CarersACT

SUBMISSION TO THE STANDING COMMITTEE ON SOCIAL POLICY AND LEGAL AFFAIRS:

INQUIRY INTO THE RECOGNITION OF UNPAID CARERS IN AUSTRALIA

AUGUST 2023

About Carers ACT

Carers ACT is the leading body for carers in the ACT, where more than 50,000 carers reside. We work to ensure that carers enjoy improved outcomes in health, wellbeing, resilience and financial security. We also work to ensure that caring is acknowledged and recognised as a shared responsibility of family, community and government.

Our purpose is to support, connect and empower carers to maintain their caring role and personal wellbeing.

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Introduction

Carers ACT welcomes the opportunity to respond to the House of Representatives Standing Committee on Social Policy and Legal Affairs' inquiry (‘the inquiry’) into the provisions and operation of the Carer Recognition Act 2010 (‘the Act’).

Our insights are informed by over three decades of engagement with carers, of which over a decade has occurred since the Act's implementation. For this inquiry, we have conducted extensive consultations, reaching out to more than 3,000 carers in Canberra, including through outreach with six existing Carers ACT groups, two facilitated focus group sessions (one online and one in person) and a survey on the inquiry themes which was completed by 140 carers. Survey results referred to throughout this submission are in reference to the findings of the aforementioned Carers ACT inquiry survey unless stated otherwise. The findings of these consultation efforts form the backbone of this submission, providing a comprehensive and contemporary understanding of the challenges faced by carers and the areas where the Act could be improved.

At the heart of our submission is support for the Statement of Australia’s carers (the Statement) and the leading principle that “carers should have the same rights, choices, and opportunities as other Australians...”. Carers ACT firmly believes that carer rights must be upheld and valued to achieve the aspirational norms that make up the Objects of the Act.

This submission will have particular regard to the Act's effectiveness in achieving its stated Objects, namely, to increase **recognition** and **awareness** of carers and **acknowledge the valuable contribution** they make to society.

Summary of Recommendations

- Establish a federal policy section within Prime Minister and Cabinet (PM&C) responsible for ensuring the Act is implemented as intended and regularly reports on how public service agencies (not just public service care agencies) are adhering to the Act.
- Create designated policy positions within all public service agencies to oversee policy impact on carers and to implement carer strategy across their agency's divisions.
- Add an obligation in the Act to require all new or amended public service policy or service provision to consider the impact on carers through the development of a statement of impact on carers.
- Implement regulation as a subordinate law to the Act, similar to the *Carers Recognition Regulation 2021* (ACT).
- Include a provision in the Act requiring review of the Act's operation and effectiveness within 5 years.
- Amend relevant legislative frameworks influencing social welfare to use a definition of 'carer' consistent with that of the Act.
- Require public service agencies to use a definition of 'carer' consistent with that of the Act in internal procedure and external publications.
- Action the recommendations of the Senate Select Committee on Work and Care final report (2023) regarding carers leave, including Recommendation 18.
- Require public service agencies to develop internal human resources policy which includes education about carers with a focus on reducing stigma and fostering a carer-inclusive culture.
- Leading by example, public service agencies provide genuinely supportive and flexible workplaces for carers. Government services recognise and support the fundamental right of carers to choose the amount of unpaid caring they do.
- Respond to carer needs and choices in respite planning and provision.
- Ensure consistent respite allocation across all Government systems.
- Fund carer specific supports within consumer directed service systems that rely on the contribution of carers to reduce the cost burden on the system. This would include funding allocated under My Aged Care, NDIS, and the National Mental Health and Suicide Prevention Agreement specifically to aid carers in delivering unpaid care.
- Support service providers to adequately educate and train staff to maintain a high-quality standard of care.
- Expand the reach of Carers Week by targeting non-carers through high visibility marketing such as television ads and should include the financial value of the contribution of carers to reduce stigma.
- Fund education campaigns in child and youth spaces, aimed at helping young carers to self-identify and providing information about supports available.
- Create promotional campaigns with a focus on the role/s of carers to help self-identification, particularly within priority groups.
- Consider the implementation of a simple carer ID card which provides evidence that someone is recognised as a carer. The card must not be means tested and should be simple to receive.
- Acknowledge the disadvantages experienced by carers because of their roles and implement initiatives that support carers to enjoy the same opportunities as other Australians.
- Review the eligibility criteria for both the Carer Allowance and Carer Payment, ensuring that workplace participation is encouraged rather than deterred.
- Provide the superannuation guarantee to people on the Carer Payment and Carer Allowance.

