



PARLIAMENT OF AUSTRALIA

Recognising, valuing and supporting unpaid carers

Inquiry into the recognition of unpaid carers

House of Representatives

Standing Committee on Social Policy and Legal Affairs

CANBERRA

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Foreword

Unpaid carers (carers) are heroes in our communities, but their roles are largely unrecognised and undervalued. Carers provide 2.2 billion hours of unpaid care each year in Australia, which would cost nearly \$80 billion to replace with formal paid care. Carers often sacrifice their careers and retirement plans, education goals, social lives, and health and wellbeing to look after the needs of others, and many do so with little support. However, demand for unpaid care is expected to outpace the number of carers taking on caring roles in the future. If we do not look after carers now, Australia will need to address an increasing carer deficit in the future as our population changes.

The Committee examined the effectiveness of the *Carer Recognition Act 2010* (the Act) in recognising and raising awareness of the role of carers, developments in the policy landscape since the Act was established and considered options for reform.

The Act aimed to increase recognition and awareness of carers and to acknowledge the valuable contribution they make to society by creating an obligation on the part of the public service and associated providers to observe its principles. In doing so, the Act represented a step forward in the recognition of Australia's carers. However, despite the best of intentions, the Act has not encouraged a cultural change in how public service agencies and their associated providers interact with and support carers. The Act is not achieving its aims because it is unenforceable, contains weak and vague statements without clear calls to action, and relies on a voluntary and inconsistent reporting system with little oversight or accountability.

The Act needs to be modernised and strengthened to encourage meaningful change in how carers are recognised and treated by the services they interact with. The Act should provide a more inclusive definition of the term 'carer', which reflects the diverse realities of care relationships. The definition should be extended to acknowledge care provided because another person has a disability, is experiencing mental ill health or a medical condition, is frail and/or aged, or is experiencing alcohol or other drug dependence. It should explicitly recognise young carers and specify that people can be in multiple care relationships.

The Act currently allows public service agencies to self-assess if they are a 'care agency'. This is not working, and stronger obligations are needed. All public service agencies must be required to consider the needs of carers and become well-informed about their role in society, regardless of whether those agencies have carer-related policies, programs, or services in place. They should take all practicable measures to ensure they and their employees and agents have an awareness of and take action to reflect the principles of the Statement for Australia's Carers in the Act in developing, implementing, providing or evaluating care supports. They should also develop internal human resources policies that have regard for the Statement for Australia's Carers, insofar as those policies may significantly affect an employee's caring role, and they should consult carers, or bodies that represent carers, when developing or evaluating care supports.

The Statement for Australia's Carers are important ideals that remain far from being realised, in part because the Act confers no rights on carers. Carers' rights should be enshrined in legislation, and the Committee recommends that the Australian Government seek legal advice to determine how this could be best achieved. Rights for carers should include being acknowledged as partners in care; being involved in planning and policy development; being provided with information regarding the person they care for in order to provide care; and accessing flexible work arrangements.

The Committee considered developments in the policy landscape since the Act was introduced, including the establishment of Carer Gateway as a single point of contact for accessing a range of carer supports and services. While the Committee received some feedback that Carer Gateway is an improvement on the carer support services that preceded it, carers say that Carer Gateway is slow and difficult to navigate, and that the supports they receive are not always helpful. Concerningly, there is a lack of quality, local respite care options available, which means that many carers are not getting a break and risk burn out. Similarly, there is a need to increase access to high-quality counselling and mental health support options for a diverse range of carers, and for further work to ensure carers' health and wellbeing is supported holistically and that carers are prioritised in the healthcare system and other settings. Improved support for First Nations carers and carers from culturally and linguistically diverse backgrounds is needed to ensure that the supports they receive are culturally and linguistically appropriate.

The Australian Government is committed to delivering a new National Carer Strategy in 2024, which is a welcome development. It is critical that the new strategy outlines how governments will work to implement the Act, to address the reasons why caring may be unviable for carers and to ensure that carers can access the supports they need. One of the goals of the strategy should be to ensure that there are enough carers to meet demand for care in the future. To do this, we must minimise the negative impacts that caring has on carers' financial security, their mental and physical wellbeing, and their social relationships. Carers must be considered as a priority, rather than as adjunct to the needs of the people they care for. The new strategy should be co-designed with and monitored by carers and carers' representatives to ensure carers are treated as genuine partners in care provision.

There is a need for more comprehensive data to inform policy and to track outcomes for carers, including a redesign of the Australian Bureau of Statistics' Survey of Disability and Carers, new funding for research and data mapping of carers and further, ongoing work to collect evidence about carers' health, wellbeing, and suicide risk factors through the Carer Wellbeing Survey.

