected in the much lower workforce participation rate of primary carers (59%) compared to non-primary carers (77 %) and non-carers (82%).

These challenges can in turn contribute to significant financial stress, and even retirement can be a challenge for unpaid carers, with recent research highlighting that a primary carer's superannuation balance is reduced by \$17,700 for every year that they care.¹

Carers also experience significantly poorer wellbeing compared to the average Australian, with 55% carers continuing to have low levels of wellbeing compared to 25% of non-caring Australians. Carers also experience higher levels of loneliness than non-carers: 39% of carers compared with just 10% of Australians reported feeling lonely always or almost always in 2022.

In Victoria alone, there are currently more than 700,000 unpaid carers across Victoria, 31% of which are primary carers and more than 10% of which are young carers under the age of 25 years. The number of Victorian carers grew 22% between the 2021 and 2016 population censuses - the largest increase of all jurisdictions in Australia - and we estimate that by 2026 the number of Victoria's unpaid carers will exceed 1 million.

About Carers Victoria

Carers Victoria is the state-wide voice for unpaid carers in Victoria. It provides a wide range of services and programs to support Victorian carers in their lives and caring roles.

Carers Victoria provides a range of other assistance to carers including opportunities for connection through events, education, and networks; provision of information and advice curated to meet the needs and interests of carers; access to funded respite; and other opportunities to improve social connectedness.

It also gives carers an opportunity to have their voice heard through policy and advocacy activities that are informed by what carers tell us matter to them, with Carers Victoria both developing its own Victorian-specific submissions and contributing to national submissions via the National Carer Network.

Executive Summary

Carers Victoria welcomes the opportunity to make this submission to the Standing Committee on Social Policy and Legal Affairs Inquiry into the recognition of unpaid carers.

This submission, informed by feedback and advice we have received from Victorian carers alongside other qualitative and quantitative data, focuses on key issues the Committee can draw upon in shaping the future approach to recognising unpaid carers federally. It spotlights those Terms of Reference where Carers Victoria adds the most value as a state-based organisation.

Unpaid carers are mission critical...

Unpaid carers are integral to the sustainable support of people with care needs. Hundreds of thousands of Victorian carers provide invaluable practical, emotional and medical support to some of our most vulnerable community members - support which cannot be replaced by our mainstream health and social services sectors.

Unpaid carers and the contributions they make to our community are worthy of universal respect and celebration.

...yet they still report a lack of meaningful recognition....

However, many unpaid carers experience multiple and complex barriers to social inclusion, economic security, education and employment due to the significant demands of their caring function. Despite the existence of both state and federal legislation, data from the 2022 National Carer Survey indicates that less than 16% of Victorian carers agree their caring role is recognised and valued by the government.ⁱⁱ

...and without that recognition, their ability to sustain their caring role may be compromised.

Without authentic recognition and practical support, these unpaid carers are placing their health and wellbeing at risk. In the long term, this may see increasing numbers of unpaid carers finding themselves unable or unwilling to sustain these roles due to impacts on their health - resulting in poorer outcomes for people with care needs, while eroding the longer-term sustainability, and financial viability, of service systems such as the National Disability Insurance Scheme (NDIS) and aged care.

Much has changed since the Act was introduced, including sweeping reforms to both the disability and aged care systems, major shifts in our health system (in part driven by the pandemic), and significant changes in the population and forecast future needs. As a result, a rapidly growing number of unpaid carers are taking on more complex and time-consuming caring roles than ever before.

The good news is that there are some real opportunities to improve recognition efforts....

This submission, focussed on the Victorian context¹ and informed by qualitative and quantitative data, outlines opportunities to enhance current national arrangements, drawing upon existing examples both in Victoria and beyond. These include:

- Progressing legislative change to embed a role for unpaid carers in policy, program and service design and review in areas where they form an established part of that system's 'ecosystem' as a means of achieving practical recognition through genuine and meaningful inclusion.
- Strengthening public accountability and reporting requirements for federal agencies to capture practical examples of where unpaid carers have been actively included and sustain the focus on practical recognition and inclusion of carers.
- Considering how the diversity of care relationships may be better reflected/accommodated through the choice of language used to define and recognise the caring role in the Act.
- Considering whether an expansion to the application of the Carer Recognition Act is required to extend to agencies funded by the federal government to deliver services and supports.
- Exploring the feasibility of a rights-based approach to future legislation, drawing on the experiences of other jurisdictions who have adopted this approach.
- Strengthening the role of the Australian Public Service and others within the scope of the Carer Recognition Act in demonstrating leading practise in the flexible employment of unpaid carers.

