

Recognition Matters

**A Carers Australia Issues Brief
prepared for the House of
Representatives Standing
Committee on Social Policy
and Legal Affairs:**

**Inquiry into the recognition
of unpaid carers**

August 2023



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1. Purpose

This Issues Brief 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.

We understand the Committee will report on the provisions and operation of the *Carer Recognition Act (2010)*¹ with the view to update and amend this Act (herein referred to as the Carer Act). We also note the adequacy of social security payments for carers – the Carer Payment, the Carer Allowance and the Carer Supplement – are out of scope for this inquiry.

To assist with the Committee’s work, Carers Australia will be providing two responses to this important Inquiry.

The first is this Issues Brief, which outlines key information on Australia’s carers, information on the Carers Recognition Acts across Australia and, in particular, the national *Carer Recognition Act*, and the extent to which the introduction of that Act is reflected in other legislation which directly affects carers.

This will be followed by a more narrowly focused submission on the effectiveness of the national *Carer Recognition Act* and its Statement for Australia’s Carers and recommendations to improve recognition, awareness and obligations on public service agencies and more broadly within policy and programs.

As the national peak body representing more than 2.65 million people who provide unpaid care and support, our vision is an Australia that values and supports all carers, where they have the same rights, choices, and opportunities as other Australians to enjoy optimum health, social and economic wellbeing, participation in family, social and community life, and employment and education.

“Care and support should not merely be seen as an act of charity. It’s a matter of human rights. Both those providing and receiving care and support have rights. That means support and care systems must respect and advance the enjoyment of human rights for all.”

UN High Commissioner for Human Rights²

2. Introduction

Fourteen years on from the Inquiry into Better Support for Carers³ by the House of Representatives (2008/9 Inquiry), it remains the case that **carers are still not ‘recognised’ and their rights and needs are not adequately embedded within reforms that affect them.**

There has been successive reform across settings and sectors since the 2008/9 Inquiry, which was the catalyst for development of the Carer Act. Many of these large-scale reforms, while well intentioned, have to some extent led to fragmentation of Australian Government funding for, and the provision of, supports and services to carers. Lack of consistent and appropriate recognition of the caring role, data collection and the

¹ Parliament of Australia, *Carers Recognition Act (2010)*, effective November 2010 [[accessed online](#)].

² United Nations, Office of the High Commissioner for Human Rights, Statement ‘Human Rights 75 - Time to transform care and support systems’ delivered 7 February 2023 [[accessed online](#)].

³ Parliament of Australia, House Standing Committee on Family, Community, Housing and Youth ‘Inquiry into better support for carers’ webpage, 2008 [[accessed online](#)].

impact of not being identified by services they interact with, are critical structural deficits in our health, aged care, mental health, disability support and social service systems.

The use of the term “carer” in this document specifically relates to the definition of carers in the current Carer Act, highlighting the *situation* that requires care and not the *relationship* between the carer and person receiving care:

“(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.

*(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.”

2.1 About carers

“Valuing the work of unpaid carers requires social and economic recognition of the importance of the relationships they build and foster, the assistance they provide to the people for whom they care, and the manifold contributions that they make to the whole community and economy. Caring relationships and roles are diverse, and each care situation is unique and may change across the life course.”

Australian Human Rights Commission⁴

There are more than 2.65 million carers in Australia⁵ each with their own story of caring and the impact it has on them and those they care for. It is essential the Committee appreciates the diversity of caring, as caring sits within a broader social, economic, and cultural context and involves dynamic interconnections and ongoing shifts in relationships across the life course. This involves diversity within and between:

- carers as individuals,
- care relationships, and
- the people being cared for.

Interface issues across complex care systems and services may be associated with crisis points for carers related to the changing or increasing needs of the person receiving care or when carers seek support for themselves. These situations can increase the intensity of the carers’ role, may change the dynamics of their relationship with the person receiving care, and impact on carers’ health, mental health, wellbeing, and financial situation. **This results in differing needs and experiences of recognition across settings and sectors with varying Australian Government interfaces.**

Carers may be caring for a partner, a child (including an adult child), a parent, a member of their extended family, a person who is “chosen” family or a friend. They may have a cultural kinship relationship with the person they care for or be in multiple care relationships.

“Becoming a carer is one of the least planned aspects of the life cycle and I don't think enough people recognise this--I certainly did not.”

“I wish [unpaid carers] appeared more visibly in our government's economic reports, because they are worth their weight in more than gold - having caring people who care for the carers is helping the health and wellbeing of millions of Australians.”

“I like meeting other carers and knowing they already have an idea of what I go through and can relate, even if our lives and the people we care for are very different.”

“Being now 85 years old I feel that caring for a person benefits my health and my mobility, kind of a full-time job! ...but nevertheless, a break could also help me to build up more steam to being able to cope!”

2022 Carer Wellbeing Survey Responses

⁴ Australian Government, Australian Human Rights Commission, ‘Investing in care: Recognising and valuing those who care, Volume 1 Research Report’ (2013), p.3 [\[accessed online\]](#).

⁵ Australian Government, Australian Bureau of Statistics (ABS), ‘Survey of Disability, Ageing and Carers (SDAC)’, 2018 [\[accessed online\]](#).

Carers can be at either end of the age continuum, noting that in 2018⁶ there were 235,000 ‘young carers’ aged 12 – 25 years and almost 230,000 over 65.

There will be differing experiences in duration of care – those who are new to the role, those who care for a comparatively short-term and those caring for more than 20 years.

Caring is often not a choice, but in some cases it will be. In 2018⁷, the three most common reasons primary carers gave for taking on a caring role were a sense of family responsibility (70%), emotional obligation (47%) and ability to provide better care than anybody else (46%).

Care may be episodic and unpredictable in the time commitment and intensity required. They may live with the person receiving care or elsewhere.

A carer may have employment and/or education commitments or be unable to have these commitments due to the number of hours of care provided and a range of other reasons.

“ [What I like most] All the things I have learnt through my caring role and being able to have empathy and provide support for other Carers.”

“I look after my wife who has leukemia and my 3 siblings who have Huntington's disease. Two nephews and one niece also have a hereditary degenerative disease. To be ready to counsel and physically assist when needed.”

“Information for carers and families should be readily available, in a range of languages. My dad's main carer is his partner, who has very limited English - when we discuss difficult concepts, we do it with a text message app that allows translations. Supporting carers and family to be fully informed so that they can provide the best care should be an essential part of health care.”

2022 Carer Wellbeing Survey Responses

Young carers face additional barriers and are at increased risk of mental health issues and disengagement from school or education opportunities due to caring responsibilities⁸.

Many young carers who have not completed their education beyond secondary school, and who have been unable to combine carer inclusive employment with their caring role, will remain on income support payments long after they have ceased their caring role.

Thirty-one per cent⁹ of all carers live in regional and rural areas. They are required to provide an intensive caring role, sometimes for more than one person, due to a lack of available services. Carers in outer regional and remote locations have lower wellbeing, higher financial distress, and more difficulty accessing services for themselves or the person they are caring for than carers overall¹⁰. As with many services, respite care is even more difficult, if not impossible, to access in many regional, rural, and remote locations. For

⁶ Op.Cit (ABS SDAC 2018)

⁷ Op.Cit (ABS SDAC 2018)

⁸ Moore, T et al (2019) ‘No space in my brain to learn: young carers and their engagement with education - An analysis of applications to the Carers Australia [Young Carer] Bursary Program 2017-2018’ Australian Centre for Child Protection, University of South Australia commissioned by Carers Australia [[accessed online](#)]

⁹ Op.Cit (ABS SDAC 2018). 31% of carers lived outside of ‘major cities’.

¹⁰ University of Canberra, ‘Caring for Yourself and Others, 2022 Carer Wellbeing Survey Full Data Report’, commissioned by Carers Australia [[accessed online](#)].

many, being able to ‘access’ respite means the person being cared for is separated by great distances from the carer and off Country, adding greater emotional, practical, and financial strain.

Unpaid care is a gender issue, where seven out of ten primary carers are women and in all aged groups there are more female carers than male carers, other than aged 75 years and over¹¹. Female carers were more likely to report a lack of choice about becoming a carer where 60.9% of female carers reported in the Carer Wellbeing Survey they had no choice about whether to be a carer or not, compared to 46.2% of male carers.

However, there are still more than 1.2 million men who are unpaid carers¹². Caring is not traditionally seen as a male role; therefore, these men are less likely to be recognised and may receive less support as a consequence. Understanding the male perspective of the caring role presents a challenge for the research community, government, organisations, service providers and community groups to better assist men who are often only reaching out for assistance when at a crisis point¹³.

Carers are also from culturally and linguistically diverse backgrounds and may identify as an Aboriginal and Torres Strait Islander. The person they are caring for may also be within these at-risk groups. The concept of being a ‘carer’ may be alien to them and a barrier to seeking help for several reasons including accessing information and finding services. This is particularly relevant for culturally and ethnically diverse populations, which also raises issues for data collection and subsequent policy and funding decisions.

SDAC (2018) identifies that up to 30% of carers in Australia are from multicultural backgrounds¹⁴ and the 2021 Census revealed that - of the people that ‘need assistance’ for one or more of the core areas of self-care, mobility and communication - more than 355,000 (24.5%) spoke a language other than English at home¹⁵.

Additionally, 14% of Aboriginal and Torres Strait Islander people are carers¹⁶ and the care they give and support they need is influenced by a range of unique historical, cultural, spiritual, and socio-economic factors. It is essential to recognise that First Nation people and communities may use the term ‘carer’ but attach

“I care for my 96-year-old father. He broke his hip last year in a fall at his home. This has increased the amount of time and effort required to care for him in his home. My youngest sister and I share the caring. I am 71 years old and I am increasingly finding it physically exhausting.”

“I do find it difficult being the carer of someone with an ‘invisible’ disability - severe chronic fatigue and depression. Especially in receiving recognition of my partner’s caring needs and my carer role from family and friends.”

“The community needs more awareness of carers and experiences of people with a disability. Unfortunately, I have suffered a lot of judgement and did not think this was fair as a young carer.”

“Caring has opened my eyes to loving and appreciating differences in others. It has taught me to be proactive and to stay informed. It has taught me patience and resilience. I believe that my caring role has made me a better person.”

2022 Carer Wellbeing Survey Responses

¹¹ Op.Cit (SDAC 2018)

¹² Op.Cit (SDAC 2018)

¹³ Smaith, G (2017) ‘Men Care Too’ Paper presented at the 7th International Carers Conference in Adelaide, SA [[accessed online](#)].

¹⁴ Op.Cit (ABS SDAC 2018).

¹⁵ ABS ‘Census of Population and Housing : Disability and carers data summary 2021’ Table 6 [[accessed online](#)].

¹⁶ ABS ‘Census of Population and Housing: Aboriginal and Torres Strait Islander people data summary 2021’ Table 2 [[accessed online](#)].

different meanings to the role, in addition to there being contrasting views of health and wellbeing. Cultural barriers to being recognised as carers by themselves, their families and communities include:

- Cultural rules or obligations relating to how someone with a disability or an older person is cared for.
- Traditions in relation to who performs a caring role and what this involves.
- Stigma attached to certain disabilities or conditions within their communities.
- Concerns about the cultural appropriateness of services for themselves or the person(s) they care for (including respite).
- Cultural opposition to seeking help and discussing ‘family business’.
- Lack of awareness of services or inability to contact services due to language barriers.
- Lack of promotion, information, and education materials available in different languages or the use of appropriate language for specific cultures, and
- Lack of services for small or emerging communities, especially outside of major cities.

Unfortunately, there is an absence of consistent Australia-wide general baseline data on lesbian, gay, bisexual, transgender, queer, intersex or asexual (LGBTQIA+) people. This is in part attributed to the way questions on identification are asked in government surveys, and no reliable and indicative data about the demography of LGBTQIA+ people who are carers, or who need formal or informal care support¹⁷. However, the 2022 Carer Wellbeing Survey¹⁸ shows LGBTQIA+ carers experience higher levels of psychological distress and lower satisfaction with their health than all carers generally. Having no reliable data is a barrier to building the evidence-base for policy to address their specific needs.