Awareness

“If you aren’t convinced that Carers are invisible, just write the word, ‘Carer’, online. It’s automatically autocorrected to ‘career’ or something else” - Survey respondent.

Our interactions with carers over the years have brought to light a serious lack of public knowledge about the caring role and their importance in society. For example, during the process of creating the ACT’s Carer Strategy, the Carer Voice panel members expressed that increasing community awareness of the value and contribution of carers was a priority outcome (ACT Government, 2018). Despite the Act's intent to amplify awareness of carers, our survey found that a substantial 87% of carers felt their role was neither comprehended nor valued by the Australian public. This lack of understanding extends to the term 'carer' itself, often misinterpreted as referring to paid support workers, leading to an undermining of the identity of unpaid carers and a diminishing of the recognition of their contributions.

Carers have voiced feelings of isolation and frustration due to this lack of understanding. They feel the unique skills they develop, often under immense pressure, such as time-management, multi-tasking, clinical and administrative skills should be explicitly acknowledged by Governments. Carers underscored the complexities and the physical, emotional, and financial strains associated with their roles; aspects often overlooked. This misunderstanding extends to self-identification, with many carers uncertain about their identity as 'unpaid carers'. The stigma associated with the term 'carer' often means that carers prefer to identify themselves as parents, siblings, friends, or other similar titles. These barriers to self-identification are particularly prevalent among First Nations and Culturally and Linguistically Diverse (CALD) carers. Consultation with CALD carer groups have highlighted how this can manifest in unique challenges, including limited knowledge of available services, unwillingness to challenge service access and quality, and resistance to the concept of carer support groups or the public discussion of family issues.

The confusion is further exacerbated by inconsistencies in government references to carers. For instance, the Australian Taxation Office uses the term “direct carer” while the Australian Institute of Health and Wellbeing refers to carers as “informal carers” in their publications. Variation in definition of ‘carer’, or lack thereof, in legislative instruments like the *National Disability Insurance Scheme Act 2013, Fair Work Act 2009, Social Security Act 1991*, and *Disability Discrimination Act 1992* exacerbate confusion about eligibility into Australia’s existing beneficial frameworks. When discussing the inquiry, carers were confused by the term ‘unpaid carer’, asking whether receiving the carer payment meant they fell outside of this term and couldn’t participate in the inquiry. Contrarily, Carers ACT also frequently hears from carers that they were “rejected” from being a carer because they did not meet carer payment eligibility, and thus thought they were unable to access any supports. Such inconsistencies hinder awareness efforts and complicate the process of self-identification for carers. Federal legislation, and relevant public service procedure must work towards a unified understanding and use of the term 'carer', consistent with the definition provided in the Act.

Carers have highlighted the need for educational campaigns in communal spaces, like schools, youth centres, libraries, and workplaces. Such initiatives could provide carers, with tools to self-identify and could equip others with the information needed to support the carers they encounter. Education and support to self-identify is particularly important for young carers, who often remain unnoticed or have their caring responsibilities underestimated due to their age. Young carers face a range of unique challenges related to their developmental stage in life and without adequate support are at risk of poorer physical health, mental health and educational outcomes than their peers (Department of Social Services, 2002).

Furthermore, high visibility marketing strategies such as TV advertisements during Carers Week were proposed, aimed at educating the public on the nature of carers' roles, and to underscore the financial value of carers (Carers Australia, 2022). By shining a light on the economic contribution carers make, it is hoped that we can dispel the stigma that carers are a burden on taxpayers, and instead highlight their crucial role in society.

