

Recognition Matters: Strengthening the *Carer Recognition Act* and carer representation within Government

**Carers Australia's 2nd
Submission to the House of
Representative Inquiry
into the recognition
of unpaid carers**

August 2023



Purpose

This response has been developed to inform the House of Representatives Standing Committee on Social Policy and Legal Affairs (Committee) for the Inquiry into the recognition of unpaid carers (Inquiry) adopted on 13 June 2023, following a referral from the Minister for Social Services, the Hon Amanda Rishworth MP.

This submission is the second Carers Australia will be providing to assist with the Committee's work. The first response outlined key information about Australia's carers, information on Carers Recognition Acts across Australia, and examined the extent to which the introduction of the Federal *Carer Recognition Act 2010* is reflected in other legislation directly affecting carers.

This submission will assess more deeply the effectiveness of the national *Carer Recognition Act* and its Statement for Australia's Carers. Much of this response will focus on identifying the necessary changes needed to the Act to enable better carer recognition outcomes.

We also draw attention to the fragmentation of responsibilities for carers across the public service landscape and within Ministerial responsibility for carers.

Introduction

Our Issues Paper provided an outline of the characteristics of carers as a vulnerable group within Australian society - a group particularly prone to physical, mental and emotional hardship, as well as economic hardship. We highlighted consistent findings of carers experiencing very high levels of poor wellbeing compared to other Australians and, for many carers, their loss of life chances and choices (including the capacity to combine education and employment with their caring role and the loss of financial security).

It was explained that carers are an important part of the bedrock of the care economy and its sustainability (noting the replacement value of unpaid care provided by family and friends in 2020 was estimated at \$77.9 billion¹). However, this contribution can come at very high cost to themselves and, for those who have had to sacrifice employment to provide care, this cost can follow them beyond their caring role and into their retirement.²

Our Issues Paper also illustrated how the introduction of the *Carer Recognition Act* failed to produce in many areas either the acknowledgement of carers, or their needs for support, in policy and program reforms which impact directly on them.

Overall, we have clearly demonstrated the importance of adequate carer recognition and that the current state of engagement with, and responsibility of, the Carer Recognition Act and its objectives are not enabling carer recognition within Australia.

¹ Deloitte Access Economics, 'The value of informal care in 2020, May 2020', [\[accessed online\]](#)

² Evaluate, *Caring Costs Us:: The economic impact on lifetime income and retirement savings of informal carers*, 2022 [\[accessed online\]](#)

The engagement of lived experience carers so far in the Inquiry, such as in quotes in our submission, other submissions, and appearances before the Committee to date, have revealed the reality of this conclusion and added a deeper layer of meaning and substance to the high-level statistical data on carers and the challenges they face.

Carer policy since the introduction of the *Carer Recognition Act*

Following the introduction of the Federal *Carer Recognition Act*, a National Carer Action Strategy (2011-14) involving the national and state and territory governments was launched in April 2011. Six priority areas were identified:

- **Priority 1 - Recognition and Respect**
Carers are recognised, valued, respected and have their rights protected.
- **Priority 2 - Information and Access**
Carers have access to appropriate and timely information which makes it easier for them to get support.
- **Priority 3 - Economic Security**
Carers have economic security and opportunities to participate in paid work.
- **Priority 4 - Services for Carers**
Carers are supported with appropriate, timely and accessible services.
- **Priority 5 - Education and Training**
Carers have skills to undertake their role and opportunities to participate in formal education and training.
- **Priority 6 - Health and Wellbeing**
The health and wellbeing of carers and their capacity to participate in social and community life is improved.

A series of actions to contribute to the achievement of these outcomes were identified, as were performance indicators. However, few were achieved.

The Strategy and Action Plan also highlighted the benefits to carers arising from aged care and disability care reform, the emphasis being on how better supports for those they care for would benefit carers, rather than addressing carers' direct needs for support.