Furthermore, LGBTQIA+ people often have additional concerns and challenges. These include being rejected or not fully understood by their biological family, and thus turn to their ‘family of choice’ for support, where for carers their involvement in decision-making may not be documented or properly authorised¹⁹. Prejudice and stigma also affect carers who may not be part of the LGBTQIA+ community but the person they care for is, and there is very limited understanding of, support for, or resourcing of services.

Data shows on average, carers have poorer financial wellbeing and are less likely to be employed compared with their counterparts with no caring responsibilities. Given this, there are also specific considerations for those at risk of homelessness or experiencing family violence due to a lack of recognition of their caring role and its impact. This includes not being identified by services they interact with in these contexts, fear for the person they care for and other family members such as children or siblings (especially the case for young carers), and shelters and other temporary accommodations not being accessible to enable them to keep performing their caring duties.

“Many carers have observed that it is not possible for anyone to understand what caring entails unless they are, or have been, a carer – that reality is not disputed. However, thanks to the generosity and candor of so many carers, the Committee has been able to gain a degree of insight. The Inquiry’s body of evidence clearly illustrates the profound physical, emotional and financial effects that providing care has on carers and on their families.”

2009 ‘Who Cares....?’ Inquiry Final Report Foreword

¹⁷ LGBTQIA+ Health Australia, ‘Inquiry: Select Committee on Work and Care Submission’ 2022 [[accessed online](#)].

¹⁸ Op.Cit (2022 CWS)

¹⁹ Op.Cit (LGBTQIA+ 2022)

“Seeking help is mentally exhausting and feels harder than it should be.”

“There’s some guilt around feeling I’m not doing enough and/or don’t deserve assistance with my role, which acts as a barrier to seeking help.”

I stopped being a carer when the person I was caring for passed away. So not only did I lose this important person I lost a big part of my own identity. I felt like the title of carer was taken away from me and that bereavement support for a carer didn’t exist and that no one directed me to any.

2022 Carer Wellbeing Survey Responses

Caring can be a rewarding yet demanding and socially isolating experience. What cannot be disputed is that carers have among the lowest levels of wellbeing of any group of Australians and are at a greater risk of poor physical and mental health. **Unfortunately, this is not new information.**

The 2008 Inquiry report *Who Cares ...? Report on the inquiry into better support for carers*²⁰ (2009 Who Cares report) highlighted the 2008 ABS publication ‘A Profile of Carers in Australia.’²¹ This report drew attention to the 34% of carers that frequently felt weary or lacking in energy, often feeling angry, resentful, or worried, and highlighted 10% had been diagnosed with a stress-related illness, noting:

“Concern for the wellbeing of carers, and an appreciation of the value of work they do, has

made carers a key social policy concern” stating that carers have the lowest wellbeing of any population group ‘surveyed so far’, with an average stress rating classified as moderate depression.”

And further,

“One concern regarding the welfare of carers is whether they are able to ‘have a life outside caring’. While caring may be emotionally satisfying, carers can experience social exclusion and isolation.”

In 2012 after the introduction of the Carer Act, the ABS released data on carers from the 2012 SDAC²² which included information under the heading ‘physical and emotional wellbeing and personal relationships’ and concluded that: “Being a carer may entail physical and emotional impacts”.

In 2012, there was a clear increase from the from the data quoted in the 2008 report, in primary carers reporting a negative impact from caring such as feeling weary, often feeling angry, resentful, or worried (50.4% compared with 34% in 2008 report) and 11.7% having a stress-related illness (from 10%). Further, only 27.8% of primary carers reported they felt satisfied due to their caring role, and 21.6% were losing touch with existing friends.

Further data was collected in the 2015²³ and 2018 SDACS, however the report no longer provided information on ‘physical and emotional wellbeing and personal relationships’ (which was replaced with ‘social and community participation, experience of negative impacts or related illness prevalence’).

In 2020 the Carers NSW biennial Carer Survey was conducted nationally for the first time, with the support of the National Carer Network. The 2020 National Carers Survey,²⁴ (noting it was conducted during the height of

²⁰ Parliament of Australia, House of Representatives Standing Committee on Family, Community, Housing and Youth ‘Who Cares ...? Report on the inquiry into better support for carers’ 2009 [accessed online].

²¹ ABS, ‘A Profile of Carers In Australia’ 2008, Catalogue number 4448.0 [accessed online].

²² ABS, ‘Caring in the Community’ , Australia: Summary of Findings, 2012’ Catalogue number 4436.0 [accessed online].

²³ Op.Cit.

²⁴ Carers NSW, ‘2020 National Carer Survey: Summary report’ [accessed online].

COVID-19 lockdown across the country), provided critical insights into the lives of over 7,700 Australian carers in 2020. In this report, nearly half of the carers were experiencing high or very high psychological distress, and one in three felt highly socially isolated.

One in three respondents said they never get time out from their caring responsibilities, with only around half having enough time to keep on top of other responsibilities. The data also revealed it was relatively uncommon for carers to be asked about their own needs when accessing services or on behalf of the person they care for, and services were much less likely to meet carers' needs than the needs of the people being cared for (noting the Carer Gateway had only just been implemented). This was followed by a 2022 survey which will be released in October 2023²⁵.

"It is difficult as it feels selfish to think of self because I don't have their physical or mental health issues, so why complain, but sometimes I would like to be the one getting some care. My relationships have changed from being a daughter to being a worker and it is difficult because my sister chose not to do any caring role and I can see the difference in how I am treated. I accept it because I put myself in this position due to my love for my family but it stings every now and again, just the same."

"Burn out. I cannot cope doing it all and to get help with this caring role is hard, requiring a lot of effort and proof. It's exhausting having to prove you need help when you're already burned out from caring role."

"As the years past so quickly, I never ever thought how hard it would be being a 24/7 carer. Now I have started the grieving process. Loss of friends that no longer visit, loss of basic human rights and my own wellbeing. Lack of government help and willingness to offer assistance. My voice not being heard at Doctors meetings. Other immediate family members just won't offer to help in the caring roll at all."

2022 Carer Wellbeing Survey Responses

The inaugural Carer Wellbeing Survey (CWS)²⁶, a collaboration between Carers Australia and University of Canberra and funded by the Australia Government Department of Social Services, was undertaken in 2021. Based on responses from 5,800 carers, results further confirmed that carers across Australia are at high risk of poorer wellbeing, higher psychological distress, poorer physical health and decreased financial and economic security compared with those without caring responsibilities.

Almost all carers surveyed in 2021 reported experiencing multiple types of challenges related to their role as carer, 67% percent regularly fearing for the future of the people they cared for and more than 40% experiencing negative impacts on their own health and relationships.

Distressingly, **only 19% of carers were able to easily organise a friend or family member to help them if they became ill or needed a break**, which is a clear decline in additional supports available from the reported 94% of carers who had sources of support outside the household in times of crisis in the 2008 profile report²⁷.

In 2022 there were 5,992 valid responses to the CWS which provided the valuable opportunity to compare data with the 2021 report and revealed that adding to the psychological distress experienced cumulatively since

²⁵ Carers NSW 'Carer Survey' webpage [[accessed online](#)].

²⁶ University of Canberra, 'Caring for Yourself and Others, The 2021 Carer Wellbeing Survey Report', commissioned by Carers Australia [[accessed online](#)]

²⁷ Op.Cit (ABS, A Profile of Carers In Australia)

2020, carers are also providing more care, including more complex care, as access to paid services reduced or in some cases ceased for long periods.

- Carers had lower wellbeing (55.2%) than the Australian population overall (25.4%).
- Nearly half (48%) of carers were experiencing moderate to high levels of psychological distress – almost twice as many as the 25% of Australian adults who experience this.
 - Rates of high psychological distress increased between 2021 and 2022 amongst carers aged 25-34 and those who had been a carer for five or more years.
 - They remained high amongst carers aged 35-44, and amongst carers who were unemployed.
- 72% of carers had an increase in intensity in their caring responsibilities due to COVID with 49.6% reporting that this is long-term.
- More than 70% reduced their own social interaction to protect the people they cared for and 60% reported reduced access to formal support services.
- 28% of carers reported having no access to support from family and friends.
 - 20% could easily organise a friend or family member to help out and 52% could organise help but it would be difficult.
- Rates of loneliness increased among carers between 2021 and 2022, with a rise in those reporting they were often or always lonely from 35.1% to 39.4%.
 - 78.2% spent less time than desired with family and friends.
- Only 17.1% of carers who responded reported having very good or excellent health, compared with 47.9% of Australian adults, with 48.6% of carers reporting fair or poor health.
 - There was a decline in general health for some groups of carers, including those aged between 25 and 44, with a more than 10% increase in those reporting poor/fair health.
 - The proportion of First Nation carers reporting poor/fair health increased by more than 10%.

"We have at times asked for help from a couple of family members who were not willing to help. The message 'it's ok to ask' doesn't take into account that people don't always agree to help."

"I am trying to juggle SO much - caring responsibilities, my own disability, parenting teenagers and my career. I constantly feel that I am failing everyone, because there's just not enough of me to do everything. I delegate what I can afford to ease some of my load, but then that contributes to financial stress as I am a sole income earner. Getting help requires so much effort - much more than I have to give."

"I have found it especially difficult to connect with others and tend to feel guilty if I consider putting myself first. Living in a regional area I have not been able to find support services for carers in my area - and nothing specific to young carers."

"I find it very difficult to navigate the health system to get the outcomes she needs to help manage her condition. The impact on my own mental health and ability to be productive at work has been significant, and it is challenging for me to adjust to a new normal where my wellbeing and my daughter's wellbeing can change at short notice."

"As a migrant it is very difficult to navigate and understand the system and the services even though they maybe there due to access to information, language barrier, etc."

2022 Carer Wellbeing Survey Responses

- Difficulty navigating systems was ‘getting worse’ for 57.7% of carers in 2022.

It is a long-standing concern that carers continue to be largely mentioned or considered only in relation to "consumers, their families and carers" without recognition of their own specific needs. The future demand for carers coupled with the cost to replace the care they provided with paid services clearly shows the urgency to address unmet needs in financial terms.

In its 2020 report on the replacement cost of informal care, Deloitte Access Economics²⁸ highlighted the contribution of informal caring is not captured in economic measures such as Gross Domestic Product (GDP), unlike that of formal carers, where:

“Calculating the value of unpaid carers is a step towards recognising their contributions and opening a dialogue on how to best support these carers to enhance utilisation in the Australian labour market and wellbeing outcomes”.

This analysis revealed that, if the Government had to replace the estimated 2.2 billion hours of care with paid care workers, within My Aged Care and the National Disability Insurance Scheme (NDIS) alone, it would have cost the Australian economy \$77.9 billion in 2020²⁹. Informal care also makes a substantial contribution to the provision of mental health services, with the Productivity Commission estimating the value of care and support provided by family and friends to be worth around \$15 billion per year in 2018-19³⁰.



A ‘Care Workforce Labour Market Study’ report³¹ released in 2021 was the first ‘whole of sector’ examination of the care and support workforce and had the sobering statement that by 2049-50 the total demand for the care and support workforce will be around double that seen today. Workforce demand is expected to exceed workforce supply, with the workforce gap continuing to grow and requiring approximately 211,430 FTE positions by 2049-50. This report also provided a pictorial depiction of the size of the ‘informal unpaid’ care population compared to the ‘formal paid’ care and support workforce (figure 1), emphasising carers must be seen as a core element of the ‘care economy’.



Using ABS data, the 2020 Deloitte Report developed a “carer ratio” which identified a stagnation in the propensity to care compared to the need for care over time. It is evident that investment is required to prepare for the modelled 23% growth in demand for primary informal carers by 2030, with a total growth of 16% required.