...and the Inquiry has a unique opportunity to shape the future - for unpaid carers and the health of our broader community - and Carers Victoria looks forward to contributing.

Through its work, the Inquiry has an exciting opportunity to shape a system that more effectively supports unpaid carers.

This is particularly timely as Australia moves rapidly towards a future which will see more community members moving into unpaid carer roles than ever before. This will see a greater reliance on carers to sustain a rapidly ageing population with significant care needs; often without a clear picture of the support which might be required to sustain their own health and wellbeing.

By putting the necessary foundations in place now, we can strengthen both the recognition and the role of unpaid carers in ways that benefit everyone - from those in care relationships through to governments seeking sustainable solutions to meeting the future needs of the community.

Carers Victoria, alongside other members of the National Carer Network, looks forward to contributing to a not-so-distant future where everyone in Australia understands the role of an unpaid carer. A future where unpaid carers can find and sustain meaningful work with the inbuilt flexibility to support them in their caring role. A future where national frameworks and strategies

¹ Carers Victoria is a member of the National Carer Network, and this submission aims to provide a Victorian specific perspective that complements submissions made by Carers Australia to this Inquiry. As a result, this submission focuses on those terms and sub-terms of reference where we can most usefully contribute.

actively involve carers so that our broader community benefits from their insights, their expertise and the continued support they provide to those in their care relationships.

Addressing the Terms of Reference

ToR 1 - The effectiveness of the Act and the associated Statement of Australia’s Carers in raising recognition and awareness of the unpaid caring role, including its obligations on public service agencies.

Establishment of the Commonwealth Carer Recognition Act (the Act) and the associated Statement of Australia’s Carers played an important role in formally recognising the value and contribution of unpaid carers in Australia over a decade ago.

The Act has served as a foundational element in efforts to transform social norms, and assist in prompting systems, institutions and the community to question their assumptions about the provision of care.

However, carers tell us that what they need is *practical* recognition, through inclusion in the discussions and decisions that affect their care relationship, for example through genuine consultation, involvement in advisory functions and/or the opportunity to contribute to the co-design of policy, programs and services.

While the current Act does place some broad obligations on federal agencies to include unpaid carers², unfortunately this has not translated into significant or ongoing opportunities for carers to meaningfully contribute to Commonwealth reforms impacting carer, disability and aged care services. This has left many carers who support people accessing those systems feeling actively excluded and unheard.

Not only does this work against the intent of the Act to recognise carers, but also means a significant opportunity to enhance system effectiveness is missed by largely excluding the perspectives and expertise of unpaid carers as a core component of the ecosystem. Available data shows that many carers are challenged by the complexities of navigating systems, potentially compromising their capacity to sustain their caring role and impacting overall system viability.

Given the experience to date, the Inquiry should consider enshrining obligations to include and engage carers in the design and review of policy, programs, and services in which they play a significant support function. These obligations can be underpinned by boosted public accountability and reporting requirements for federal agencies to capture practical examples of where unpaid carers have been actively included.

The approach adopted in new Victorian Mental Health and Wellbeing legislation – itself directly informed by the Final Report of the Victorian Royal Commission into Mental Health – provides a model of promise that could provide a helpful example for the Inquiry’s consideration.

An example of embedding a role for carers: Victorian Mental Health reforms

In response to a 2019 Victorian Royal Commission, the Victorian Government has introduced specific mechanisms to embed inclusion and representation of carers of people living with mental illness and/or psychological distress as separate but equal stakeholders.¹

² The current Act places obligations on Public Service Agencies to:

- Take all practicable measures to ensure action reflects the principles of the Statement for Australia’s Carers in developing, implementing, providing or evaluating care supports.
- Consult carers, or bodies that represent carers, when developing or evaluating care supports.
- Prepare a report on its compliance...in each reporting period.