While many men are carers, most of Australia's carers are women and this has significant implications for the lives of women, the gender pay and superannuation earnings gaps, and the representation of women in leadership roles. The new strategy should include gender equality as a key priority area. This will require work to overcoming harmful gender norms that mean that the burden of care largely falls on women's shoulders and policies that encourage more men to become carers. Further work is required to address the financial disadvantages carers experience over their lifetime, including supporting flexible work arrangements for carers, introducing an income tax credit for carers returning to the paid workforce and consideration of other options to incentivise and recognise the impact of caring through the income tax and superannuation systems. A community education

campaign is needed to promote recognition and awareness of carers' rights and the diversity of carers, to address gender stereotypes and reduce stigma, and to drive positive workplace cultures for carers.

I want to acknowledge the important work of the former Committee Chair, the late Peta Murphy MP, who led this inquiry until her death in December 2023. Peta was committed to making a difference in public life and brought compassion, intellect, integrity, and good humour to her work on this Committee and in everything she did.

Ms Susan Templeman MP
Chair

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Terms of reference

House of Representatives Standing Committee on Social Policy and Legal Affairs will inquire into and report on the provisions and operation of the *Carer Recognition Act 2010* (the Act) in relation to unpaid carers, with a view to reform through legislative amendment. Limited to the objects of the current Act, the inquiry will have regard to:

- the effectiveness of the Act and the associated Statement of Australia's Carers in raising recognition and awareness of the unpaid caring role, including its obligations on public service agencies
- developments in the policy landscape at a Commonwealth level since the Act's passage in 2010
- the effectiveness of existing state, territory and international recognition of unpaid care (statutory or other practice)
- how to better identify the role of unpaid carers in Australian society and the role of a reformed Act, with regard to:
- understanding the value of unpaid care,
- the needs of specific cohorts such as young carers, First Nations carers, LGBTIQ+ carers, or culturally and linguistically diverse carers,
- the meaningful role that flexible workplaces play in unpaid care, and
- the Government's broad agenda in relation to the care and support economy, the importance of employment participation, and a strong focus on gender equity, and
- any other related matters, noting that the adequacy of payments for carers is out of scope for this inquiry.

In conduct of the inquiry, the Committee should consider:

- the views of individual unpaid carers, carers representatives and advocacy organisations, broader representation that relate to unpaid care, not limited to people with disability, women's organisations, family, organisations, and community service providers,
- where possible, the submissions and evidence presented to the Senate Select Committee on Work and Care, in addition to the interim and final reports, including all relevant recommendations to the terms of reference of this inquiry, to reduce duplication.

List of recommendations

Recommendation 1

- 2.131** The Committee recommends that the meaning of carer under section 5 of the Carer Recognition Act 2010 (the Act) be modernised and contextualised as a ‘care relationship’ to be more inclusive of the diversity of caring roles and to make it easier for carers to self-identify.
- 2.132** The Committee considers that a person is in a ‘care relationship’ with another person if the first person (the carer) provides care for one or more of the following reasons:
- the other person has a disability
 - the other person is experiencing mental ill health
 - the other person has a medical condition, including a terminal or chronic illness
 - the other person is frail and/or aged
 - the other person is experiencing alcohol or other drug dependence.
- 2.133** The Committee considers the Act should specify that:
- a person can be in multiple care relationships
 - children and young people under the age of 25 who provide care are young carers.

Recommendation 2

- 2.135** The Committee recommends that the Australian Government works with the state and territories to harmonise the definition of carer across all carer recognition legislation, acknowledging respective Australian Government and state and territory care arrangements, and in data collection and reporting about the value of unpaid care.

Recommendation 3

- 2.136** The Committee recommends that the Australian Government conduct a review of all federal laws relating to carers, and make amendments where needed, to ensure consistency with the revised Act. The review should be conducted within one year of the revised Act being established.

Recommendation 4

2.140 The Committee recommends that, by December 2024, the Australian Government seek legal advice to determine how best to establish rights for carers. These rights should include:

- being acknowledged as partners in care
- being involved in planning and policy development
- being provided with information regarding the person they care for in order to provide care
- accessing flexible work arrangements.

Recommendation 5

2.143 The Committee recommends that the Statement for Australia's Carers is amended to include explicit recognition of:

- First Nations carers
- culturally and linguistically diverse carers
- lesbian, gay, bisexual, transgender, intersex, queer/questioning, asexual and other sexually or gender diverse (LGBTIQA+) carers
- young carers.

Recommendation 6

2.147 The Committee recommends that the definition of 'public service care agency' under section 4 of the Act, and any further reference to 'public service care agency' is omitted.