If carers are unable to continue their caring role at the same or increased intensity (as has been required during COVID), the health, aged care and disability care systems which are already stretched and struggling with workforce constraints, and in a tight fiscal environment, will have to provide more.

²⁸ Op.Cit (The value of informal care in 2020)

²⁹ Deloitte Access Economics, ‘The value of informal care in 2020’, prepared for Carers Australia [[accessed online](#)].

³⁰ Australian Government, National Skills Commission, ‘Care Workforce Labour Market Study: Final Report’ 2021 [[accessed online](#)]

³¹ Op.Cit (Care Workforce Labour Market Study)

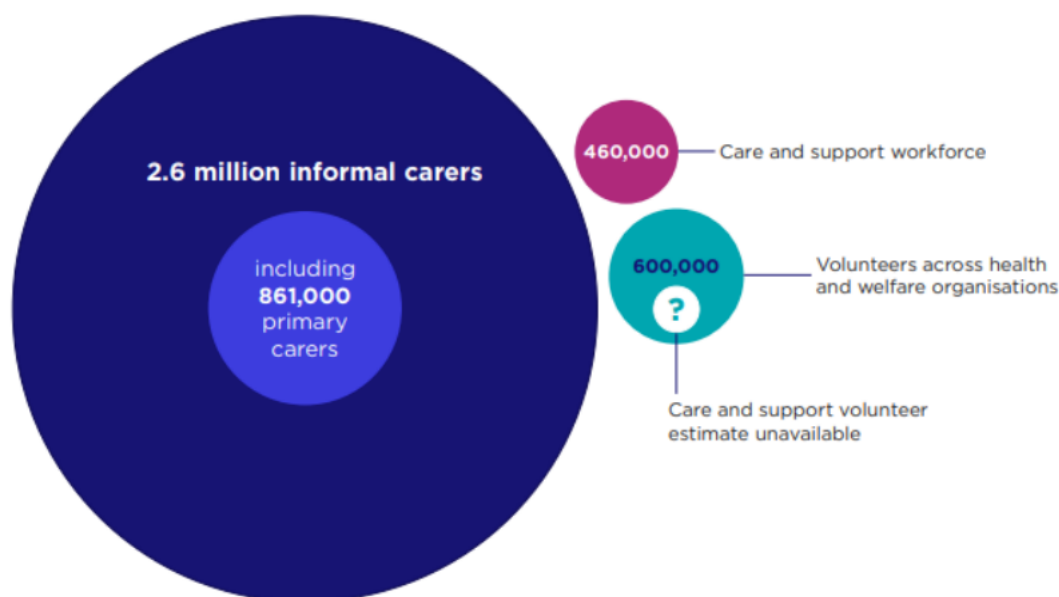


Figure 1: Relative size of the informal care and support 'workforce' (figure 43 – 'Care Workforce Labour Market Study')

Despite the unique nature of the caring experience and the wide array of responsibilities it may entail, one consistency is they are disproportionately worse off financially than non-carers, and this factor must be recognised in the context of understanding the 'value' of unpaid care.

Data from the Survey of Disability, Ageing and Carers (henceforth referred to as SDAC) shows a consistency in carers reduced engagement in the workforce, where the following is a comparison of 2008 and 2018 data:

- 63% of all carers were employed, compared to 48% of primary carers and 73% of non-carers (2008).
 - 77% of all carers were employed, compared to 59% of primary carers and 81% of non-carers (2018).
- Almost half of all primary carers (48%) had hours of caring at least equivalent to a traditional full-time paid job of 40 hours or more per week. A further 21% spent from 20 hours to less than 40 hours per week caring; and 30% spent less than 20 hours per week caring (2008).
 - Of those informal carers who were caring for someone who had a profound core activity limitation, 59% were caring for more than 40 hours a week, including 64% of younger people. 20% were providing 20-39 hours of care per week (2018).
- 27% of all carers and 33% of primary carers were in the lowest quintile of equivalised gross household income (19% of non-carers). Only 13% of all carers were in the highest quintile (2008).
 - 50% of primary carers lived in a household in the lowest two quintiles, twice that of non-carers (26%). 13.2% lived in a household in the highest quintile (26% of non-carers) (2018)
- The most common main source of personal cash income for all carers was wages and salaries, own business or partnership income (47% of all carers) (2008)
 - The main source of income for carers was wages or salary (56.1%) then government pension or allowance (2018).
- Carers (40%) were much more likely than non-carers (24%) to have a government pension or allowance as main source of income (57% of primary carers) (2008).
 - Primary carers were more than twice as likely to receive a government pension or allowance (38.4%) than other carers (17.2%) and non-carers (9.2%) (2018).

“Now is the time for some bold and innovating thinking on how to value unpaid caring work in Australia – to ensure that no woman will live in poverty in her retirement because she chose to care during her lifetime. To achieve real change in the valuing of unpaid caring work, it will be necessary to undertake a combination of reforms.”

Australian Human Right Commission³²

The share of the Australian population who provide informal care at least weekly (13.8% in 2018) is slightly higher than the average share across OECD countries (12.6%)³³. Economic and financial uncertainty and instability is a leading driver in carers needing to access services and information. In 2020, the estimated earnings foregone for primary and non-primary carers was \$11.4 billion and \$3.8 billion respectively³⁴. Combined, the opportunity cost for all carers is \$15.2 billion which is equivalent to 0.8% of GDP and 10.6% of the value of formal health care.

We also draw attention to the Disability Royal Commission Report³⁵ that estimates the financial burden associated with the lack of inclusive housing and communities falls predominantly on informal carers. These costs include inaccessible housing, barriers to accessing transport and increased risk of homelessness and or need access to specialist homelessness services.

2022 CWS data³⁶ also provides an insight into the ‘value’ of unpaid care in terms of carers providing this support in-lieu of formal paid services, and their own employment. Carers were almost twice as likely to be under-employed as other Australians: 44.8% of carers who were in the workforce were doing fewer hours of work than desired compared to 23.1% of the Australian workforce. Of these carers, 69.4% said caring was the sole reason for working less than desired.

Further, 54.4% of carers experienced at least one significant financial stress event in the previous 12 months, such as being unable to pay bills on time, going without meals, or having to ask for financial assistance, compared to 32.2% of Australian adults. This is compared to 22% of carers in the 2008 ABS Profile that ‘had

“I want dignity and respect for myself and my son, that we are seen as valuable members of the community's in which we dwell. That our amazing daily concrete/actual and potential contributions to society are substantial. Without the existence of carers society would collapse. Also, the diversity of carers and those cared for adds to the richness of life, and we are an integral part of humanity.”

“Being a carer has given me the opportunity to reevaluate myself, my life, my goals and expectations. It has provided me an intense course in life's real priorities, has taught me the value of health and grounded me.”

“Being a carer has many, many challenges. Your world changes, and you see things differently than before. What I like the most is celebrating each person's uniqueness.”

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³² Op.Cit (AHRC, Investing in care: Recognising and valuing those who care)

³³ Evaluate, ‘Caring Costs Us; The economic impact on lifetime income and retirement savings of informal carers – a report for Carers Australia’, 2022 [[accessed online](#)].

³⁴ Op.Cit (Deloitte, The value of informal care in 2020)

³⁵ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, ‘Research Report - The economic cost of violence, abuse, neglect and exploitation of people with disability’ February 2023 [[accessed online](#)].

³⁶ Op.Cit (2022 CWS)

taken dissaving actions, such as borrowing money, in the previous 12 months; 19% had cash-flow problems; and 15% had difficulty paying bills³⁷.

In 2022 the 'Caring Costs Us: The economic impact on lifetime income and retirement savings of informal carers' report was released. The modelling revealed a quarter of people who become primary carers face a real reduction in lifetime earnings of more than \$497,500 and a real reduction in their superannuation balance at age 67 of more than \$216,000³⁸. This report was commissioned by Carers Australia and the National Carer Network to highlight the economic impact of unpaid care on the lifetime income and retirement savings of Australian carers.

Overall, the Caring Costs Us Report demonstrates significant disparity in governments' willingness to fund formal care services compared to investing in adequate financial assistance for carers to sustainably continue their caring roles and have security at retirement age. It draws attention to a 2015 international study examining the fiscal implications of measures to allow carers to return to the workforce by significantly increasing the availability of formal care support. The study found that while the return of carers to the formal workforce would significantly increase economic growth and the fiscal position of governments, those gains would only amount to about 14% of the costs of the additional formal care services that would be required to allow it to happen.

3. Carer recognition and legislation

3.1 2009 Better support for carers inquiry – basis of the Carer Recognition Act 2010

On Tuesday 14 May 2008, the Minister for Families, Housing, Community Services and Indigenous Affairs, The Hon Jenny Macklin MP, requested the House of Representatives Standing Committee on Family, Community, Housing and Youth conduct an inquiry into better support for carers (2008 Carer Inquiry)³⁹. As outlined in the Terms of Reference for this Inquiry, carers were defined as 'individuals providing unpaid support for others with ongoing needs due to a long-term medical condition, a mental illness, a disability or frailty'. The response to this Inquiry was overwhelming – 1,305 submissions, 92% from carers themselves, 14 public hearings between July 2008 and February 2009 and 17 media releases from the Committee.

The Committee's 2009 Who Cares report⁴⁰ was the catalyst for several key pieces of reform related to carers, and had several recommendations focused on improving recognition across portfolios, including through legislation. Our focus in this Issues Brief is on Recommendation 4 of the Inquiry:

"That the Minister seek to develop a nationally consistent carer recognition framework, comprising national carer recognition legislation, which complements state and territory carer legislation; and a national carer strategy which builds on and complements state and territory carer policies."

The Government endorsed this recommendation⁴¹.

It is important to understand that, since the 2009 Who Cares Report and subsequent Government responses, various reform processes have occurred and much has changed. This includes policy

³⁷ Op.Cit (ABS, A Profile of Carers In Australia)

³⁸ Op.Cit (Evaluate, Caring Costs Us)

³⁹ Op.Cit (Parliament of Australia, 2008 Inquiry webpage).

⁴⁰ Op.Cit (Parliament of Australia, Who Cares Report).

⁴¹ Australian Government, Department of Families, Housing, Community Services and Indigenous Affairs 'Government Response to the House of Representatives Standing Committee on Family, Community, Housing and Youth report: Who Cares ...? Report on the inquiry into better support for carers' 2009 [\[accessed online\]](#).

developments not envisaged in the report which also impact on carers, some of which have reflected the Inquiry's recommendations but in other cases those recommendations have been lost.

In the first instance, focus is on changes at the ministerial level related to establishing the Carer Act, where we draw attention to the following:

- The National People with Disabilities and Carer Council was active in 2008 following ratification of the United Nations Convention on the Rights of Persons with Disabilities to 'provide a means for people with disabilities, and their families, friends and carers, to have an ongoing voice in the development of the policies and strategies that affect their lives.'⁴²
 - In 2013, several years after the Carer Act came into effect, this Council was replaced with the Disability and Carers Industry Advisory Council with the narrower focus of 'employment opportunities for the disabled and also the growing disability [paid] carers industry'⁴³. However, following allocation of funding for four years for establishment and activity in the 2014-15 Federal Budget,⁴⁴ there is no record of activity for this Council.
- The Health, Community and Disability Services Ministerial Council (HCDSB) which was outlined as responsible for development of the Carer Act in the 2009 Who Cares Report, was replaced by the Disability Reform Council in 2013 and then the Disability Reform Ministerial Council (DRMC) in 2020.
 - The DRMC reports to National Cabinet signifying the importance government places on matters affecting people with disability on introduction of the NDIS Act (2013)⁴⁵.
 - There is no ministerial level committee considering the needs of unpaid carers, across portfolios or state/territory and Federal government policy.
- There was a Parliamentary Secretary for Disabilities and Carers from March 2010 – March 2013⁴⁶
 - There has been no Parliamentary Secretary, Assistant Minister or Minister for Carers since.

These timelines also coincide with establishment of the *National Disability Insurance Scheme (NDIS) Act 2013* (NDIS Act) and was one year prior to the National Carers Strategy lapsing.