The Commission recommended that there be specific consultation with the family, carers, kin and supporters; and that people with lived experience of caring be employed (alongside people with lived experience of mental illness or psychological distress) to lead and shape the design, commissioning and delivery of services.

The responding Victorian Mental Health and Wellbeing Act comes into force in September, providing a strong example of practical recognition of unpaid carers.

*The Victorian Mental Health and Wellbeing Act is available at
<https://www.legislation.vic.gov.au/as-made/acts/mental-health-and-wellbeing-act-2022>*

ToR 2: Developments in the policy landscape at a Commonwealth level since the Act's passage in 2010

Carers Australia will be addressing this term of reference in further detail as part of its submission/s to the Inquiry and hence Carers Victoria will not make detailed comment on this item. We would however be happy to discuss these changes, and what it has meant for Victorian carers and their recognition, further if that would assist the Inquiry.

ToR 3: The effectiveness of existing state, territory and international recognition of unpaid care (statutory or other practice)

The Victorian experience

The *Victorian Carer Recognition Act* was passed in 2012. Table 1 overleaf provides a high-level comparison of this and the current Commonwealth legislation. To note:

- The Victorian legislation is grounded in the concept of care relationships, rather than the term carer per se. We have found this to be useful language, as it has the flexibility to accommodate of myriad of care relationships that exist, including:
 - those where one unpaid carer may be supporting multiple people and/or be a carer themselves³; and/or
 - care relationships where the person providing the care does not necessarily identify with the language of carer (*see Carers Victoria response to ToR 4b below*).
- Victorian legislation appears to have broader application, in that it expressly captures government funded care agencies, their delivery partners and/or funded third parties.

In an environment where governments increasingly deliver services and supports through partnership and/or other arrangements involving third party, the Inquiry should consider whether the federal definition should be extended to cover such circumstances.

Learnings from international experiences

While this submission focusses on the experiences of carers in Victoria, Carers Victoria notes that internationally, there have been substantial reforms to carer legislation in countries that share similarities with Australia, such as the Care Act (2014) in England, the Carers (Scotland) Act (2016) and the Social Services & Well-being (Wales) Act 2014. These foundational pieces of legislation enshrine important carer rights, such as the right to an adult carer support plan or young carer statement to identify each carer's personal outcomes and needs for support.

In considering the underpinning approach to statutory recognition of carers, these international schemes may provide beneficial elements with the potential to be tailored to an Australian context.

³ For example, it is estimated between 25 and 30% of carers support more than one person and each person with care needs may have more than one carer, such as instances where the care relationship involves multiple parents supporting a child with specific care needs. Without a framework that allows for recognition of how this role is shared, the weight of caring often falls to one parent (frequently the mother).

Table 1 - Comparison of Commonwealth and Victoria Carer Recognition Legislation

	COMMONWEALTH	VICTORIA
PURPOSE/ OBJECTS	<ol style="list-style-type: none"> To increase recognition and awareness of carers and to acknowledge the valuable contribution they make to society. 	<ol style="list-style-type: none"> Recognise, promote and value the role of people in care relationships; Recognise the different needs of persons in care relationships; Support and recognise that care relationships bring benefits to the persons in the care relationship and to the community; Enact care relationship principles to promote understanding of the significance of care relationships.
DEFINITION	An individual who provides personal care, support and assistance to another individual who needs it because that other individual (a) has a disability; or (b) has a medical condition (including a terminal or chronic illness); or (c) has a mental illness; or (d) is frail and aged.	Consistent with Commonwealth definition with added reference to individuals who have custody and guardianship of a child under a permanent care order, a protection order or a under a childcare agreement under the Children, Youth and Families Act 2005.
APPLICATION	<ol style="list-style-type: none"> Public service agency (PSA) and public service care agency. Associated providers. 	<ol style="list-style-type: none"> Public service care agencies meaning (a) a public service body within the meaning of the Public Administration Act 2004; or (b) a council within the meaning of the Local Government Act 2020. Funded care agencies. Any person or body that has entered into a contract or funding arrangement with a funded care agency to undertake all or part of the funded care agency's responsibilities in relation to the provision of programs or services that directly impact on carers and the persons for whom they care, but only in relation to those activities; and Any person, or class of person, or body that is prescribed by the regulations.