Recommendations:

- Amend relevant legislative frameworks influencing social welfare to use a definition of 'carer' consistent with that of the Act.
- Require public service agencies to use a definition of 'carer' consistent with that of the Act in internal procedure and external publications.
- Require public service agencies to develop internal human resources policy which includes education about carers.
- Fund education campaigns in child and youth spaces, aimed at helping young carers to self-identify and providing information about supports available.
- Expand the reach of Carers Week by targeting non-carers through high visibility marketing such as television ads and should include the financial value of the contribution of carers to reduce stigma.
- Create wide reaching promotional campaigns with a focus on addressing stigma and valuing the caring role, particularly within priority groups.

Recognition

Respect

"Awareness is about knowing; recognition is about respecting" – Carer group participant.

Real recognition, as described by carers, extends beyond mere awareness and includes respect for their role. It is also about enabling carers to experience everyday normalities that other Australians take for granted.

For carers to feel recognised, they need practical support that respects their contribution and aids them in their roles. This support should extend to navigation, case management, and administration support. Carers, particularly those who are employed or of mature age, report being overwhelmed by the burdens of repetitive documentation requirements and complex system navigation. To mitigate this, carers have suggested more funding for local support services to provide casework style supports, lightening the overall administration load.

The lack of recognition faced by carers is solidified by government actions which appear to seek input from carers, only for this input to be disrespected by having outcomes be disregarded or suppressed. For example, the Field Test undertaken by DSS on Carer Payment and Carer Allowance in January of 2019 was extended by several months to include further carer consultation. However, as of 2023 these findings are yet to be made public. We firmly believe that the carer voice is not to be used as a mere 'check box', rather it should be the foundation for respectful and meaningful change.

Recognition may also be achieved through a national carer identification (ID) card, which carers proposed during the consultations. This non-monetary form of recognition would not only validate carers but also encourage businesses to offer a token of appreciation through benefits or discounts to carers, further supporting participation in everyday society and providing opportunity for awareness. The ID card should be simple to apply for and not subjected to means testing, similar to the application process for the 'We Care' card in Victoria.

The need for financial support, in addition to tangible recognition, is also crucial. Carers bear the long-term financial burden of extra costs associated with their responsibilities, such as transport costs, medical fees, and the reduced capacity for employment, which can significantly impact their lifetime financial stability. The Australian Bureau of Statistics (2018) found that 50.2% of all carers lived in households in the lowest two income quintiles. While the adequacy of carer payments is not in scope, carers voiced the need for a revision of the eligibility requirements for carer payments, specifically, removing means testing as this disregards the financial burdens of carers. For carers who were ineligible for payments because of means testing, the loss of recognition of their caring role was often of greater concern than the loss of financial support.

Recognising the complex role of carers requires more than just awareness, it demands tangible actions that convey respect. And while significant work is needed to meet these needs, it's important to remember that a small amount of money or a piece of paper (such as an ID card) can go a long way in showing carers the respect they deserve.

Recommendations:

- Consider the implementation of a simple carer ID card which provides evidence that someone is recognised as a carer. The card must not be means tested and should be simple to receive.
- Review the eligibility criteria for both the Carer Allowance and Carer Payment, ensuring that workplace participation is encouraged rather than deterred.
- Acknowledge the disadvantages experienced by carers because of their roles and implement initiatives that support carers to enjoy the same opportunities as other Australians.

Consideration

"As a good society we should look after our families and loved ones. We just need the support that makes this most possible" - Survey respondent.

A significant call for greater recognition of carers' roles and needs in the policy-making process across all public service agencies, not just those in care or social services, has been echoed throughout our consultations. This perspective is supported by the fact that a mere 3% of carers felt that government agencies adequately consider the impact on carers during a service or policy change, indicating a substantial gap in consideration. The hardship that carers experience often arises not from the caring responsibilities themselves, but from the lack of consideration and foresight from the systems around them.

This lack of consideration manifests in practical terms as difficulties navigating bureaucracy and time-consuming administrative tasks. We heard that it is rarely the caring responsibility itself that makes a person's caring role unbearable; it is the ongoing, compounding lack of consideration from the systems surrounding them. Examples we heard of unbearable inconsideration included being required to provide Power of Attorney documentation multiple times across different government departments, receiving an NDIS plan that the carer was not included in contributing to but is expected to implement, a changed bus timetable after months supporting their care recipient to learn the bus route to day program safely or waiting on hold for hours to speak to Services Australia when the carer has a half hour lunch break and is being performance managed for requiring "too much" time off to care. These issues that carers raised as leading to their stress and burnout could all easily be addressed by public service agencies if consideration and a little foresight was given.