We draw the Committee's attention to a statement made in the 2009 Who Cares Report foreword in the context of the other evidence provided in this Issues Brief on the need for changes to improve recognition, and subsequently, the lives of carers:

"As Chair of the Committee it is my view that many of the report's recommendations are a starting point only, providing a baseline for more fundamental and significant reforms to systems of support for carers. In considering the report, I urge the Australian Government and others to look beyond the specifics of the recommendations and to also consider their context and intent – that is to significantly improve the lives of carers and those they care for. Importantly, implementation of reform will be key to effecting meaningful change. It is my sincere hope that this report and its recommendations will act as a stimulus for action."

⁴² National People with Disabilities and Carer Council, 'Shut Out: The Experience of People with Disabilities and their Families in Australia' 2009, prepared for the Australian Government during National Disability Strategy development [[accessed online](#)].

⁴³ Parliament of Australia, Senate Estimates, '2014-15 budget estimates hearing report' (May 2014) Chapter 2 - Social Services Portfolio [[accessed online](#)].

⁴⁴ Australian Government, Department of Treasury, 'Budget 2014-15 Budget Measures' Paper no.2 [[accessed online](#)]. p.194

⁴⁵ Australian Government, Department of Social Services, 'Disability Reform Ministerial Council' webpage (updated 23/6/23) [[accessed online](#)].

⁴⁶ Australian Government, 'Former Ministers and Parliamentary Secretaries' webpage [[accessed online](#)].

3.2 A National Carers Strategy

A key component to recommendation 4 was a commitment by the Australian Government to develop a National Carer Recognition Framework, which subsequently consisted of the Carer Act and the National Carer Strategy. The National Carer Strategy⁴⁷ was launched in April 2011 to ‘give effect to the principles of the *Carer Recognition Act 2010*’ and clearly outlined six priority areas that contained ‘long-term policy directions’ and “*represents the Australian Government’s long-term commitment to carers*”.

The supplementary Implementation Plan⁴⁸ outlined there would be three 3-year Action Plans which would extend to 2020 (refer to image 2) and outlined clear governance, monitoring and reporting mechanisms to ensure these were achieved.

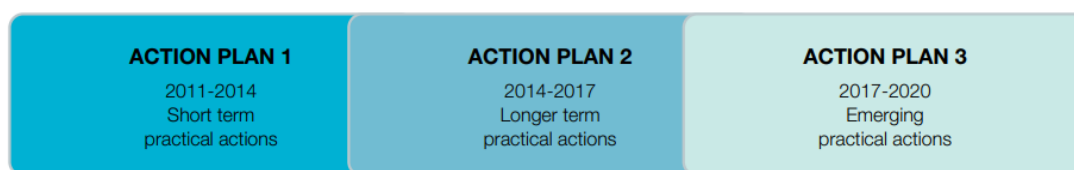


Image 2: Image from the National Carer Strategy Implementation Plan outlining Action Plan timelines (p.9)

The first Action Plan⁴⁹ was released as a companion document to the Implementation Plan and lists short term tangible actions for areas the Government identified, with a focus on:

- practical actions that will make a difference to carers and the people they care for without making major changes to service systems; and
- influencing actions that should be undertaken to ensure carers’ needs are addressed in broader reforms to disability, mental health, aged care and health services.

Action Plan 2 was to focus on longer term practical solutions, which according to the Implementation Plan, were to be identified in 2014, where ‘reform agendas and policy directions will be revisited if required’.

The Implementation Plan also outlined interrelated reporting and evaluation processes, consisting of annual progress reports to COAG’s Standing Council of Community and Disability Services, and the Standing Council on Health, as well as publicly available, and evaluation reports, the first of which was to be released in 2015. A Progress Report⁵⁰ outlining activities was released in 2011-12. Carers Australia has a copy of this but cannot locate it online. There was no Action Plan 2 or subsequent Action Plan 3, which was to focus on identifying emerging policy issues that need practical responses and also involve ‘sustaining effort on longer term practical actions that have been successful as part of the second Action Plan.’

“We have achieved a lot in the first 12 months of the National Carers Strategy, but there is much more to be done. Over the next 12 months, we will continue to work hard to promote the National Carer Strategy and build on our achievements to support carers in Australia.”

National Carer Strategy Progress Report 2011-2012

⁴⁷ Australian Government, ‘National Carers Strategy’ 2011 [accessed online].

⁴⁸ Australian Government, Department of Families, Housing, Community Services and Indigenous Affairs ‘National Carer Strategy Implementation Plan’ ISBN: 978-1-921975-76-9 [accessed electronic copy].

⁴⁹ Australian Government, FaHCSIA ‘National Carer Strategy Action Plan (2011-2014)’ ISBN: 978-1-921975-75-2 [accessed hardcopy].

⁵⁰ Australian Government, FaHCSIA ‘National Carer Strategy Progress Report 2011-12’ ISBN: 978-1-921975-77-6 [accessed hardcopy].

While the *Carer Recognition Act 2010* formally acknowledges the valuable social and economic contribution of carers in Australia, it is unclear why the National Carer Strategy’s second Action Plan was not developed, nor any Progress Reports provided beyond 2011-12 that are accessible, or any evaluation activities as outlined in the Implementation Plan.

We note the most recent carer recognition legislation introduced in the Australian Capital Territory (2021) and Tasmania (2023) have the state/territory carer strategies embedded, and the national Labor Government’s pre-election commitment to re-establish a National Carers Strategy in its first term⁵¹:

“Labor recognises that carers have been too often overlooked in policy development and not treated as a vulnerable group in their own right. An Albanese Labor Government will develop a new National Carers Strategy, in consultation with carers, peak bodies and service providers, during its first term of government.”

3.3 State and Territory Recognition Acts

All states and territories in Australia now have their own recognition legislation, with NSW (2010), Victoria (2012), the ACT (2021) and Tasmania (2023), joining Western Australia (2004), South Australia (2005), the Northern Territory (2006) and Queensland (2008).

However, as table 1 outlines, the Acts vary in several respects. These variations include:

““The lack of understanding and recognition for what we do in the eyes of society and the government, the fact [is] that it can be so relentless.”

“A system that doesn’t recognise extreme poverty, especially impacts or inability to afford medical care and that assumes family/friends are in some supply when there are zero. I have a son who doesn’t like to identify as having a disability and every process of disclosure without his consent reduces his mental health, so impossible choices are often at play as well as a complete lack of understanding or acknowledgement of what I’m actually doing as a carer...so it goes round and round. The worst bit is it is not [my son] its the system around him and me.”

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- Definition of carer - the ACT does not include a definition of ‘carer’ at all, and rather focusses on the ‘care relationship’, where Victoria, while having a short definition of ‘carer’ also focuses on ‘care relationship’.
- Recognition of person receiving care – Victoria and the ACT include principles (the equivalent of the Statement for Australia’s Carers) focused on the treatment of the person receiving care, differentiated from the person providing care.
- Reference to older persons - some Acts do not specifically reference ‘frail aged’, Queensland refers to frailty without an age limitation, and Victoria does not refer to frailty but includes the broader term ‘older’.
- Reason for care - Queensland does not include mental illness explicitly, though it includes pain, and Tasmania includes alcohol or other drugs of dependence.
- Inclusion of foster carers – the ACT explicitly mentions foster carers, while in other cases they may be covered as persons who receive financial assistance from the State/Territory or the

⁵¹ Carers Australia, ‘Who Cares for Carers in the 2022 Federal Election? Pre-election survey summary’ 2022 [[accessed online](#)].

Commonwealth Government (however described)
in relation to carrying out the carer role.

- Inclusion of kinship situations –the ACT and Tasmania include kinship care and Queensland is specific in including grandparent carers if they are ‘the primary care-giver and decision-maker for the child’.
- There are differences between equivalents of the national Statement for Carers (noting they are called Charters or Principles) where some include specific reference to Aboriginal and Torres Strait Islanders, culturally and ethnically diverse communities, young people and carers living in rural and remote locations.
- Review periods - Several Acts include review periods, for example, South Australia’s Act outlines that the Minister must carry out a review of the operation and effectiveness of the Act within a certain timeframe and table the report at both Houses of Parliament.
- Governance processes – several Acts include governance processes which outline establishment of a committee (or equivalent) and its activities. For example, NSW provides for a Carers Advisory Council in legislation including membership (via Ministerial appointment), procedure, function, reporting and remuneration, and that the majority of members are carers.

Table 1: Carer recognition Acts in Australia: comparison of key elements

Component of carer recognition Act	AUS	NSW	QLD	VIC	TAS	WA	SA	NT	ACT
Scope includes foster and/or kinship situations	X	X	•	•	•	X	X	X	•
Scope includes alcohol or other drug of dependence	X	X	X	X	•	X	X	X	X
Review period	X	•	X	X	•	•	•	•	•
Obligations on public sector (general)	•	•	•	X	X	X	X	X	X
Obligations on public sector care agencies (or like)	•	•	•	•	•	•	•	•	•
Obligations on funded providers/organisations	•	X	X	•	•	•	•	•	•
Reporting obligations	•	•	X	•	•	•	•	•	•
Includes obligations focused on person receiving care	X	X	X	•	X	X	X	X	•
Includes Governance e.g. Carer Council	X	•	•	X	X	•	•	X	•
Includes Strategy (or like)	X	X	X	X	•	X	X	X	•
Statement for Carers (or like)	•	•	•	•	•	•	•	•	•

While all of the recognition legislation aims to ‘raise awareness’ of recognition for carers, no Acts explicitly provide any rights for carers. Most Acts explicitly state the Act conveys no rights or legal enforceability or provides that the Act is a subordinate instrument. The **Northern Territory Carers Recognition Act (2006)**⁵² and **South Australian Carers Recognition Act (2005)**⁵³ are silent on the issue.

⁵² Northern Territory Carers Recognition Act (2006) [[accessed online](#)].

⁵³ South Australia Carers Recognition Act (2005) [[accessed online](#)].

Some Acts confer obligations on certain public sector agencies, and/or on public sector care agencies (or the like), and/or on service providers and individuals funded by government funds. The exception being the **Western Australia Carers Recognition Act (2004)**⁵⁴ which appears to require these obligations to be met unless another law expressly prohibits it, where at Part 2(s6):

“(1) Subject to any other written law, an applicable organisation must take all practicable measures to ensure that the organisation and its officers, employees or agents comply with the Carers Charter in providing a service of that organisation.”

Further at Part 3(s9):

“(2) The Council may, in writing, request a reporting organisation to provide any information relevant to the exercise of the Council’s functions.

(3) A reporting organisation must, as far as practicable, comply with a request under subsection (2) unless the organisation is expressly prohibited from doing so under another written law

However, note the Western Australian Act is “An Act to provide for the recognition of carers by certain persons and bodies, and for related purposes” and is very detailed in who is covered as an organisation.

The **Queensland Carers (Recognition) Act (2008)**⁵⁵ states at Part 2 s1 “This Act binds all persons, including the State” however it then states at Part 2 s8:

“(1) It is Parliament’s intention that this part be complied with.

(2) However, this part is directory only and does not create rights or impose legally enforceable obligations on the State, a public authority or anyone else.

(3) Failure to comply with this part does not affect the validity of any decision.

(4) Subsection (5) applies to a public authority that must, under another Act or law, consider, or comply with, principles or requirements (other considerations) in the exercise of the authority’s functions or powers.

(5) This part does not apply to the public authority to the extent that the principles of the carers charter or requirements under this part would conflict with, or otherwise detract from, the public authority properly considering or complying with the other considerations”.

With respect to the other states and territories:

The **NSW Carers (Recognition) Act (2010)**⁵⁶ stipulates in Part 1(s9):

“(1) Nothing in this Act gives rise to, or can be taken into account in, any civil cause of action, and without limiting the generality of the foregoing, nothing in this Act:

(a) operates to create in any person any legal rights not in existence before the enactment of this Act, or

(b) affects the validity, or provides grounds for review, of any judicial or administrative act or omission.”