Recommendation 7

2.148 The Committee recommends that Part 3 of the Act be amended to require all public service agencies and associated providers to:

- take all practicable measures to ensure that it and its employees and agents have an awareness of, and take action to, reflect the principles of the Statement for Australia's Carers in developing, implementing, providing or evaluating care supports
- develop internal human resources policies, so far as they may significantly affect an employee's caring role, having due regard to the Statement for Australia's Carers
- consult carers, or bodies that represent carers, when developing or evaluating care supports.

2.149 In addition, all public service agencies should be required to, in each reporting period, prepare a report that is to be included in the agency's annual report, on:

- the agency's compliance with its obligations under the Act
- its associated providers' compliance with their obligations under the Act.

Recommendation 8

2.151 The Committee recommends that the Act be amended to include a provision that requires the Minister, every five years, to review the operation and effectiveness of the Act, the Statement for Australia's Carers, and the National Carer Strategy. A report on the Minister's review must be tabled in Parliament.

Recommendation 9

3.117 The Committee recommends that, in the next funding agreement, the Australian Government ensure there is a simple process for carers to gain support when it is most needed and strengthen the supports provided to carers via Carer Gateway by:

- improving the quality and consistency of advice and client service by Carer Gateway support providers through enhanced training and performance monitoring
- expanding the operating hours of the helpline, including providing access to 24-hour crisis support
- better integrating Carer Gateway with other key services that carers interact with, such as My Aged Care, the National Disability Insurance Scheme and Centrelink
- relaxing requirements for carer assessments to be conducted in order to access support and ensuring that, under normal circumstances, carers receive no more than one assessment each year
- allowing carers more flexibility to access supports that meet their needs such as practical and physical help at home
- providing transparency around what supports carers are eligible to access, and more agency to carers to decide how to spend their support budgets.

3.118 These reforms should be co-designed with carers and carers representatives.

Recommendation 10

3.121 The Committee recommends that the Australian Government work with the carer sector to identify capacity building for high-quality, respite care options that are appropriate for a diverse range of carers and the people they care for, including those that require complex care.

Recommendation 11

- 3.123 The Committee recommends that the Australian Government examine how to increase access to high-quality counselling and mental health support options for a diverse range of carers.**

Recommendation 12

- 3.125 The Committee recommends that the new National Carer Strategy prioritise carers' health and wellbeing, including through:**
- **the implementation of standardised assessment frameworks for carers in healthcare settings**
 - **training for practitioners and other workers who interact with carers in identifying and supporting carers**
 - **consistent reporting of carer suicides and suicidality.**

Recommendation 13

- 3.128 The Committee recommends that the new National Carer Strategy include targeted support for First Nations and culturally and linguistically diverse (CALD) carers, including:**
- **enhanced training and guidelines to encourage cultural safety and appropriate support for diverse communities for Carer Gateway service providers**
 - **fostering collaborative links between Carer Gateway service providers and First Nations and CALD community organisations to encourage culturally diverse carers to seek support and to help them navigate the support system**
 - **funding for First Nations and CALD community organisations to deliver Carer Gateway services**
 - **establishing diversity targets to encourage greater engagement by Carer Gateway service providers with diverse communities and more diversity in service users.**

Recommendation 14

- 3.130 The Committee recommends that, by December 2024, the suite of available training options offered by Carer Gateway be expanded to include manual handling, first aid, medication management and wound care, mental health first aid and suicide intervention. Options for in-person and online training should be provided.**

Recommendation 15

- 3.134 The Committee recommends that the Australian Government establish a process to handle complaints and address breaches of the Carer Recognition Act 2010.**

Recommendation 16

- 3.136 The Committee recommends that the new National Carer Strategy:**
- gives effect to the principles of the Act
 - includes actions to address the negative impacts that caring has on carers' financial security, their mental and physical wellbeing, and their social relationships
 - is co-designed and monitored by carers and their representatives
 - has robust action plans, outcomes measurement and reporting and evaluation frameworks.

Recommendation 17

- 3.138 The Committee recommends that the Australian Bureau of Statistics' (ABS) Survey of Disability and Carers (SDAC) be redesigned prior to the conduct of the 2025 survey to be representative of all carers as defined in a revised Act.**
- 3.139 The ABS should develop actions to ensure that First Nations carers, CALD carers and LGBTIQA+ carers are accurately represented in the SDAC.**

Recommendation 18

- 3.141 The Committee recommends that the Australian Government:**
- fund research and data mapping of carers
 - review the scope and design of the Carer Wellbeing Survey to ensure that it is representative of all carers, is longitudinal and collects sufficient evidence about carers' health, wellbeing, and suicide risk factors.

Recommendation 19

- 3.144 The Committee recommends that gender equality be included as a key priority of the new National Carer Strategy, to be addressed by actions that:**
- overcome harmful gender norms that devalue caring roles and disadvantage women
 - encourage more men to become carers and improve access to the types of supports men need

- address the financial disadvantages carers experience over their lifetime.