	COMMONWEALTH	VICTORIA
OBLIGATIONS	<ol style="list-style-type: none"> 1. PSA to take all practicable measures to ensure its employees and agents are aware and understand the Statement for Australia’s Carers. 2. Develop each PSA’s internal human resources policies with regard to the Statement for Australia’s Carers. <p>Further obligations on PSAs:</p> <ol style="list-style-type: none"> 3. Take all practicable measures to ensure action reflects the principles of the Statement for Australia’s Carers in developing, implementing, providing or evaluating care supports. 4. Consult carers, or bodies that represent carers, when developing or evaluating care supports. 5. Prepare a report on its compliance with section 7 and this section in each reporting period. 	<p>Funded care agency meaning a person or body that is funded by a public service care agency and has responsibility for programs or services that directly impact on carers and the persons for whom they care must ensure:</p> <ol style="list-style-type: none"> 1. Employees and agents have an awareness and understanding of the care relationship principles. 2. That persons who are in care relationships and who are receiving services in relation to the care relationship have an awareness and understanding of the care relationship principles. 3. Reflect the care relationship principles in developing, providing or evaluating support and assistance for persons in care relationships.
OTHER SUPPORTING ACTIVITIES	National Carer Strategy - not renewed since 2014	<p>The Victorian Carer Strategy (2018 - present) commits to assisting Victorian carers through a range of initiatives including:</p> <ul style="list-style-type: none"> • Flexible respite and support options to improve health and wellbeing through the Support for Carers Program. • Public transport concessions. • Support to enter the workforce. • Improved identification of young carers in education settings.

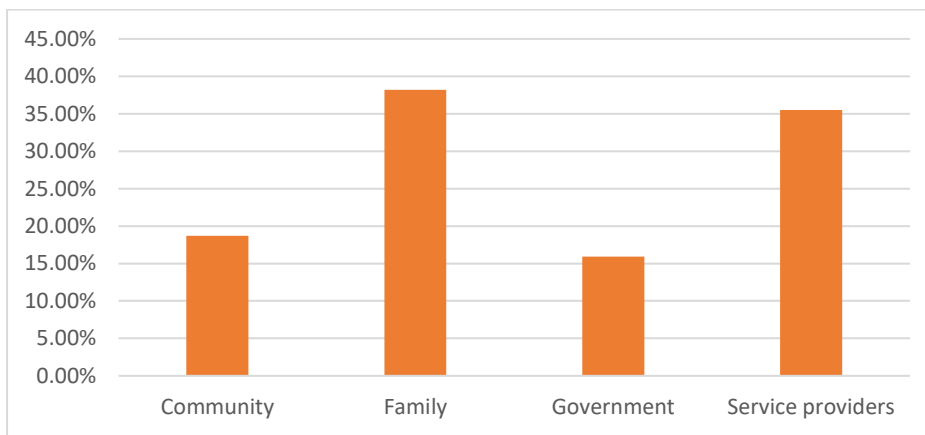
Tor 4: How to better identify the role of unpaid carers in Australian society and the role of a reformed Act, with regard to:

a. Understanding the value of unpaid care

It is estimated that currently, the economic replacement value of the support provided by Victoria’s unpaid carers exceeds \$19 B per annum in this state alone. However, the worth of unpaid care extends well beyond the economic to the value that unpaid care makes to the lives of the people in their care relationship, their communities and broader society.

Despite this, the role of carers is often hidden or not well understood. Carers report experiences of being excluded or misunderstood in a range of settings including healthcare and education, with government often the group perceived to have the lowest recognition of the caring role in Victoria (Figure 1).

Figure 1 - Recognition of care role - percentage of carers surveyed who agreed that their role was recognised by their community, family, government and services providers.



(Source: 2022 National Carer Survey, Victorian results).

b. The needs of specific cohorts such as young carers, First Nations carers, LGBTIQ+ carers, or culturally and linguistically diverse carers

Carers Victoria welcomes the Committee’s recognition of the importance of understanding and responding to the diverse needs of carers. As noted earlier, this is an area where Carers Victoria has found the use of the construct of supporting care relationships to be particularly valuable, as it provides flexibility to accommodate the diversity of care relationships, as well as the diversity of people in those relationships.