⁵⁴ Western Australia Carers Recognition Act (2004) [\[accessed online\]](#)

⁵⁵ Queensland Carers Recognition Act (2008) [\[accessed online\]](#)

⁵⁶ NSW Carers (Recognition) Act (2010) [\[accessed online\]](#)

(2) If a public sector agency is required by another law to consider particular matters, or to comply with particular requirements, in the exercise of its functions, nothing in this Act is to be taken to require the agency to act inconsistently with that law.”

The **Australian Capital Territory Carers Recognition Act (2021)**⁵⁷ provides at Part 5 ‘Miscellaneous’:

“(12) The Legislative Assembly does not intend by this Act to create in any person any legal right or give rise to any civil cause of action.”

(13) If a provision in this Act (other than section 11) is inconsistent with a provision in any other territory law, the provision in the other territory law prevails to the extent of the inconsistency”

However, in the Acts prelude it states:

“The value of a penalty unit for an offence against this law is \$160 for an individual and \$810 for a corporation.”

The **Victorian Carers Recognition Act (2014)**⁵⁸ says at Part 1(s6):

“If there is any inconsistency between this Act (other than section 12) and any other Act, the provisions of the other Act prevail.”

This is followed by Part 2(s10):

“The care relationship principles set out in this Part do not create, or confer on any person, any right or entitlement enforceable at law.”

Part 8 of the **Tasmanian Carer Recognition Act (2023)**⁵⁹ with provides at Part 3(s8) that:

“(1) Nothing in this Act gives rise to, or is to be taken into account in, any civil cause of action.

(2) Without limiting subsection (1), nothing in this Act –

(a) operates to create in any person any legal rights; or

(b) affects the validity, or provides grounds for review, of any judicial or administrative act or omission.

(3) If an Agency is required by another law to consider particular matters, or to comply with particular requirements, in the performance or exercise of the Agency’s functions or powers, nothing in this Act is to be taken to require the Agency to act inconsistently with that law.”

Outside of State/territory Acts, all governments have access to the Acts online with some having specific ‘consumer’ and/or provider webpages and supplementary resources. For example, NSW Department of Communities and Justice webpage for ‘Carers’⁶⁰ have resources and information for carers, health professionals, service providers, educators and employees, reporting templates, the NSW Carers Strategy, and carer stories.

⁵⁷ ACT Carers Recognition Act (2021) [[accessed online](#)]

⁵⁸ Victoria Carers Recognition Act (2014) [[accessed online](#)]

⁵⁹ Tasmanian Carer Recognition Act (2023) [[accessed online](#)]

⁶⁰ NSW Government, Department of Communities and Justice ‘Carers’ webpage [[accessed online](#)].

3.4 Carer Recognition Act (2010) Federal Government obligations

The Carer Act is supplemented by the Carer Recognition Act 2010 Guidelines⁶¹ which ‘informs APS agencies and associated providers about their responsibilities under the Act and how these responsibilities can be met in the context of policy, program and service delivery’.

“[There is] not enough support and our needs don’t seem to be considered. The Carers recognition Act just seems to be lip service. It feels as though I’m not valued/recognised at all and extremely worried about the future.”

“I’ve been a carer of multiple people over many years. I’ve been self-reliant, self-sufficient, resilient, and pro-active with other carers. I’ve learnt a lot and passed it on to others. I now witness some carers receiving wonderful support and other carers left in the wilderness, barely surviving.”

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Public service agencies covered by the Act are those that are Agencies within the meaning the *Public Service Act 1999* and is a Department, an Executive Agency or a Statutory Agency, which have the following obligations:

- Each public service agency is to take of all practicable measures to ensure that its employees and agents have an awareness and understanding of the Statement for Australia’s Carers - *Part 3 s7(1)*
- Each public service agency’s internal human resources policies, so far as they may significantly affect an employee’s caring role, are to be developed having due regard to the Statement for Australia’s Carers - *Part 3 s7(2)*

However, there is no requirement for APS agencies that are not ‘public service care agencies’ to formally report on the compliance with the Act.

Carers Australia notes the Attorney General’s Department chooses to report on compliance with the Carer Act in its [2021-22 Annual Report](#), however the Australian Public Service Commission, Workplace Gender Equality Agency, and Fair Work Ombudsman do not. In addition, the Department of Prime Minister and Cabinet do not report on compliance, despite currently leading the NDIS Review, development of the National Strategy to Achieve Gender Equality, and the Care and Support Economy Taskforce.

Public service care agencies are defined under the Act as those agencies that are responsible for the development, implementation, provision or evaluation of care supports. Each APS agency is to self-assess if they are a public service care agency, and ‘should consider whether any area or areas within that agency are responsible for the development, implementation, provision or evaluation of care supports.’

Care supports are defined as:

“...any policies, program or services that are directed to carers or the persons for whom they care. This refers to any policy, program or service that targets carers as a priority group within Australia, or targets the people for whom they care. For instance, care supports include policies, programs or services that are directly associated with carers, or with care recipients who have a high likelihood of requiring the support of a carer.

Care supports also include policies, programs and services that are directed to individuals who have a disability, a medical condition, a mental illness or are frail aged, and who may require the personal care, support or assistance provided by a carer. Care supports do not extend to mainstream supports

⁶¹ Australian Government, Department of Social Services ‘Carer Recognition Act 2010 Guidelines: A guide for Australian Public Service Agencies for the implementation of the Carer Recognition Act 2010’ April 2016 [[accessed online](#)]

which are directed to society more broadly. For example, Medicare benefits and other benefits aimed at society as a whole, but which happen to include carers, are not intended to be covered.”

For APS agencies that self-identify as a public service care agency, they have the same obligations as APS agencies in addition to:

- Each public service care agency is to take all practicable measures to ensure that it, and all its employees and agents, take action to reflect the principles of the Statement for Australia’s Carers in developing, implementing, providing or evaluating care supports - *Part 3 s8(1.)*
- Each public service care agency is to consult carers, or bodies that represent carers when developing or evaluating care supports - *Part 3 s8(2.)*
- Each public service care agency must prepare a report on its compliance with section 7 and this section in each reporting period. The report must be included in the agency’s annual report for the reporting period - *Part 3 s8(3).*

Table 2 provides an outline of several APS agencies that should be considered public service care agencies, and if they reported on compliance within the 2021-22 annual report. **What is evident is the level of reporting and compliance is inconsistent and, in some cases, negligible. There is also ambiguity in which agencies are self-identifying and why some are not.**

Table 2: Public Service Care Agency compliance with reporting obligations of the Carer Act (Part 3 s38(3))

Public service care agency	Report	Comment
Department of Health and Ageing	✓	Activities are spread throughout report, mainly linked to ‘disability and carers’ and not clearly linked to obligations under the Carer Act.
Services Australia	✓ ?	‘Carer Recognition Act 2010 report’ states “We also work with partner agencies to ensure that carer policies and service delivery align with the statement and the 6 priority areas identified in the Australian Government’s National Carers Strategy Action Plan (2011-2014)” suggesting the compliance section is added each year from previous years without review.
Department of Social Services	✓	Appendix D Compliance with the Carer Recognition Act provides a comprehensive statement of compliance clearly set out to show activity under each obligation.
NDIS Quality & Safeguards Commission	✓ ?	States compliance with obligations under section 7 and 8 of the Act however no detail is provided.
Australian Commission on Safety and Quality in Health Care	X	Despite the ‘Strategic Plan Priority 2: Partnering with consumers - patients, consumers, carers and the community are engaged in understanding and improving health care for all’
National Mental Health Commission	✓ ?	Under ‘Carer Recognition’ states “Although the Commission is not a public service care agency as defined by the Carer Recognition Act 2010, through its core functions and day to day work the Commission supports the Statement for Australia’s Carers and its 10 key principles that set out how carers should be treated and considered in policy, program and service delivery settings.” Unclear why this APS agency is self-identifying as not a public service care agency given the agency’s remit and the definition of care service agency.
Aged Care Quality and Safety Commission	✓ ?	Reports under ‘staff with carer responsibilities’ and outlines obligations as an APS agency, not as a public service care agency. States that it meets

Public service care agency	Report	Comment
		obligations by providing personal/carers leave for all employees – where it is not clear that this does not include leave for general parental responsibilities as opposed to the definition per the Carer Act.
Australian Human Rights Commission	X	Despite being the independent statutory organisation to protect and promote human rights in Australia and internationally, including rights under the <i>Sex Discrimination Act</i> (for employers to directly discriminate against a person because of their responsibilities to care for a family member), the <i>Disability Discrimination Act</i> , and current work towards a national Human Rights Act to ensure that the rights of all people are protected, all of the time. Note authors of the ‘Investing in care: Recognising and valuing those who care’ report (Citation 5).
National Disability Insurance Agency	✓	‘Compliance with Carer Recognition Act’ provides a comprehensive statement of compliance clearly set out to show activity under each obligation.
Department of Veterans' Affairs	✓	‘Appendix F: Carer recognition’ provides a comprehensive statement of compliance clearly set out to show activity under each obligation. Clearly states “DVA is a public service care agency as defined in the Carer Recognition Act 2010.”
Hearing Australia	X	Annual Report information clearly states this is a public service care agency per the Carer Act definition: “We provide Australians with a wide range of information, education, research and clinical services, including the fitting of hearing devices and follow-up services. This includes providing Government funded hearing services to: children and young adults under the age of 26 years Aboriginal and Torres Strait Islander adults aged over 50 years or who are participating in Community Development Programs pension concession card holders recipients of Centrelink sickness allowance holders of a Department of Veterans' Affairs Gold and White card, and National Disability Insurance Scheme (NDIS) participants.”
Australian Digital Health Agency	X	Annual Report information clearly states this is a public service care agency per the Carer Act definition including those related to My Health Record, advance care planning, telehealth, and MyMedicare.
The Department of Education, Skills and Employment (now Department of Employment and Workplace Relations)	X	Annual Report information clearly states this is a public service care agency per the Carer Act definition including the Review of the Disability Standards for Education. Further, until cessation on 31 Dec 2022, this Department had the Mid-Career Checkpoint program which ‘supports eligible carers who are looking to return to the workforce or carers who have recently returned to paid employment and would like to advance their career. The program is an Australian Government initiative to assist people who have spent time out of the workforce undertaking caring responsibilities and are now looking to return to paid employment’ and is responsible for Fee-Free TAFE , which also specifically targets ‘unpaid carers’ as a priority group.
Australian Bureau of Statistics	X	Despite undertaking the main data collection activity with carers and reporting for government to inform policy related to carers (SDAC).

The final category within the Carer Act that is provided with obligations are associated providers which are defined as:

“people or bodies contracted or funded by public service care agencies to develop, implement, provide or evaluate care supports, that is policies, programmes and services that are directed to carers and the people they care for, and their immediate subcontractors.”

All associated providers have the following obligations under the Act:

- Must take all practicable measures to ensure that its officers, employees and agents have an awareness and understanding of the Statement for Australia’s Carers - *Part 3 s9(a)*.
- Must take all practicable measures to ensure that it, and its officers, employees and agents, take action to reflect the principles of the Statement in developing, implementing, providing or evaluating care supports - *Part 3 s9(b)*.

The Carer Act does not set out reporting requirements for associated providers. It is up to the public sector care agency to stipulate such reporting requirements in their funding agreements.