Recommendation 20

3.148 The Committee recommends that the Australian Public Service Commission (APSC) review Australian Public Service employment principles and workplace policies and practices for compliance with a revised Act and provide best practice guidance and examples. The APSC should commence the review one year after a revised Act has been established.

Recommendation 21

3.150 The Committee recommends that the Australian Government introduce an income tax credit for carers returning to the paid workforce and consider other options to incentivise and recognise the impact of caring through the income tax and superannuation systems.

Recommendation 22

3.152 The Committee recommends that an ongoing community education campaign form part of the new National Carer Strategy. The campaign should:

- promote recognition and awareness of carers' rights and the diversity of carers
- address harmful gender stereotypes and reduce stigma associated with caring roles
- drive positive workplace cultures for carers
- aim to inform the public, and the services and industries that carers rely on, about carers' needs and how to better support them
- include targeted information and strategies appropriate for First Nations and CALD communities.



Abbreviations

ABS	Australian Bureau of Statistics
AHHA	Australian Healthcare and Hospitals Association
AHRC	Australian Human Rights Commission
AIHW	Australian Institute of Health and Wellbeing
APS	Australian Public Service
APSC	Australian Public Service Commission
CALD	culturally and linguistically diverse
CARITO	Carers' Income Tax Offset
DSS	Department of Social Services
DVA	Department of Veterans' Affairs
ECCV	Ethnic Communities' Council of Victoria
FaHCSIA	Department of Families, Housing, Community Services and Indigenous Affairs
KPI	Key Performance Indicator
LEA	Lived Experience Australia Ltd
LGBT	lesbian, gay, bisexual, transgender
LGBTIQA+	lesbian, gay, bisexual, transgender, intersex, queer/questioning, asexual and other sexually or gender diverse identities
NATSIWA	National Aboriginal Torres Strait Islander Women's Alliance
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDISQSC	NDIS Quality and Safeguards Commission
new strategy	new National Carer Strategy
OPAN	Older Person's Advocacy Network
QAMH	Queensland Alliance for Mental Health
SDAC	Survey of Disability, Ageing and Carers
Select Committee	Senate Select Committee on Work and Care
the 2011 strategy	National Carer Strategy 2011
the Act	<i>Carer Recognition Act 2010</i>
the Statement	The Statement for Australia's Carers
UK	United Kingdom



1. Introduction

Content warning

- 1.1 This report, and the evidence it is based on, includes material that can be confronting and disturbing. Sometimes words can cause sadness, distress or can trigger traumatic memories for people. For some people, these responses can be overwhelming. If you need to talk to someone, the following services are available:
- Mental Health Carer Helpline - 1300 554 660
 - Lifeline - 131 114
 - Beyondblue - 1300 224 636.

Background

- 1.2 At least one in every ten Australians, or around 2.65 million people in 2018, provides unpaid or informal care for someone with a disability, medical condition, mental illness or who is frail because of their age. Around 861,000 Australians in 2018 were primary carers, which means they provided the most informal assistance to another person with core activities such as mobility, self-care and communication.¹
- 1.3 In Australia, informal, unpaid carers are treated differently from formal, paid carers, even though the support they provide can be similarly ongoing and can involve the same activities and intensity of care. Often, unpaid carers take on caring roles because of a lack of available, accessible, and affordable formal care, and do so with limited access to supports including respite.² This inquiry focused on the needs of unpaid carers, and references to ‘carers’ in this report should be taken to mean informal, unpaid carers unless otherwise specified.
- 1.4 Australian carers provide 2.2 billion hours of unpaid care each year. If these hours were provided as paid formal care, this care would have a value of \$77.9 billion per year. The demand for unpaid care is expected to grow by 23 per cent between 2020 and 2030 as Australia’s population changes.³ However, the growth in the number of carers taking on a caring role is not expected to keep pace (16 per cent),

¹ Australian Bureau of Statistics (ABS), *Disability, Ageing and Carers, Australia: Summary of Findings*, 2018, www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release, viewed 3 August 2023.

² Carers Australia, *Submission 111*, page 29.