It is also often noted that the adequacy of support, particularly under the NDIS, heavily impacts carers. Often, they bear the brunt of advocating for better supports for their care recipients, and absorbing the financial strain when government supports fall short. Likewise, as outlined in the Statement, carers emphasised the necessity to consider their needs separately from those of the care recipients. For instance, agencies like the Department of Health (2022, pg. 132) fulfil their reporting obligations under the Act by also grouping them in with disability confidence. This lack of distinction renders carers secondary, and their unique needs ignored. Carers ACT have witnessed that the paradigm shift in the aged care, disability, and mental health sectors towards consumer directed care (CDC) (Phillipson et al., 2019), has meant funding of individualised supports is specifically tied to the needs of the care recipient, while carers' needs and goals are frequently left out of the service planning conversation and not given priority when funded services are allocated.

To ensure carers' needs are recognised, the creation of designated policy positions within public service agencies is proposed. These positions could oversee the implementation of carer strategy across departments and ensure that policy and program changes include mandatory statements for the impact on carers. This approach will ensure carer needs are at the forefront, demonstrating genuine recognition of their critical role in society.

Recommendations:

- Add an obligation in the Act to require all new or amended public service policy or service provision to consider the impact on carers through the development of a statement of impact on carers.
- Create designated policy positions within all public service agencies to oversee policy impact on carers and to implement carer strategy across their agency’s departments.
- Fund carer specific supports within consumer directed service systems that rely on the contribution of carers to reduce the cost burden on the system. This would include funding allocated under My Aged Care, NDIS, and the National Mental Health and Suicide Prevention Agreement specifically to aid carers in delivering unpaid care.

Acknowledgement of Contribution

Financial Stability and Workforce Participation

“We forgo our careers and if we manage to stay in the workforce, we forgo opportunities for professional development and progression. We forgo our current and future economic security because our employment income and superannuation is reduced… We don't get to have disposable income or holidays. These aren't choices we have made, this is just how life turned out…” - survey respondent.

The economic strain that carers endure, resulting from their substantial responsibilities, can be overwhelming. The 2022 Carers Australia ‘Caring Costs Us’ survey found that on average, a person’s lifetime earnings are reduced by $39,600 for every year they are a primary carer (Network of Carers Associations, 2022, pg. 32). Financial hardship is a recurrent theme raised by carers, brought about by a reduced capacity to participate in the workforce due to their caring role. Notably, Australian carers experience considerably poorer employment outcomes, with a 52.2% employment to population ratio compared with 75.9% for people without caring responsibilities (ABS, 2018). Such financial instability does not only affect carers economically but also deprives them of the positive mental health benefits that can come from being part of a workplace.

Stigma often permeates carers' experiences in the workforce, with many carers perceived as unreliable or suspected of exaggerating their circumstances to gain special treatment. This calls for a shift in the workforce's perception, recognising carers as resilient, advanced multitaskers. "*If you want a job done, give it to a carer! Guaranteed we will get done faster than anyone else*," a focus group participant attested. Recognising that there are carers in a workplace and supporting them to manage their caring responsibilities and work can reduce stress, improve commitment to the organisation, decrease staff turnover, and improve job satisfaction and performance (CIPD, 2020).

The call for additional paid carers leave was a prominent discussion among carers. They often deplete their annual leave allocation due to caring responsibilities, leaving them with no time for self-care or relaxation. The fear of losing their jobs due to their need for leave creates further stress, pushing many to work even when they're unwell. The introduction of additional paid carer leave provisions, akin to the Family & Domestic Violence Leave provisions, was highly advocated for. This, they feel, would acknowledge the challenges of their role, stimulate workplace participation, and provide a platform for educating the workforce about carers. There was also an overwhelming desire for truly flexible workplaces, with carers proposing that public service agencies pioneer this approach. Suggestions included additional carer leave, work-from-home options, and individualised work plans, among others. Carers believe that the Carer ID card, as discussed earlier, could play a role in advocating for such flexible arrangements.