Neither the Act nor the Strategy appeared to inform the Living Longer, Living Better aged care reforms implemented in 2014. Indeed, carer support programs within aged care which were valued by carers were discontinued. It is not surprising then that the Royal Commission into Aged Care Quality and Safety identified that:

“The Australian Government should ensure that informal carers are properly supported. The current aged care system fails to do so and provides reactive, inadequate support. Supports are often not provided until the strain on a caring relationship has already reached crisis point.”³

Indeed, the Commission’s first recommendation provided a definition for a new Aged Care Act which included the entitlements of older people accessing the aged care system and support for carers. The Commission then went on to make a number of recommendations for improved carer support.⁴

A loss of carer support was also an outcome of the introduction of the National Disability Insurance Scheme (NDIS) in 2013. Carer respite funding for mental health carers and young carers was transferred to the general funding bucket to support the activities of the NDIS. Most importantly, unlike in aged care, respite was not identified as a support service available under the NDIS for a very long time.

We acknowledge that improvements to carer supports have been made over the years since the introduction of the Act and the Strategy. However, in many ways these improvements have been needed to fill gaps in carer support that had been removed, rather than building on existing supports to expand coverage, access and inclusivity. Some examples of targeted carer support include, but are not limited to:

- New or additional funding to support different categories of carers over the years.
- The introduction of the Young Carer Bursary to support young carers in continuing their education and reducing their need to undertake paid work at the same time as their study and caring duties.
- The introduction of the Carer Gateway in 2020 which was designed to provide a national, integrated carer support system equitably distributed across the country. It provides a range of support through a ‘one-stop shop’ model, combining respite brokerage, peer support, counselling, training, information and advice, and a modest amount of financial assistance. Gateway services are channelled through a number of government designated providers. The Gateway replaced what was previously a more haphazard provision of carer support services across the country, where not all providers offered the full suite of support. The Carer Gateway website and call centre also added a central source of information for carers – provided they identify as or understand the term carer. The Gateway is not without its problems, which is not unusual in the early years of the implementation of new programs, and it is currently under review by the Department of Social Services. However, in many respects, the Gateway represented a leap forward.

Despite these initiatives, it is still clear that carer recognition is an ongoing issue for Australia’s 2.65 million carers, begging the question: why has the *Carer Recognition Act* had little impact on the recognition of carers?

³ Royal Commission into the Quality and Safety of Aged Care, 2021, Final Report and List of Recommendations [\[accessed online\]](#)

Carers Australia believes there are three main reasons the *Carer Recognition Act* has not had a significant impact on the recognition of carers.

- **First, there is a widespread lack of understanding or acknowledgement of the Act.**
The current Act is not well known either by carers themselves or by many Australian public servants and agencies who deal with matters that directly impact carers. Nor is the Act familiar to many service providers in the aged care, disability care, health, education and employment sectors. This reflects the very low profile of carers more generally and the minimisation of the challenges they face within Australian society as a whole. Carers tend to think of themselves as invisible. The social and political lens is on those they care for, and carers tend to be seen as subsidiary background.
- **Second, the Act fails to include measures to support the enforcement of carer recognition activities and initiatives.**
Carers Australia is of the opinion a major deficit in the Act is it is not legally binding on anyone or anything other than with reference to the human resources policies of Australian Public Service agencies, and that Australian Public Service employees and agents have an awareness and understanding of the Statement for Australia's Carers (which in our experience they frequently do not).
- **Last, there are insufficient measures included to assess compliance with the Act.**
It is vital that accountability is improved to ensure all requirements are met by public service care agencies to report on their compliance with the Act and to consult with carers and their representative bodies when developing and evaluating carer supports.

Provisions of the Carer Recognition Act and suggested Amendments

The definition of carers

In the *Carer Recognition Act 2010*⁵ the definition of carers is:

*(1) For the purpose of this Act, a **carer** is 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.

*(2) An individual is not a **carer** in respect of care, support and assistance he or she provides:*

(a) under a contract of service or a contract for the provision of services; or

⁵ Parliament of Australia, Carer Recognition Act (2010) [accessed online]

(b) in the course of doing voluntary work for a charitable, welfare or community organisation; or

(c) as part of the requirements of a course of education or training.