³ Department of Social Services (DSS), *Submission 70*, page 6.

leading to an increasing 'carer gap' in the future.⁴ This has implications for the sustainability of care provision.⁵

Diversity of carers

- 1.5 Carers have diverse stories about the impact caring has on them and the people they care for. A carer's experience of caring is shaped by their broader social, economic and cultural context, and their care relationships, including the needs and expectations of the person or people they care for. A carer's experience of caring is also shaped by the support they receive and their interactions with service providers.
- 1.6 Carers can be grandparents, parents, partners, children, siblings, kin, foster carers, friends and neighbours. Most provide care out of love or a sense of duty or believe they can provide better care for the person needing assistance than anyone else can. Some provide care for a single person, while others provide care to several people. Some have other people who share the caring load, while others provide care on their own. Some provide short-term care, while some will look after the needs of others for many years, such as when a person requires care until the end of their life.⁶
- 1.7 Far more women than men provide unpaid care. In 2018, 71.8 per cent of primary carers were women. Furthermore, women are more likely than men to report a lack of choice about becoming a carer.⁷ Women's caring roles contribute to about one third of the gender pay gap and can have lifelong impacts on their financial security and risk of poverty and homelessness.⁸ Women retire with 23.1 per cent less superannuation than men of the same age.⁹
- 1.8 In 2018, there were more than 1.2 million men who are carers.¹⁰ Men are more likely to take on a caring role later in life, with men over 75 years being the only age group where there are more male carers than women.¹¹
- 1.9 More than one third (37.4 per cent) of primary carers have disability. In 2018, this was twice the rate of non-carers (15.3 per cent).¹²

⁴ Carers Australia, *Submission 111*, page 12.

⁵ Carers Australia, *Submission 111*, page 12; Kiind, *Submission 51*, page 5; Australian Federation of Disability Organisations, *Submission 137*, pages 7 and 11.

⁶ Carers Australia, *Submission 111*, pages 5-6.

⁷ Carers Australia, *Submission 111*, page 7.

⁸ Chief Executive Women, *Submission 134*, page 2. See also: Kiind, *Submission 51*, page 5; GenWest, *Submission 65*, page 5.

⁹ Chief Executive Women, *Submission 134*, page 2.

¹⁰ Carers Australia, *Submission 111*, page 7.

¹¹ ABS, *Disability, Ageing and Carers, Australia: Summary of Findings*, 2018, www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release, viewed 3 August 2023.

¹² ABS, *Disability, Ageing and Carers, Australia: Summary of Findings*, 2018, www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release, viewed 3 August 2023.

- 1.10 Carers can be any age. In 2018, there were 235,000 young carers aged 12 to 25 years and almost 230,000 carers aged over 65 years.¹³
- 1.11 Many people who provide care, including young people, First Nations carers and carers from culturally and linguistically diverse (CALD) communities, may not recognise the term 'carer' or identify themselves as carers. This can be a barrier to seeking support.¹⁴ The prevalence of 'hidden carers' means that current data collection about carers may underestimate the number of carers, which can impact policy and funding decisions.¹⁵ In 2021, of the people who required assistance with core activities, more than 355,000 (24.5 per cent) spoke a language other than English at home.¹⁶
- 1.12 Nearly a third (31 per cent) of all carers live in regional, rural and remote areas and have more difficulty accessing services for themselves or those they care for than Australians who live in major cities.¹⁷
- 1.13 There is limited data on carers who identify as lesbian, gay, bisexual, transgender, intersex, queer/questioning, asexual and other sexually or gender diverse identities (LGBTIQ+). However, there is evidence to suggest LGBTIQ+ carers have higher levels of psychological distress and lower health satisfaction, and experience additional challenges to other carers.¹⁸

Box 1.1 Carer's experiences of caring

How do I encapsulate all of that fear, worry, anger, loss, disappointment, regret, sadness, confusion, guilt, loneliness, prejudice and judgement? It is not really possible. It's really hard for others to imagine what it's like to fear for your loved ones ... there is also love, joy, pride, inspiration, growth, kindness, grace and humour. All of these things are felt more deeply because of the struggles to get to them.¹⁹

I want to emphasise the challenge of being an unrecognised carer. With the high burden of care going unacknowledged every day, adding having to negotiate with the medical profession, education system, Centrelink and eventually NDIS, is incredibly demanding. It has left me with accumulated stress and exhaustion. On top of this, neuro-developmental disorders are so poorly understood, even in the higher education institutions that are training the future professionals that are meant to support our kids and us. When this is matched with the unabashed stigma, it is incredibly isolating. I

¹³ ABS, *Disability, Ageing and Carers, Australia: Summary of Findings*, 2018, www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release, viewed 3 August 2023.

¹⁴ Carers ACT, *Submission 58*, page 3; Ethnic Communities' Council of Victoria, *Submission 99*, page 3; Carers Australia, *Submission 111*, page 7.

¹⁵ Carers Australia, *Submission 111*, page 7; Australian Healthcare and Hospitals Association, *Submission 8*, page 14.

¹⁶ Carers Australia, *Submission 111*, page 7.

¹⁷ Carers Australia, *Submission 111*, page 6.

¹⁸ Carers Australia, *Submission 111*, page 8.