Associated providers, per the definition provided in the Carer Act, would include (but is not limited to):

- Any Australian Government funded aged care provider including:
 - Commonwealth Home Support Program (CHSP) providers.
 - Home Care Package (HCP) providers.
 - Regional Assessment Services (RAS) funded organisations and their assessors.
 - Residential Aged care providers.
 - Dementia Support Program providers and Dementia and Aged Care Services Fund recipients.
 - Respite providers including residential, center-based, and in-home (day and overnight).
 - Aged Care Volunteer Visitor Scheme (ACVVS) Providers.
- Carer Gateway Service Providers.
- Any Australian Government funded disability support providers:
 - NDIS Local Area Coordinators (LAC).
 - Early Childhood Early Intervention (ECEI) Partners in the Community.
 - NDIS service providers.
 - Disability Employment Service (DES) providers.
- Inclusion Support Program funded ‘Agencies’ and those ECEI providers receiving Inclusion Development Funds via the Australian Government Department of Education.
- Any Department of Veterans’ Affairs funded service provider.
- Australian Government funded Primary Health Networks.
- Australian Government funded mental health service providers, including Headpace, Head to Health and Psychosocial Support Program providers

In addition to the state and territory-based carer recognition legislation, carers are potentially affected by other legislation, including human rights, equal opportunities and anti-discrimination legislation which may be international, national, or state and territory based.

“The National Carer Strategy also has a role in ensuring these reforms support the vision and priority areas. In particular, it is important to ensure that reforms to carer

support programs across the service and support systems are complementary and do not create gaps or disadvantage carer groups”

National Carers Strategy Implementation Plan (lapsed).

3.5 International carer recognition

Internationally, Australia and the United Kingdom are often cited as the most advanced examples in establishing carers’ rights and, for Australia, the Carer Recognition Act (2010) is often quoted. What is not noted is the Carer Act is currently not rights-based to the extent it has any legal impact, nor is it implemented or monitored consistently in what obligations are outlined related to ‘recognition’.

Few countries have the equivalent of what we would describe as a Carers Recognition Act. Those that do are largely confined to entitlements to support, which in many cases is delivered through local government organisations such as councils, and through provincial and state governments. However, carers’ rights in relation to support are often delivered in separate legislation, such as Acts relating to employment (the right to paid and unpaid leave and flexible working conditions), financial support, subsidisation for particular kinds of support such as respite and health insurance.

The **United Kingdom** has introduced three Acts over time establishing carer entitlements.

- The *Carers (Recognition and Services) Act 1995*⁶² establishes a right to assessment and provision of support by local authorities where there is no formal definition of carer beyond someone who “provides or intends to provide a substantial amount of care on a regular basis for the relevant person”, and relevant persons are identified by reference to other Acts including the Children Act 1989, Chronically Sick and Disabled Persons Act 1970 and Carers and Disabled Children Act 2000.
- A *Carers (Equal Opportunity) Act*⁶³ was introduced in 2004 and placed a duty on local authorities to inform carers of their right to a Carer Assessment for support which would ensure that work, life-long learning and leisure be considered in the needs assessment. It also gives local authorities more power to gain the help of housing, health, education and other departments in providing support to carers.
- The *Care Act 2014*⁶⁴ combines various existing legislation and, importantly, it embodies the rights of people receiving support because they have disability or are aged and the rights of their carers in one Act, putting carers on an equal footing with the people they care for.

The *Care Act 2014* also emphasises that local authorities’ assessments, both for carers and those they care for, should consider what people seeking support want to achieve in their lives. It stipulates that local authorities have a duty to ensure the people they work with have access to an advocate in certain circumstances, and a duty on local authorities to promote the individual’s wellbeing, defined as:

- “(a) personal dignity (including treatment of the individual with respect);*
- (b) physical and mental health and emotional well-being;*
- (c) protection from abuse and neglect;*
- (d) control by the individual over day-to-day life (including over care and support, or support provided to the individual and the way in which it is provided);*
- (e) participation in work, education, training or recreation;*

⁶² United Kingdom *Carers (Recognition and Services) Act 1995* [[Accessed online](#)]

⁶³ United Kingdom *Carers (Equal Opportunity) Act 2004* [[Accessed online](#)]

⁶⁴ United Kingdom *Care Act 2014* [[Accessed online](#)]

- (f) *social and economic well-being;*
- (g) *domestic, family and personal relationships;*
- (h) *suitability of living accommodation;*
- (i) *the individual's contribution to society."*

Carers Australia researched carer recognition across 28 **European Union** (EU) member countries, and while many of these countries provided support for carers in legislative instruments, only three have legislation which can be considered as the equivalent of a Carer Recognition Act.

Portugal introduced a Statute for Informal Carers in 2021⁶⁵ which defines an 'informal carer' as:

"a spouse or de facto cohabitant, relative or akin up to the 4th degree of the straight line or collateral line of the carer, who accompanies and takes care of the care recipient on a permanent basis, under the same roof, and this without receiving any remuneration for professional activity or for the care provided".

The Statute also includes an equivalent of a Statement for Australia's Carers, outlining a series of rights relating to the 'possibility' of carers to receive supports and 'benefit' from actions:

- Be accompanied and receive training to improve their skills and the quality of the care they provide.
- Receive information from professionals in the areas of health and social security as well as about the condition of the person they care for.
- Have access to information and counselling.
- Benefit from psychological support from the health services, whenever necessary, and even after the death of the cared-for person.
- Benefit from rest periods aimed at their wellbeing and emotional balance.
- Benefit from the support allowance to the main informal carer, as provided for in the law.
- Reconcile their caregiving and professional responsibilities.
- Benefit from the student worker regime, when attending an educational establishment.
- Be heard in the definition of public policies affecting informal carers.

Italy has introduced Provisions for the Recognition and Support of Family Caregivers⁶⁶ where carers are defined as *"individuals who take care in a continuously, voluntary and free way of a person for whom she/he feels affection who is not able to perform daily tasks by herself/himself"*. Within this recognition, the carer should be helped by a 'support network' made up of social workers, nurses, GPs and voluntary organisations, and be based not only on services and care allowances but also on psychological and 'relational' help (including self-help). This bill also favors early retirement for carers, especially for those who have difficulty in reconciling work and care, and includes a wide range of support services for carers.

In 2019, the Government of **Belgium**⁶⁷ approved two royal decrees with the following provisions:

- A person providing care to someone with impaired independence will be able to request an official recognition as 'informal carer' through the submission of a declaration of honour to the compulsory

⁶⁵ Eurocarers, Towards carer-friendly societies: European Country Profiles, Portugal [[Accessed online](#)]

⁶⁶ Eurocarers, Towards carer-friendly societies: European Country Profiles, Italy [[Accessed online](#)]

⁶⁷ Eurocarers, Towards carer-friendly societies: European Country Profiles, Belgium [[Accessed online](#)]

health insurance and will, as a result, have access to a series of social rights, including a paid care leave as well as flexible working conditions. Health insurance services will check that the beneficiaries comply with a set of specific criteria regarding the relationship between the carer and care recipient.

- For recognised informal carers, the full-time leave scheme for medical assistance will be extended from 12 to 18 months.
- Measures will be put in place to alleviate the administrative burden faced by informal carers.
- Civil servants and employees of public authorities will have access to a carer's leave.

Closer to home, **New Zealand** has a Carers Strategy (2008) and a Carers Strategy Action Plan 2019-2023⁶⁸, however it has no equivalent recognition Act. Within the Carers Strategy, a carer is defined as *“individuals, family, whānau and āiga providing care for someone close to them who needs additional assistance with their everyday living because of a disability, health condition, illness or injury”*.

Other than these countries, we researched China, Taiwan, Singapore, Malaysia, India, Japan, Indonesia and South Korea – but found nothing of particular relevance except in relation to provision of some supports such as carers leave in Japan and isolated projects in some of the others. There was something of a trend in focusing on carers of the elderly. Neither the United States or Canada have the national equivalent of a recognition Act, although some states in US and provinces in Canada do.

4. Policy inconsistencies

It is widely acknowledged that policy-making has tended to be developed in distinct administrative silos even though most interventions will almost certainly have wider implications.⁶⁹ Several studies outline the impact of policy consistency on perceptions of policy meaningfulness and legitimacy, with a recent study stating policy consistency could be a valuable strategy for governments to strengthen successful policy implementation.⁷⁰

A carer's role is distinctly different from generalised familial support or parenting and as such the information needs are different. Although a carer is most often a close family members or friend, it is important to acknowledge the distinction between 'family' and 'parents' with carers, as defined in the Carer Act.

This section aims to provide the Committee with examples of where inconsistency of how the term 'carer' per the Act is used, defined or omitted in Australian Government policy, with a focus on disability, aged care, mental health and social services policy. We also provide a brief overview of the diversity of caring as it relates to each of these systems.

“Becoming a carer is not a choice. Some people find that they are thrust into the role without warning after the birth of a child with an illness or disability, or following a traumatic event or accident involving a loved one. For others, becoming a carer is a more gradual process, though ultimately equally devastating. When does a husband, or a wife, recognise that they have also become a carer for their partner with dementia for example? While every caring situation is unique, the love, grief, guilt, fear, anger and frustration, coupled with sheer physical and mental exhaustion are all part and parcel of carers' lived experiences.”

2009 'Who Cares....?' Inquiry Final Report Foreword

⁶⁸ New Zealand, Ministry of Social Development, New Zealand's Carers' Strategy [Accessed online](#)

⁶⁹ B Hudson, D Hunter & S Peckham (2019) 'Policy failure and the policy-implementation gap: can policy support programs help?' *Policy Design and Practice* Vol 2(1) [accessed via [Taylor & Francis Online](#)].

⁷⁰ N van Engen, B Steijn & L Tummers (2018) 'Do consistent government policies lead to greater meaningfulness and legitimacy on the front line?' *Public Administration* Vol 97(1):97-115 [accessed via [Wiley Online Library](#)]

4.1 Definition is important

Clear and consistent use of terms is essential for ongoing recognition through policy, processes and the flow-on service provision. Definitions, by which words are given meaning, is central to this and for carer recognition across portfolios.

Caring roles may involve ongoing and high intensity care and support of many aspects of a person's lives, can involve activities that paid 'formal' roles might offer if they were available, accessible and affordable, and is done most often without adequate access to respite or other supports.

The role of a carer is different from child-rearing or parenting and it is important to highlight definitions within children's services policy, noting state and territory carer recognition Acts and state-federal government funding possibilities. In this context, 'carers'⁷¹ are people who have been screened and have received authorisation to provide placements in their private households for children in funded out-of-home care, and:

- Relative/kinship carers – are in situations where children are unable to live at home, but a relative, close family friend or member of the child's community is willing to care for the child.
- Foster carers - when children are unable to live at home or receive care from a relative. Foster carers are not related to the children.
- Long-term guardianship carers – when children are placed with long-term guardianship carers (who may or may not be related to the child) when a care and protection order has transferred full parental responsibility to a carer.

"How little it is recognised or how people try to say "oh I had to do that for my child too that's just like my parenting experiences." When you have a child 100% dependent on you for 98% of thing it is not the same."

"When accessing services as a carer for your children, so much is attributed to 'normal parental responsibility' when it's not - as a carer for a child with disability there is no recognition of the impact of the caring role on your own disability or access to health care - it seems [that the] system assumes that if you're a carer you are fit, and wealthy"

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"A number of parents and family members of people with disability spoke of the impact that a caring role has on them as individuals and on the family as a whole. In particular, families said that in their view governments and society did not recognise and value the intensity of being a carer and its effect on their social participation and economic independence."

DRC Interim Report

When policy does not qualify how 'carer' is being used *and* how this relates to the Carer Act, the confusion this creates can result in:

⁷¹ Australian Government, Australian Institute of Health and Welfare, 'Child protection Australia 2020–21' Table 7.1: types of carers (last updated 26/05/22) [[accessed online](#)]

- Issues with services identifying carers and sign-posting or referring to appropriate services the individual is eligible for.
- Issues with carers self-identifying, and therefore not seeking carer-specific supports or reacting to communication and awareness activities related to these – exacerbating loneliness and isolation.
- Confusion over rights and responsibilities, particularly as it relates to substitute decision-making and guardianship, in addition to child safety and broader justice issues.
- Decreased understanding and recognition of the caring role (per the Carer Act) as well as the essential roles of others, for example, foster or kinship carers.
- Assumptions about the relationship the carer has with the person receiving care, especially as it relates to parental rights and responsibilities, or the validity of the carer and their rights if they are not 'family'.
- Difficulties understanding rights and which apply to carer per the Act or people more generally, for example, requesting flexible working arrangements, discrimination based on caring responsibilities, and leave provisions such as the general entitlement to personal and carers leave (except for casuals) versus unpaid carers leave (including casuals) under the National Employment Standards.
- Confusion between unpaid 'informal' carers and paid 'formal' care workers, particularly within aged care, disability support and childcare.
- Reinforced stereotypes and negatively influencing how others think about carers and caring, which increases the likelihood of a carer experiencing stigma or discrimination associated with being a carer, and especially when the term has been attached to abuse or labelled as 'derogatory'.