*(3) To avoid doubt, an individual is not a **carer** merely because he or she:*

(a) is the spouse, de facto partner, parent, child or other relative of an individual, or is the guardian of an individual; or

(b) lives with an individual who requires care.

It is Carers Australia's view that the Act should be expanded to explicitly include carers of people with drug and alcohol addiction. The stigma attached to the people being cared for and the inadequacy of services available to them lead many of their carers to lack awareness that they too are eligible for support. They may also be unaware that alcohol and substance use is included in the impairment tables for the Disability Support Pension. Both the 2021 and 2022 Carer Wellbeing Surveys identified that carer wellbeing was particularly low amongst these carers, and the person they care for was least likely to access help of a medical or other support service.⁶ We note that a carer of someone who has alcohol or other drug dependence is included in the recently introduced *Tasmanian Carer Recognition Act 2023*⁷

The Statement for Australia's Carers

Ideally, the Carer Recognition Act should include a **Statement or Charter of Rights for Carers** in the same way as rights are conferred on people with disability in disability related legislation and as will be the case with respect to older people in the new Aged Care Act. As it stands, the Statement for Carers may best be described as ethical and policy guidance.

We understand that, in the absence of a Human Rights Act which could confer specific rights on carers, the Commonwealth Government must rely on its 'external affairs power' provided in s51 (xxix) of the Constitution and the ratification of international treaties to insert human rights into its legislation.⁸

Legislation conferring rights on people with disabilities relies on the United Nations Convention on the Rights of People with Disability (CRPD)⁹ and the International Covenant on Economic, Social and Cultural Rights (ICESCR)¹⁰. The new rights-based Aged Care Act will also rely on these treaties.

Unfortunately, in the case of carers, these conventions have limited specific application (unless they are among the nearly 40% of primary carers with disability¹¹), but they do have the effect of establishing some rights applicable to families in specific cases.

⁶ Carers Australia, 2022 Carer Wellbeing Survey [accessed online]

⁷ Tasmania, Carer Recognition Act 2023 (accessed online)

⁸ Rule of Law Institute, Explainer – The Treaty Process in Australia, 2020, [accessed online]

⁹ United Nations Convention on the Rights of People with Disabilities [accessed online]

¹⁰ International Covenant on Economic, Social and Cultural Rights (ICESCR) [accessed online]

¹¹ Australian Bureau of Statistics (ABS), Survey of Disability, Ageing and Carers (SDAC), 2018 [accessed online]

For example, in the preamble to the *Convention of the Rights of People with Disability*) it is stated that:

The family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities”.

The problem is that not all carers are family members in the common meaning of the term. A number of carers are friends of the person they are caring for and would not be included in this definition unless the term “family” was intended to include “chosen family”.

Then there is Article 28:3 in relation to families living in poverty:

To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care.

Again, not all carers live in poverty, but they should be provided with training, counselling, respite care and, in some cases, financial assistance.

The *International Convention on Economic, Social and Cultural Rights* (ICESCR) confers general rights in relation to:

- The right to self determination and to freely pursue their economic, social and cultural development.¹²
- To take part in cultural life.¹³
- The right to education.¹⁴
- The right to employment.¹⁵
- Equal opportunity for everyone to be promoted in his employment to an appropriate higher level, subject to no considerations other than those of seniority and competence.¹⁶
- The right to the enjoyment of the highest attainable standard of physical and mental health.¹⁷

However, other statements in the *Carer Recognition Act* cannot be referenced to international treaty obligations.

We note one possible solution to the conundrum of having some statements which can be backed by international treaties and others that cannot, is to identify some statements as rights and others as ethical imperatives and guidance. The distinction can be identified by using the words “carers have a right to” with respect to some statements and “carers should be” in relation to others. We have employed this approach

¹² Ibid. Article 1.1

¹³ Ibid. Article 15.1 (a)

¹⁴ Ibid. Article 13:1

¹⁵ Ibid. Part III, Article 6:1

¹⁶ Ibid. Article 7 (c)

¹⁷ Ibid. Article 12.1

in our suggested changes and additions to the Statement for Carers identified below. We do not consider these changes exhaustive and are aware that other people or organisations making submissions to this inquiry are likely to have other suggestions.