However, some carers conceded that even with supportive workplaces, they could not sustain long-term employment due to their demanding roles. Superannuation became a point of concern as many carers feared a future of financial instability due to their diminished or non-existent ability to contribute to superannuation. The ‘Caring Costs Us’ survey substantiate these concerns; highlighting that the superannuation balance at age 67 of a parent or family member who becomes a primary carer for a child is reduced by about $17,700 for every year that they are a carer (Network of Carers Associations, 2022, pg.32).

Finally, carers expressed their discontent with the limitations placed on their work hours by the eligibility requirements for carer payments. Given the barriers to employment and the known financial implications of the caring role, the conditions for accessing financial support should not deter workforce participation. As one survey respondent put it, "*If the carer payment is on the poverty line, then we shouldn’t be taking away this stable payment, we should be encouraging carers to work for their own financial and social benefits.*"

Recommendations:

- Action the recommendations of the Senate Select Committee on Work and Care final report (2023) regarding carers leave, including Recommendation 18 asking that “The Australian Government consider the adequacy of existing leave arrangements and investigate potential improvements in leave arrangements in the *Fair Work Act 2009*, including separate carer's leave and annual leave”
- Provide the superannuation guarantee to people on the Carer Payment and Carer Allowance.
- Deliver carer awareness training in workplaces with a focus on reducing stigma and fostering a carer-inclusive culture.
- Leading by example, public service agencies provide genuinely supportive and flexible for workplaces for carers.

Choice and Respite Care

“I constantly feel trapped in my role. Respite care is difficult to access, people who are not carers do not recognise that it is a stressful role or something that requires relief” - survey respondent.

In order to have the “same rights, choices and opportunities as other Australians” as outlined in the Statement for Australia’s Carers, carers must be able to choose how much caring they do, what type of care they provide and what supports and services they receive. Yet, as one survey respondent pointedly said, "*Being an unpaid carer is not a choice for me, as there is no alternative support available to the people I care for.*"

There is an undeniable shortage of options for respite care, contributing to a dire wellbeing implication - the lack of free time. As research, like the studies by Goodin et al. (2005) and Sharif et al. (2018), indicates, a lack of at least 2.5 hours of free time per day directly correlates with heightened stress levels. Unfortunately, carers seldom have the luxury of these hours. At present, the amount of care provided by carers often supersedes their personal choice due to the care recipient's needs, severely restricting the carers' own personal time and choice. This translates into reports of low levels of overall wellbeing, increased feelings of loneliness, and moderate to high levels of psychological distress.

Respite care should be carer-driven. The eligibility of such a service should not rely solely on care recipients reaching out; rather, it should cater to the carer's need for a break. At present, carers seeking a break from their caring role are at the mercy of their care recipient and the respite system they fall under. The vast difference between support systems which determine when and for how long carers are allowed to take a break was an issue identified by carers. For carers of people receiving My Aged Care support, they can access up to 63 days of respite care. For carers of people who receive NDIS, only 28 days of short-term accommodation are available per year and only if agreed to as a participant goal. For mental health carers, even those 28 days may not be accessible if their care recipient is unable to meet the eligibility threshold for psychosocial disability. Even if they are on a NDIS plan, barriers like care recipient consent and limited mental health respite options stand in the way of respite access. Carers spoke of numerous instances where, in a desperate bid to secure some form of respite, they have tried to get themselves admitted to emergency health facilities. This grim scenario speaks volumes about the dearth of options for carers and the crucial need for change.

Likewise, the quality of care from respite and support workers was raised in almost every consultation, with an alarmingly large number of examples where care recipients were injured or hospitalised because of the poor quality of support. This led to carers feeling that there was no alternative but to perpetually take on all responsibility of care. As a carer group attendee lamented, "*How can I rest when I have no trust in the support worker?*". Inadequate training and lack of skilled support workers result in poor quality care, often jeopardizing the safety of care recipients.