¹⁹ Ms Alyssa Weirman, *Committee Hansard*, 4 October 2023, pages 12-13.

have been blamed and I have felt so alone. Even when I am lucky to find providers and supports that understand neuro-divergence, it has still been in isolation.²⁰

[Carers] contribute exorbitant hours, and are not rewarded with superannuation; sick leave; holiday pay; and long service leave is out of the question because it is a job for life ... but they do it because they care for their loved ones.²¹

It's essential that we're not invisible and that we have a voice. It's important that we support the most vulnerable in our society, and we ourselves are one of the most vulnerable cohorts as well. We're financially disadvantaged and socially isolated, and we have poor health outcomes and the risk of relationship breakdown. Too often a diagnosis can be a one-way trip to poverty, health issues and family breakdown. I really feel that we should be empowering carers, not taking them for granted and eroding them to the point of physical, mental and financial exhaustion. I'd like to see us do more than recognise carers. We need to help them.²²

My caring role has taught me a lot, like resilience and confidence, and I think a lot of courage to manage all the hardships that have come along with it, but it's definitely been a big challenge. It has impacted my schooling probably the most. I've had lots of absences throughout my time in primary school and high school, and I think having everything to manage with a caring role and dealing with those family crises really has a big impact on your ability to concentrate and also contribute in your education.²³

Consequences of caring

- 1.14 Caring roles can be meaningful and rewarding, but also demanding, exhausting, frustrating, and isolating.²⁴ While carers do not want the people they care for to think of themselves as burdens, caring comes at a cost to the carer and affects all aspects of their life. This includes their employment, superannuation and overall financial position, their physical and emotional wellbeing, and their social relationships.
- 1.15 It can be difficult for carers to find a job or maintain their employment because of the demands of their caring role. In 2018, only 28.6 per cent of primary carers providing more than 40 hours of care per week were employed. By contrast, 52.8 per cent of carers providing less than 20 hours of care per week were employed.²⁵

²⁰ Name Withheld, *Submission 143*, pages 3-4.

²¹ Name Withheld, *Submission 47*, page 1.

²² Belinda, *Committee Hansard*, 4 October 2023, page 15.

²³ Ms Jacqueline de Mamiel, Young Carer Participant, Little Dreamers Australia, *Committee Hansard*, 4 October 2023, page 2.

²⁴ MS Australia, *Submission 91*, page 3; Name Withheld, *Submission 47*, page 1; Mr Colin Allchurch, *Submission 30*, page 1; Autism Awareness Australia, *Submission 44*, page 2; Carers Australia, *Submission 111*, page 9; Name Withheld, *Submission 6*, page 4; Mr Kyle Hayes, *Submission 100*, page 2.

²⁵ ABS, *Disability, Ageing and Carers, Australia: Summary of Findings*, 2018, www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release, viewed 3 August 2023.

- 1.16 Primary carers are twice more likely to live in households that have low income. In 2018, the rate of primary carers living in a household with low income was 50.2 per cent, compared to 25.8 per cent of non-carers.²⁶
- 1.17 Research commissioned by Carers Australia estimated that a primary carer's superannuation balance is reduced by \$17,700 for every year they provide care.²⁷ The modelling found that a quarter of primary carers will have their lifetime earnings reduced by more than \$497,500 and a real reduction in their superannuation balance at age 67 of more than \$216,000.²⁸
- 1.18 Carers are more than twice as likely as other Australians to have low wellbeing, high levels of psychological distress and an increased risk of suicidality.²⁹ In 2022, carers were twice more likely to report low wellbeing (55.2 per cent) compared to other Australians (25.4 per cent).³⁰
- 1.19 In 2022, the Carer Wellbeing Survey³¹ found that nearly half (48 per cent) of carers surveyed reported experiencing moderate to high levels of psychological distress and 39.4 per cent said they were often or always lonely.³² Only 17.1 per cent of carers reported having very good or excellent health, compared with 47.9 per cent of other Australians.³³
- 1.20 Most carers receive little support from family and friends. In 2022, 28 per cent of carers had no access to support from friends and family if, for example, they fell ill or needed a break, while more than half (52 per cent) said they could organise help, but it would be difficult.³⁴

Carer Recognition Act 2010

- 1.21 In 2009, the House of Representatives Standing Committee on Family, Community, Housing and Youth reported on its inquiry into improving support for carers. It acknowledged the 'weight of evidence urging an improvement in carer recognition and carer rights through specific carer recognition legislation and associated policy.'³⁵ The Committee made 50 recommendations aimed at improving outcomes for carers, including that the Australian Government develop, with the states and territories, a nationally consistent carer recognition framework, comprising of:

²⁶ ABS, *Disability, Ageing and Carers, Australia: Summary of Findings*, 2018, www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release, viewed 3 August 2023.