A revised Carer Statement

With respect to revising the existing Statement for Australia's Carers, Carers Australia has several suggestions that range from updating language to better reflect present understandings of inclusivity, to the addition of other statements for inclusion. It should be noted these recommendations reflect the current view of Carers Australia. Any revisions to the Act should be subject to much wider consultations which include harvesting the input of carers themselves, just as is the case for the current widespread engagement of consumers and their families and carers prior to the drafting of the new *Aged Care Act* and for revisions to the *Disability Services Act*.

Statement 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.

Carers Australia recommends this statement should be revised to **replace "sex" with "gender identification"**.

Statement 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.

Carers Australia recommends the following be added to this statement: **They should have the right to participate fully in education and be supported to do this, including through the provision of replacement care for the person they care for, to enable them to participate fully at all levels education and training.**

Statement 3:

The valuable social and economic contribution that carers make to society should be recognised and supported.

Carers Australia recommends, in addition, it should be recognised that: **Carers should be regarded as an essential part of the care economy and the bedrock of its sustainability.**

Statement 4:

Carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life.

Carers Australia recommends this be rephrased to read: Carers **have the right** to be supported to enjoy optimum **physical and mental health** and to participate in family, social and community life.

Statement 5:

Carers should be acknowledged as individuals with their own needs within and beyond the caring role.

Carers Australia recommends adding: **and their right to engage in education, employment and social and cultural life should be taken into account in assessment of their needs.**

Statement 6:

The relationship between carers and the persons for whom they care should be recognised and respected.

Carers Australia recommends adding: **including by entities providing support to those they care for across the healthcare (including mental health), disability sector, drug and alcohol services, palliative care and aged care sectors.**

Statement 7:

Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.

Carers Australia recommends that this statement be rephrased as:

Carers should be regarded as partners in care with other care providers in the provision of care, acknowledging their unique knowledge and experience, and receive information from professionals in the areas of the physical and mental health of the person they care for with the permission of the person they care for.

Statement 8:

Carers have the right to be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education.

Carers Australia recommends the wording “where appropriate” be removed and the statement be rephrased as: **Carers have the right to engage in employment and should be able to access flexible employment in order to combine work and care.**

Statement 9:

Support for carers should be timely, responsive, appropriate and accessible.

Carers Australia recommends adding: **including information about supports available.**

In addition to these Statements and the edits noted, Carers Australia also recommends the addition of several new statements be considered. These include:

Statement 10: Carers should be regarded as an essential part of the care economy and a bedrock of its sustainability.

Statement 11: Carers and their representatives should have ample opportunities to influence the outcomes of legislation and policy which directly impacts on them, and their views should be valued and respected. This should include, at a minimum: aged care, disability care, and health (including drug and alcohol dependency), as well as policy in relation to veterans, employment policy (including Government employment services), and social security policy and services.

The Extent to which the Carer Recognition Act should impact on related Acts

It is the view of Carers Australia that the *Carer Recognition Act* is considered and referenced in other Acts which impinge on, or relate to, carers unless it would undermine or is shown to be totally irrelevant to, the purpose and provisions of that Act. Once again, in addition to legislation relating specifically to carers, primary pieces of legislation would be in the areas of aged care, disability care, some health policy provisions, legislation pertaining to defence and veterans, employment support services, some acts relating to education, and elements of the Social Security Act. Of course, any legislation in relation specifically to carers should reference the *Carer Recognition Act*.

Ministerial representation, Machinery of Government and Measurement of Outcomes

It has been highlighted in this submission, and particularly in our Issues Brief, that following the 2008-9 Senate Inquiry into carers and the introduction of the *Carer Recognition Act*, organisational representation, strategy and action plans undertaken in good faith and with initial enthusiasm lost their way. The disengagement with carer policy occurred over a comparatively short period of time after the initial buzz of carer consciousness settled down and new governments, ministerial arrangements and wider policy changes introduced a new set of priorities, especially in relation to the people carers care for.