Finally, there needs to be acknowledgment that for many carers, work acts as a form of respite. Thus, it is crucial to enable such opportunities, helping carers reclaim some sense of normality. One respondent's bleak comment encapsulates the urgency of the situation: "*I'm restricted by my carer role, so choices, opportunities are no longer part of my life*". Creative and practical solutions, such as basic home maintenance support, were also proposed to assist working carers manage their home chores without being overwhelmed, thereby allowing them to focus more on their caring responsibilities. Regular respite care was raised as a significant need, particularly for carers of the frail aged, providing carers with the opportunity to work or recharge. To respect carers' contributions, it is high time we invest in infrastructure and services that genuinely support them.

Recommendations:

- Government services recognise and support the fundamental right of carers to choose the amount of unpaid caring they do.
- Respond to carer needs and choices in respite planning and provision.
- Support service providers to adequately educate and train staff to maintain a high quality standard of care.
- Ensure consistent respite allocation across all Government systems.

Accountability

"Get government departments on board with respect for carers… My advocacy role takes up nearly half of my caring capacity. It's endless." - Survey respondent.

Carers ACT notes that while the intended objectives of the Act are admirable, awareness of the Act among carers alone is alarmingly low. In our consultations, a staggering 81% of carers were unaware of the Act's existence before this inquiry was announced. Of those who knew about it, only 4% felt it had made any difference to the recognition and support they received. This lack of impact was largely attributed to a perceived absence of accountability in the Act's implementation.

Throughout our consultations, carers consistently raised concerns about the Act's accountability. They highlighted the Act's limited obligations and expressed scepticism about its ability to achieve its aims under these conditions. Reoccurring questions were raised about oversight including, who was responsible for ensuring the Act's implementation and enforcing the obligations it places on public service agencies and what the consequences are, if any, for agencies failing to meet these obligations. Although the ACT's own *Carers Recognition Act 2021* (ACT) has only been in effect for a short period of time, we foresee that the regulatory aspect of the legislation will increase accountability and transparency within care and carer support agencies.

Currently, while the federal Act is overseen by the Department of Social Services and does include obligations for public service care agencies and associated providers, there is no government representative directly accountable for overseeing the Act's implementation. Carers ACT proposes the establishment of a Federal policy section dedicated to ensuring the Act is properly implemented. This section could address issues previously raised in this submission, such as inconsiderate practices and language inconsistencies across public service agencies. It would also support our earlier recommendation for designated policy positions within public service agencies, who would be responsible for implementing carer strategies and reviewing impacts on carers within their departments.

Furthermore, it is worth noting that the Act has not been reviewed in 13 years. This lack of review is a source of frustration for many carers, especially when they see other Acts being discussed and reviewed regularly. Carers expressed concern that their valuable time and input might be wasted if the Act were to be neglected again for another decade. Thus, in addition to the creation of a dedicated federal policy section, we recommend more regular reviews of the Act to ensure it remains effective and relevant for carers' evolving needs and circumstances.

Recommendations:

- Establish a federal policy section within Prime Minister and Cabinet (PM&C) responsible for ensuring the Act is implemented as intended and regularly reports on how public service agencies (not just public service care agencies) are adhering to the Act.
- Implement regulation as a subordinate law to the Act, similar to the *Carers Recognition Regulation 2021* (ACT).
- Include a provision in the Act requiring review of the Act's operation and effectiveness within 5 years.

Conclusion

"We're not asking for more, we're just asking for the same" – survey respondent.

Carers ACT used this inquiry as a unique opportunity to consult directly with carers about the Carer Recognition Act and the themes of the inquiry's terms of reference. We had a huge response from carers who were engaged and passionate about providing their feedback. We hope we have reflected these views in a way that leads to meaningful change for carers now, and in the future. We implore the committee to consider the recommendations outlined in this submission and look forward to seeing responsive and creative changes implemented in relation to the recognition of unpaid carers in Australia. Should there be any further consultation regarding the inquiry or carer policy development, Carers ACT is eager to participate. For a copy of the survey, consultation questions or anonymised responses, please contact the Carers ACT Policy and Advocacy Team at carer.advocacy@carersact.org.au.

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