²⁷ Carers Victoria, *Submission 109*, page 1; Carers ACT, *Submission 58*, page 8.

²⁸ Carers Australia, *Submission 111*, page 15.

²⁹ Suicide Prevention Australia, *Submission 22*, page 2.

³⁰ DSS, *Submission 70*, page 7.

³¹ The Carer Wellbeing Survey is a collaboration between Carers Australia and the University of Canberra and is funded by DSS.

³² Carers Australia, *Submission 111*, page 11.

³³ Carers Australia, *Submission 111*, page 11.

³⁴ Carers Australia, *Submission 111*, page 11.

³⁵ House of Representatives Standing Committee on Family, Community, Housing and Youth, *Who Cares...?: Report on the inquiry into Better Support for Carers*, May 2009, page 64.

- national carer recognition legislation, which complements state and territory carer legislation
 - a national carer strategy that builds on and complements state and territory carer policies.³⁶
- 1.22 The Australian Government agreed with many of the Committee's recommendations and the Carer Recognition Bill 2010 (the Bill) was introduced to Parliament in September 2010.
- 1.23 In her second reading speech, then Parliamentary Secretary for Community Services, the Hon. Julie Collins MP, said that the Bill 'formally acknowledges the vital contribution that carers make to Australian society and complements carer recognition legislation already in place in some states and territories.'³⁷ The Hon. Julie Collins MP added that implementation of the Bill will 'drive increased awareness and understanding of the role and contribution of carers as well as a much-needed cultural and attitudinal shift so that carers' interests are taken into account by public service agencies and service providers.'³⁸
- 1.24 Other contributions to the debate on the Bill raised concerns that the recognition for carers provided by the Bill was purely symbolic.³⁹ For example, Senator the Hon. Mitch Fifield said:
- Yes, we are all in heated agreement that carers deserve recognition, but let us not pretend that this piece of legislation conveys or confers any new rights on carers despite what the act says at its opening, because later in the act it makes it clear that it does no such thing.⁴⁰
- 1.25 The Bill passed both Houses on 28 October 2010 and the *Carer Recognition Act 2010* (the Act) commenced on 18 November 2010.
- 1.26 The object of the Act is to 'increase recognition and awareness of carers and to acknowledge the valuable contribution they make to society'.⁴¹

Definition of carer

- 1.27 The Act defines a 'carer' as an individual who provides personal care, support and assistance to another individual because the other individual either:
- has a disability; or

³⁶ House of Representatives Standing Committee on Family, Community, Housing and Youth, *Who Cares...?: Report on the inquiry into Better Support for Carers*, May 2009, page 65.

³⁷ The Hon. Julie Collins MP, Parliamentary Secretary for Community Services, *House of Representatives Hansard*, 29 September 2010, page 114.

³⁸ The Hon. Julie Collins MP, Parliamentary Secretary for Community Services, *House of Representatives Hansard*, 29 September 2010, page 114.

³⁹ The Hon. Mr Kevin Andrews MP, *House of Representatives Hansard*, 21 October 2010, page 1192; Senator the Hon Mitch Fifield, *House of Representatives Hansard*, 28 October 2010, page 1043.

⁴⁰ Senator the Hon Mitch Fifield, *House of Representatives Hansard*, 28 October 2010, page 1043.

⁴¹ *Carer Recognition Act 2010*, Part 1.

- has a medical condition, including terminal or chronic illness; or
 - has a mental illness; or
 - is frail and aged.⁴²
- 1.28 The Act excludes certain individuals from the definition of ‘carer,’ including individuals providing care, support or assistance:
- under a contract of service or a contract for the provision of a service; or
 - in the course of doing voluntary work for a charitable welfare or community organisation; or
 - as part of the requirements of a course or education or training.⁴³
- 1.29 The Act includes the clarification that an individual is not a carer merely because they:
- are the spouse, de facto partner, parent, child or other relative of an individual, or is the guardian of an individual; or
 - live with an individual who requires care.⁴⁴

Statement for Australia’s Carers

- 1.30 Part 2, Schedule 1 of the Act sets out a ‘Statement for Australia’s Carers’ (the Statement):
- 1 All carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality.
 - 2 Children and young people who are carers should have the same rights as all children and young people and should be supported to reach their full potential.
 - 3 The valuable social and economic contribution that carers make to society should be recognised and supported.
 - 4 Carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life.
 - 5 Carers should be acknowledged as individuals with their own needs within and beyond the caring role.
 - 6 The relationship between carers and the persons for whom they care should be recognised and respected.

⁴² *Carer Recognition Act 2010*, subsection 5(1).

⁴³ *Carer Recognition Act 2010*, subsection 5(2).