"Caring is rewarding. However your own life is put on hold. The system which is in place lacks the integrity to identify, resolve and assist when help is needed. Help is limited. There is no flexibility in offered services. There is no help when you need it most, always a waiting list. No contingency plan for emergency assistance. Having to deal with multiple departments before being approved for assistance.

Most importantly, decision makers do not understand what carers do or need but make decisions on what help they will offer. A carers role changes continuously. In the end, most people like myself give up and don't accept services because it doesn't meet my needs and I still have to contribute financially. I may as well do it myself. As a carer, I am constantly reprimanded for not accepting help during the most difficult times. When I ask for help there is always a catch, so I don't ask anymore."

2022 Carer Wellbeing Survey Response

As an example of the latter two points, Carers Australia felt compelled issue a [media release](#) following a Disability Royal Commission report⁷² that provided an overview of responses to the violence and abuse of people with disability. This report highlighted cases in which 'carers' were perpetrators of abuse, however when reading the full context of each reference made to 'carers', most often the abuse was perpetrated by a paid disability care worker.

⁷² Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 'Overview of responses to the Rights and attitudes Issues paper' April 2021 [\[accessed online\]](#).

Data collection

“Performance reporting is not possible without access to adequate data. An absence of adequate data undermines the basis for performance reporting, and can adversely affect policy making.”

Productivity Commission - Review of the National Disability Agreement Study Report ⁷³

It is important to note the definitions used by the main sources of data collection and reporting determine adequate coverage of carers in Australia. Some of the issues that occur as a result of this have been demonstrated in this brief, such as carer identification by services they interact with, carer self-identification. Carer definitions have flow on effects for subsequent policy and funding decisions.

Appropriate and consistent data collection and reporting is also a factor in understanding the ‘value’ of unpaid care and the subsequent impact on care and support workforce policy and broader fiscal measures. Differentiating carers (per the Carer Act) from ‘families’ and ‘parents’ is also important.

The **Australian Bureau of Statistics** is responsible for the Census and SDAC. The SDAC is the most comprehensive single source of information on carers published by the Australian Bureau of Statistics. The Census also provides information on carers but it is confined to a two week snapshot and we have some difficulties with an attenuated description of care which is biased toward physical support activities.

We also note issues with SDAC survey, starting with limitations on collecting data that covers the full scope of those covered by the Carer Act, where the survey only collects data on carers of people ‘living with disability and long-term health conditions or older people’, although it is possible to narrow down to some extent the broad category of condition of the person being cared for by accessing the ABS Table Builder and, where possible, de-identified information gathered.

Further, the survey is largely focused on ‘primary carers’ who are ‘*a person aged 15 years and over who provides the most informal assistance to a person with disability for the core activities of mobility, self-care and communication*’. It gives the impression that people in the “not primary carer” category provide less significant care.

These issues are important, as SDAC data is linked to reporting on outcomes across portfolios, for example Australia’s Disability Strategy, National Disability Agreements (NDAs), social security payments, and various service delivery initiatives and programs. SDAC data is also used extensively by the **Australian Institute of Health and Welfare**, which reports on outcomes across portfolios.

4.2 Disability policy

Diversity of caring

The Carer Recognition Act specifically includes ‘disability’ (1)(a) as a reason where a carer may be required, acknowledging however that many people living with disability may also be living with the other listed reasons for requiring care (medical condition including a terminal or chronic illness, mental illness, frail and aged).

Not all people with a disability have, want or will need a carer. But for those who do, the care being provided may also be across a range of disabilities and comorbidities, differing impacts of the disability and/or intensity of care, and the care recipient may or may not be an NDIS participant.

⁷³ Australian Government, Productivity Commission, ‘Review of the National Disability Agreement Study Report’ 2018 [[accessed online](#)]

This includes carers of children with disability in the early childhood early intervention (ECEI) system (under 9 years), school aged children or young people with disability, and importantly, carers of adult children with disability who will often be older carers. A carer can also still be a ‘carer’ regardless of where the person they are providing care for lives – which could be in the same household, in another house (which may or may not be Supported Independent Living) or residential disability care.

A carer can be living with disability themselves and may also be a participant of the NDIS. In fact, in 2018 more than one-third (37.4%) of primary carers lived with disability, twice the rate of non-carers (15.3%).⁷⁴

Governance

At departmental-level, the first element is the [NDIS Independent Advisory Council](#) (IAC) which was established following introduction of the NDIS Act in 2013 with the function of advising the NDIA Board on the most important issues affecting participants, carers and families. The first meeting took place in 2021, and there is carer representation on the IAC, where it is explicitly required within the NDIS Act.

- The [NDIA’s Disability Representative and Carer Organisations \(DRCO’s\)](#) group (formerly the CEO Forum) is the main platform for the disability sector to engage, discuss, collaborate and co-design the NDIS and work with the IAC. Carers are represented on the DRCO, and on the CEO Forum prior to 2021.

The second governance structure at the Departmental level is DSS’s [Australia’s Disability Strategy Advisory Council](#) which was established in December 2021 when Australia’s Disability Strategy 2021-2031 was launched, to provide advice to all levels of government including the Australian, state, territory and local governments. All members of this Council are required to be people with disability.

- The [DSS National Disability Representative Organisations \(DRO’s\)](#) group formed in 2017 to provide ‘advice to the Government on breaking down barriers and improving social and economic participation and engage with a range of ministers and portfolios.’
 - Carer representation is via a ‘member of a member’ where the Disability Australia Consortium is on the DRO, and one of their members is the National Mental Health Consumer and Carer Forum (NMHCCF). The NMHCCF⁷⁵ is not an organisation, rather a forum via auspicing with Mental Health Australia. While invaluable to provide lived experience representation in certain situations, it is specific to mental ill health, and is both consumers and carers. As such there is no broad carer representation via the DRO.

Table 3: Carer representation within disability policy governance

Governance	Carer representation
DSS National Disability and Carers Advisory Council (<i>ceased 2018</i>)	✓
NDIS Independent Advisory Council (<i>from 2020</i>)	✓
DSS Australia’s Disability Strategy Advisory Council (<i>from 2021</i>)	X
NDIA’s Disability Representative and Carer Organisations (<i>from 2021</i>)	✓

⁷⁴ Australian Bureau of Statistics (ABS), Survey of Disability, Ageing and Carers, (2018), [[accessed online](#)].

⁷⁵ ‘National Mental Health Consumer and Carer Forum’ webpage [[accessed online](#)]. Note Carers Australia have an ‘organisational representative’ lived experience carer on the National Mental Health Consumer and Carer Forum.

DSS Disability Representative Organisations (DRO's) (from 2017)	x
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Further evidence in this section shows that inconsistent and fractured carer representation is clearly reflected in policy, including in the NDIS Reviews consultation processes focused on working with the DRO's, and funding provided to them for this specific purpose and to assist with lived experience voices.

Australia's Disability Strategy

Australia's Disability Strategy 2021-2031⁷⁶ is *"an aspirational road map pointing the way ahead. It represents our national commitment to enabling every Australian to meet their potential, to achieve, to have a fair go and to have real choices. In Australia's Disability Strategy 2021–2031, we affirm the values of respect, inclusion and equality and espouse them as fundamental to our national identity."*

Table 4 outlines areas where carers are recognised (or not), if this is consistent with the Act (2010), noting the strategy states a large part of the consultation towards development was through a series of workshops held directly with DSS's DRO's (refer to table 3).

Table 4: Key area of Australia's Disability Strategy – examples related to recognition of carers

Key area of Australia's Disability Strategy – examples related to inconsistency in recognition of carers	
Guiding Principles which Governments have agreed to use when developing policies, programs, services and systems.	
- These do not include any principles related to carers or families	
Appendix 4 outlines the roles and responsibilities of Governments.	
- None are explicit to 'carers and families', and whilst listing several pieces of relevant legislation there is no reference to the Carer Act.	
Community Attitudes Targeted Action Plan where two jurisdictions include activity related to the jurisdictional carer recognition legislation.	
- 'Australian Government Actions' has no explicit reference to carers, or to the Carer Act	
Safety Targeted Action Plan lists where reporting will capture available information from Australian Government agencies, state, territory and local governments, the AHRC, state and territory human rights/antidiscrimination bodies, the NDIA, information from people with disability, DROs and the Strategy's Advisory Council.	
- DRO and Strategy's Advisory Council carer representation issues – refer to table 3	
Early Childhood Targeted Action Plan where 'the program will be directly targeted at parents and carers, therefore a co-design process will ensure lived experience informs the program's deliverables.' One jurisdiction include activity related to the jurisdictional carer recognition legislation.	
- 'Australian Government Actions' has no explicit reference to carers or the Carer Act	
The strategy states that a large part of the consultation towards development was a 'series of workshops' held directly with DRO's.	
- DRO carer representation issue – refer to table 3.	
The Australia's Disability Strategy's Engagement Plan where carers are only referenced in a footnote: 'Key stakeholder groups include people with disability, family members and carers of people with disability; organisations representing	

⁷⁶ Australian Government, DSS 'Australia's Disability Strategy 2021-2031' 2021 [[accessed online](#)].

Key area of Australia's Disability Strategy – examples related to inconsistency in recognition of carers

people with disability, family members, carers or service providers; technical experts and academics; organisations or individuals representing the mainstream sectors aligned with the Strategy's Outcome Areas.'

For comparison, the previous [2010–2020 National Disability Strategy](#) had more robust carer representation during development through work of the National Disability and Carers Advisory Council and this was subsequently reflected in the now abandoned National Carers strategy which stated *"The National Carer Strategy does not sit in isolation. It is an integral part of the Australian Government's broader social inclusion agenda and it sits alongside and complements the National Disability Strategy."*

In the previous Disability Strategy:

"Carers in this context refers to all those who provide care, support and assistance to a person with disability as a family member, friend, neighbour or work colleague. Many people with disability are carers too. The National Carer Strategy will address carer issues more specifically and is expected to be released during 2011."

Outcome 6 - Personal and community support included 'informal care and support' where Policy Direction 4 acknowledged and supported the role of families and carers:

"The relationship between people with disability, their families and carers is often one of mutual support. Better outcomes for people with disability will also mean better and more sustainable outcomes for carers and families. Universal access to goods, services, spaces and places helps to create a sustainable world for carers too, especially for long-term carers and those at crisis point. There are sound reasons for doing more—over the next fifty years there will be an increase in the number of people needing care and support, but a decrease in ratio of carers."

- One of the priorities under the outcome area 'personal and community support' is 'informal and carer support'
 - The measure is 'Providing enough services and alternative care arrangements to give carers of people with disability the support they need' which being tracked across two measures
 - [Measure for carer satisfaction with support](#): Proportion of carers who are satisfied with the range of services available to assist in caring role
 - Data source: SDAC and notes *"Data are restricted to primary carers aged 15 and over living in households, and excludes those who did not know the range of services available or did not answer."*
 - [Access to alternative care](#): Proportion of informal carers of people with disability who report no unmet need for respite care
 - Data source: SDAC and notes: *"Due to available data, the population for this measure is restricted to primary carers."*

Poor data collection on respite has also been identified where the [AIHW states](#):

"The Strategy would like to see the following tracked – proportion of informal carers of people with disability who report that alternative care arrangements are available and affordable. Available data do not currently allow this. This measure is part of the Informal and carer supports priority of the Strategy. This priority is about providing enough services and alternative care arrangements to give carers of people with disability the support they need. The desired outcome is that more carers of people with disability say they can access alternative care arrangements when they need to."