In portfolios with a less heightened awareness of carers, but nevertheless introduced policy and programs which had the capacity to address many of their challenges (such as education and employment), Carers Australia and other carer related advocacy got little traction despite ongoing engagements through submissions to consultations in these areas. Furthermore, we experienced difficulty in seeking out and engaging with relevant stakeholders across government.

It is imperative that carers and the organisations representing them have access to a central place to call home at the national level within the plethora of ministers, departments and agencies which are key to addressing their diverse needs. Within the current Government, the Minister for Social Services has direct responsibility for carers however the Social Services portfolio does not cover all the policies, programs and services which address carers' needs. In particular, it is not responsible for aged care which has a high impact on the 35.5% of carers caring for older people¹⁸ and which provides some services to carers,

¹⁸ Australian Bureau of Statistics (ABS), Survey of Disability, Ageing and Carers (SDAC), 2018, Table Builder [\[accessed online\]](#)

including respite. However, there is no branch for carers within the Department of Health and Ageing structure in either the aged care division or the health divisions.

Finally, Carers Australia recommends the establishment of a new National Carers Strategy which works to unpack and reflect all elements of the Statement for Carers and has robust action plans and outcomes measurement. It should form the basis for improvements in carer support across portfolios, provide for lived experiences carer input, be reported on annually, and be sustained over time.

We note a number of states have established Advisory Councils for Carers to advance their interests. Tasmania has recently established a Ministerial Advisory Council for Carers, while NSW, Western Australia, and Queensland have Care Advisory Councils reporting to relevant ministers.

Recommendations

- 1. We recommend a comprehensive review of the Carer Recognition Act and services provided to carers. It should encompass the support they receive in different areas of need. This review should be substantially inclusive of carers with lived experience. Consultations should be widely promoted and should provide sufficient time for notably time poor carers to consider and to respond to the issues raised. We would recommend a period of at least three months for responses to consultation papers. The consultation should be widely promoted (including in mainstream and social media) and offer opportunities for webinars, “town hall” meetings online and in person, and written responses via submissions, emails and surveys.**
- 2. The national Government should have a Minister or Assistant Minister for Carers to lead a whole-of-government approach to carer recognition, inclusion, and support.**
- 3. The Government should establish an Office for Carers to focus on the needs and interests of carers, particularly those carers who are vulnerable, at risk or disadvantaged.**
- 4. Regardless of whether an Office for Carers is established, a high-level cross-departmental forum should be established to coordinate legislation, policy, programs and services impacting on cares so that they are effectively linked across Commonwealth portfolios.**
- 5. A revised National Carer Strategy and Implementation Plan with robust outcome measures and reporting requirements should be established and renewed at regular intervals as required. This will require identifying data needed to monitor the social and economic impact of national carer policies and programs.**
- 6. Barrers to education, employment and financial wellbeing for carers need to be identified and addressed.**
- 7. Introduce strengthened compliance and reporting requirements within government including an Australian Public Service Commission review of APS Employment Principles and workplace policies and practices against obligations under the Act to**

provide best practice examples for non-public service care agencies and non-government employers.

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About Carers Australia

Carers Australia is the national peak body representing the diversity of the 2.65 million 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.

In collaboration with our members, the peak carer organisations in each state and territory, we collectively form the National Carer Network and are an established infrastructure that represents the views of carers at the national level.

Our vision is an Australia that values and supports all carers, where all carers should have the same rights, choices, and opportunities as other Australians to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment, and education.

Carers Australia acknowledges Aboriginal and/or Torres Strait Islander peoples and communities as the traditional custodians of the land we work on and pay our respects to Elders past, present and emerging. As an inclusive organisation we celebrate people of all backgrounds, genders, sexualities, cultures, bodies, and abilities.

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