This emphasis on care relationships can assist programmatic and policy responses to reach individuals who may not identify with the term ‘carer’, due to cultural or social expectations of care provision within family or community settings.

Research undertaken by the Multicultural Centre for Women’s Health notes cross-cultural understandings of ‘caring’ vary significantly and can involve obligations to undertake significant and possibly onerous care roles. This is likely to be a factor in low carer self-identification within immigrant and refugee families and uptake in carer-centred supports.ⁱⁱⁱ Similarly, people reflect very different understandings of the care role and the term ‘carer’ itself. As noted in the 2017 *‘Dealing with it Myself’* report, “there is no direct equivalent of the term ‘carer’ in many languages.”^{iv}

Consultations undertaken by Carers Victoria in 2019 show that these beliefs and barriers are not exclusive to culturally and linguistically diverse carers but are also present for carers from Australia's First Nations, young carers, and carers who identify as LGBTIQ+. Carers from diverse communities such as these are more likely to face barriers to accessing information and services - particularly in seeking out culturally specific or targeted programs - compared with those who do not belong to a diverse community.

Common themes that relate to the needs of specific cohorts such as young carers, First Nations carers, LGBTIQ+ carers, or culturally and linguistically diverse carers, include:

1. A lack of self-identification with the term 'carer',
2. A lack of carer support programs specifically designed response to the needs of these cohorts,
3. Issues with stigma, including the common perception that accessing respite means the carer has "failed" in their caring role,
4. A preference for meeting individual needs, and
5. Concerns around allowing unknown service provider staff into the home, related to cultural safety.

It is critical to the improved engagement and outcomes of diverse carer groups that specific measures are taken to gain access to the full spectrum of carer perspectives, including through addressing cohort-specific barriers these carers may experience.

The Inquiry should consider adoption of the language of care relationships in future arrangements to accommodate the significant diversity that exists across the unpaid carer population and in particular, those who do not identify with the term 'carer'.

c. The meaningful role that flexible workplaces play in unpaid care

Carers Victoria notes that this Inquiry will consider the work of the Senate Select Committee on Work and Care. A unique feature of Victorian arrangements highlighted in its evidence to that Committee has also been summarised here for the Inquiry's reference/interest.

A key challenge for unpaid carers can arise when their caring role makes it difficult for them to gain, or retain, paid employment. While many workplaces are now offering significantly greater workplace flexibility than existed prior to pandemic lockdowns, having a workplace that is both understanding of the caring role and able to provide the flexibility needed to combine this with paid employment can still be challenging.

For example, data from the 2022 National Carer Survey indicated that over 60% of carers in paid employment had chosen their employer based on the offer of flexible working arrangements. In an era of workforce shortages, offering workplace flexibility has potential benefits for both employers and carers seeking/in paid employment.

It is however recognised that it can be challenging for a carer to seek workplace flexibility. In Victoria, the Equal Opportunity Act (2010) provides specific protections for carers who request flexible work arrangements to manage their caring responsibilities - the only Australian jurisdiction where carer status is a protected attribute in terms of workplace discrimination within equal opportunity legislation and carers can access individualised advice from the Victorian Equal Opportunity and Human Rights Commission about their request for workplace flexibility and access to conciliation services if need be. The Commission can also authorise research to inform its advocacy about the needs of carers in the workplace.⁹

In considering matters related to workplace flexibility, the Inquiry might consider opportunities to place positive obligations on the Australian Public Service (and potentially those it subcontracts for service delivery) to lead the way in both setting benchmarks and modelling best practise in the employment and flexible workplace support of unpaid carers.

References

ⁱ Evaluate (2022), *Caring Costs Us: The economic impact on lifetime income and retirement savings of informal carers*. A report for Carers Australia; accessed [online](#) 12 August 2023.

ⁱⁱ 2022 National Carer Survey; Victorian results.

ⁱⁱⁱ Aryal R. (2017) *Dealing with it myself: Supporting Immigrant and Refugee Carers in Australia*, Multicultural Centre for Women's Health: Melbourne, page 3.

^{iv} Ibid, page 13.

^v Victorian Equal Opportunity and Human Rights Commission Annual Report 2020-21.