At this time, we highlight that the [NDIS Family and Carer Outcomes Report](#) surveys measure the outcomes for participants and their families and carers who are part of the NDIS, however it groups together ‘families and carers’.

The National Disability Agreement (NDA)

The NDA is a high-level agreement between the Commonwealth and State and Territory Governments, which commenced in 2009 and was updated in 2012. The purpose of the NDA is to “*affirm the commitment of all governments to work in partnership, and with stakeholders including people with disability their families and carers, to improve outcomes for people with disability and to clarify roles and responsibilities*”

State and Territory governments are responsible for the provision of specialist disability services provided under the NDA, except disability employment services. The Commonwealth Government is responsible for the oversight and funding of employment services for people with disability and the provision of income support. All governments share responsibility for National Disability Insurance Scheme (NDIS) policy, funding and governance.

One of the three aims is ‘families and carers are well supported’, and performance is assessed against the two benchmarks identified in the NDA which is supplemented with an indication of the level of participation by people with a disability in social and community activities. However, performance reporting via the Productivity Commission [Performance Reporting Dashboard](#) has no performance measurement or reporting on the aim related to families and carers.

We highlight a Productivity Commission Report⁷⁷ which reviewed the NDA and was provided to the Australian Government on 25 January 2019, yet there has not been a government response⁷⁸ despite the Disability Royal Commission, NDIS Review and ongoing work of the Joint Select Committee on the NDIS.

This report stated roles and responsibilities in the NDA need to be updated to ‘reflect contemporary policy settings, to reduce uncertainty and to address gaps in several areas’ — including in relation to advocacy, carers, and the interface between the NDIS and mainstream service systems. In particular, the report identified:

- “There are widespread concerns about future support for carers outside the NDIS, particularly as funding of some existing programs (such as for carer respite) is being rolled into the NDIS. The Australian Government has announced some services, but it is not clear what State and Territory Governments intend to provide or how they will interface with Commonwealth services (Box 3 ‘Support for carers’).”
- Recommendation 3.4 – “The new NDA should set out the responsibilities of the Australian, State and Territory Governments to provide disability services outside the NDIS, in particular where there is lack of clarity including for... carer services, in particular respite services.”

In addition, the Commission commented that a benchmark for Outcome C: “Families and Carers are well supported” was not specified in the NDA and has not been established since the NDA was revised in 2012, representing a gap in the NDA performance reporting framework.

National Disability Insurance Scheme (NDIS)

⁷⁷ Op.Cit (Productivity Commission, NDA Report 2018)

⁷⁸ <https://www.pc.gov.au/inquiries/completed/disability-agreement#report>

To illustrate examples related to the NDIS, our focus is on the [National Disability Insurance Scheme Act 2013](#) (NDIS Act) and the [NDIS Rules](#) which are legislative instruments made under the Act.

The NDIS Act includes a definition of carer that is consistent with the Carer Act:

(3)(c)(ii) In giving effect to the objects of the Act, regard is to be had to: ...the Carer Recognition Act 2010.

Further, Part 2(1)(31) Principles relating to plans includes:

(c) where relevant, consider and respect the role of family, carers and other persons who are significant in the life of the participant; and

(ca) where relevant, recognise and respect the relationship between participants and their families and carers.

Section 4 on ‘General principles guiding actions under the NDIS Act’ include:

(3) People with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime...

(12) The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected, and

(12A) The relationship between people with disability and their families and carers is to be recognised and respected.

However, there is no reference to carers in the Code of Conduct Rules, despite general principles (3), (12) and (12A) and the other NDIS Act provisions:

National Disability Insurance Scheme (Code of Conduct) Rules 2018 sets out the NDIS Code of Conduct which applies to all NDIS providers and persons employed or otherwise engaged by them, and reflects the core values and principles set out in the National Standards for Disability Services, the National Mental Health Standards and the NDIS Act.

“I Hate being called “an Informal support” by the NDIS. I am his wife and carer.”

“[What I least like] Not knowing how to negotiate the NDIS review and accessing new services. Feeling like I am never going to be on the radar of LAC...”

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4.3 Aged care policy

The [Aged Care Act 1997](#) (the Aged Care Act is built around Government subsidised services for older people including a range of services offered in the community, home care, residential care and flexible care) and the obligations on providers. Interestingly, despite the introduction of the *Carer Recognition Act* and subsequent amendments to the *Aged Care Act* following on from the Living Longer, Living Better Federal Government reforms to aged care in 2014, there are only five mentions of carers in the Act and only one mention of families in the body of the Act. There is no definition of “carer” in the Act. However, under Division 1, which stipulates the Objects of the Act, section (g) includes the “encouragement of diverse, flexible and responsive care services” which:

- (i) *are appropriate to meet the needs of the recipients of those services and the carers of those recipients;*
- (ii) *(facilitate the independence of, and choice available to, those recipients and carers*

There are other mentions of carers with respect to disclosure of information, determination of assets and the definition of respite care. Access to respite care is substantially covered but very much restricted to procedural matters.

In reality, the Living Longer, Living Better reforms did not produce discernible improvements in access to respite in either residential care facilities or in the community. The inadequacy of access to respite was commented on the 2017 Tune Review of Aged Care⁷⁹ and resulted in an Aged Care Financing Authority review of respite⁸⁰ in 2018 with 19 recommendations for improvements. These were not acted on at the time because they were inter-related with other changes in aged care that were still in development. As in the past, carer needs seemed to fall to the bottom of the list of priorities. The need for improved carer recognition and for improved support, especially respite, featured in the Final Report and Recommendations of the Royal Commission into Aged Care Quality and Safety.

Indeed, the Commission’s Final Report⁸¹ put a very heavy emphasis on the value of carers and their need for better recognition and better support, especially with respect to respite. In their own words:

“Informal carers are a critical element of the care system for older people. They reduce the need for formal care, supplement the care provided by aged care services, and maintain critical social and community connections. In 2018, around 428,500 people were informal primary carers for someone aged 65 years or older.”

The Commission’s first recommendation⁸² stipulates support for carers in the definition of aged care under the new Act:

The new Act should define aged care as:

- 2 (a) *support and care for people to maintain their independence as they age, including support and care to ameliorate age-related deterioration their social, mental and physical capacities to function independently*
- 2 (b) *supports, including respite for informal carers of people receiving aged care.*⁸³

⁷⁹Department of Health and Aged Care, Legislated Review of Aged Care 2017 Report [\[accessed online\]](#)

⁸⁰ Aged Care Financing Authority (ACFA), Report on Respite for Aged Care Recipients, 2018, [\[accessed online\]](#)

⁸¹ Royal Commission into Aged Care Quality and Safety, Final Report, Volume 1, 2021, [\[accessed online\]](#)

⁸² Royal Commission into Aged Care Quality and Safety, Recommendations, 2021, [\[accessed online\]](#)

⁸³Royal Commission into Aged Care Quality and Safety, 2021, Recommendation 1 [accessed online](#)

Importantly, the Royal Commission went on to make specific recommendations in relation to carer support. Since the Royal Commission, a number of reforms have been introduced which have benefited carers.

- The subsidies for residential respite care (which were considerably lower than for permanent care) are now more closely aligned with permanent care subsidies, which hopefully will make offering respite places more attractive to providers.
- A [National Dementia Action Plan 2023-2033](#) has been developed and is very carer inclusive. In addition, innovative, dedicated community respite programs for people with dementia and their carers are being piloted. We note however that not all carers of the aged care for someone with dementia, and we are unaware of reform activity in relation to these other carers and those they care for.
- New Home Care assessments for older people which also identify carer strain and need for support from the Carer Gateway are also being piloted.

The real test will be carer inclusiveness in the new Aged Care Act under development. Unfortunately, we are aware the carer inclusive definition of aged care recommended by the Royal Commission is not being adopted and **we have concerns the Act will have little focus on carers.**

Governance

At the Ministerial level, the [National Aged Care Advisory Council](#) was established as part of governance arrangements arising from the aged care reforms. The Advisory Council provides advice to Government on key matters relating to the aged care sector. Advice from the Advisory Council reflects the diverse needs and expectations of older people and their families and carers, regardless of their location or circumstance, and recognises the need to protect the interests of the vulnerable and disadvantaged. The Advisory Council reports to the Minister for Health and Aged Care and the Minister for Aged Care.

In addition to the National Aged Care Advisory Council, the Australian Government established the [Council of Elders](#). The Council of Elders provides advice from older people to the Government about aged care reform and ageing generally.

However, neither group has specific carer-representation.

A new independent [Inspector-General of Aged Care](#) has been established to review, monitor and report on the administration and governance of the aged care system. We are heartened that, to date, Carers Australia has been included in consumer consultations offered by the Interim Inspector-General.

Also for Consideration: Australia's Aged Care Workforce Strategy

In 2018 an Aged Carer Workforce Taskforce was formed to advise the Minister for Aged Care on supporting safe, quality aged care for senior Australians. It produced a Strategy report in 2018⁸⁴.

Interestingly, Appendix C Glossary of this Strategy includes:

"Carer: A carer is a person who provides personal care, support and assistance to a consumer. The definition is consistent with that used in the Carer Recognition Act 2010. This does not include a member of the organisation's workforce such as a person who is contracted or paid to provide those services or a person who provides the services in the course of doing voluntary work for a charitable, welfare or community organisation."

Other key comments in the Strategy that impact on carers include the following.

⁸⁴ Aged Care Workforce Strategy Taskforce, A Matter of Care: Australia's Aged Care Workforce Strategy, 2018 [\[accessed online\]](#)

- *“It is imperative that our definition of ‘aged care consumer’ be extended beyond those people accessing or using care services to proactively include their families, carers and entities trusted or designated to act on their behalf, and the local community. Each has a perspective that needs to be heard and may not always be aligned. Genuine consumer insight will come from deeper engagement with each of these critical stakeholders.”*

Under the heading “Uncovering fundamental truths driving the industry” it identifies the need to:

- *“reframe the idea of care, including the notion that the care industry is solely the domain of government. Reframing caring is a social challenge. It is about quality of life as people age. This begins with understanding that care for older people is broader than organised professional care. In the first instance, it typically involves informal carers, peer-to-peer support and caring for themselves.”*

It identified that:

- *“Consumer experience surveys must capture the views of people receiving care as well as their families and carers. Each is likely to have a different impression of care and their views must be incorporated in service design”.*

5. Closing comment

We hope this brief provides a good overview of carers, their needs and the value they contribute to the sustainability of the aged care and disability care systems and, indeed, to the health needs of those they care for. We have sought to highlight this value is often not well recognised in the legislation, policy and Government consultation processes which impact upon them.

We are pleased to see the new Inquiry's Terms of Reference appear broader than simply a definition of 'who is a carer'. This is because true recognition, and the appropriate policy and service responses that follow, require looking at the diversity of caring, issues related to financial security, the economic value of carers and the broader reform agenda across portfolios. In this context, Carers Australia strongly encourages the Committee to review the 2009 Inquiry report and the lapsed National Carers Strategy when considering their recommendations. That Committee's report included the following statement from the Chair:

"As Chair of the Committee it is my view that many of the report's recommendations are a starting point only, providing a baseline for more fundamental and significant reforms to systems of support for carers. In considering the report, I urge the Australian Government and others to look beyond the specifics of the recommendations and to also consider their context and intent – that is to significantly improve the lives of carers and those they care for. Importantly, implementation of reform will be key to effecting meaningful change. It is my sincere hope that this report and its recommendations will act as a stimulus for action".⁸⁵

We hope the findings of this Inquiry will land on more fertile ground than the 2009 Inquiry.

⁸⁵ House of Representatives Standing Committee on Family, Community, Housing and Youth. Who Cares? Report on the Inquiry into better support for carers, 2009 ([accessed online](#))

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 represent 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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