⁴⁴ *Carer Recognition Act 2010*, subsection 5(3).

- 7 Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.
- 8 Carers should be treated with dignity and respect.
- 9 Carers should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education.
- 10 Support for carers should be timely, responsive, appropriate and accessible.⁴⁵

Obligations

1.31 The Act:

- Places obligations on public service agencies and associated providers to ensure employees and agents are aware of and understand the Statement and ensure internal human resources policies have regard to the Statement (Part 3, section 7).
- Obliges each 'public service care agency'⁴⁶ to:
 - Take all practicable measures to ensure that it, and its employees and agents, take action to reflect the principles of the Statement in developing, implementing, providing or evaluating care supports.
 - Consult carers, or bodies that represent carers, when developing or evaluating care supports.
 - Prepare a report on its compliance with section 7 of the Act in each reporting period. The report must be included in the agency's annual report for the reporting period (Part 3, section 8).
- Obliges 'associated providers', that is, individuals and organisations who have a contract, subcontract or funding arrangement with public service care agencies, to take all practicable measures to ensure that officers, employees and agents:
 - have an awareness and understanding of the Statement
 - take action to reflect the principles of the Statement while developing, implementing, providing or evaluating care supports (Part 3, section 9).

Limitations

1.32 The Act (Part 4, section 10) expressly states limits on the enforceability of the obligations set out in Part 3:

- The Act does not create rights or duties that are legally enforceable in judicial or other proceedings.

⁴⁵ *Carer Recognition Act 2010*, Part 2, Schedule 1.

⁴⁶ *Public service care agencies* are defined by Act as those agencies responsible for the development, implementation, provision or evaluation of care supports. It is up to public service agencies to determine whether they are a public service care agency for the purpose of the Act.

- A failure to comply with the Act does not affect the validity of any decision and is not a ground for the review or challenge of any decision.
 - If a public service agency, or an associated provider, is required by another law of the Commonwealth, or by a law of a State or Territory, to consider particular matters, or to comply with particular requirements, in the exercise of its functions or powers, nothing in the Act is to be taken to require the agency, or the associated provider, to act inconsistently with that law.
- 1.33 Furthermore, the Act is not intended to apply to the exclusion of any law of a State or Territory that establishes a Carers Charter (however described), or that otherwise provides for the recognition of carers (Part 4, section 11).
- 1.34 Prior to the Bill passing Parliament, the Senate Standing Committee for the Scrutiny of Bills drew attention to the apparent contradiction of imposing obligations while prohibiting legal enforceability of those obligations:
- Although the legislation imposes ‘obligations’ on public service agencies and associated care providers (sections 7-9), the Act does not create legally enforceable rights or duties. Subsection 10(2) states that failure to comply with the Act does not affect the validity of any decision and is not a ground on which such a decision may be challenged.
- This provision is likely to remove any realistic prospect of applying for the main types of remedies available in judicial review proceedings. Nonetheless, this is consistent with the purposes of the legislation and the scheme is premised on the lack of enforceable legal rights or obligations.⁴⁷
- 1.35 Nevertheless, the Senate Standing Committee for the Scrutiny of Bills concluded that, ‘in the circumstances, the Committee makes no further comment on this provision.’⁴⁸

Policy context

- 1.36 The Department of Social Services (DSS) is responsible for Australian Government carer payments, policy and legislation. DSS and Services Australia administer the Carer Payment and the Carer Allowance.
- Carer Payment is an income support payment to assist carers who are unable to support themselves through paid employment due to the care they provide:
 - Carers can cease providing care for up to 25 hours a week to participate in employment while remaining qualified for Carer Payment.
 - Carers have 63 ‘respite’ days each calendar year where they may take a break from caring without impacting their Carer Payment.

⁴⁷ Senate Standing Committee for the Scrutiny of Bills, *Alert Digest*, No. 5 of 2010, 12 May 2010, page 15.

⁴⁸ Senate Standing Committee for the Scrutiny of Bills, *Alert Digest*, No. 5 of 2010, 12 May 2010, page 15.

- Carer Allowance is a supplementary payment for carers who provide a level of daily care and attention for people who need significant additional care.⁴⁹
- 1.37 In December 2022, 628,805 carers were receiving Carer Allowance and 303,520 were receiving Carer Payment. Of these, 277,195 were receiving both payments.⁵⁰
- 1.38 Carers Australia delivers the Young Carer Bursary Program on behalf of the Australian Government, which aims to assist young carers financially to reduce the need to undertake part-time work whilst studying and managing caring responsibilities. In April 2023, the program increased the number of bursaries available to around 1,600 each year and raised the annual bursary amount from \$3,000 to \$3,768.⁵¹
- 1.39 The states and territories have their own carer policies and carer recognition legislation, which vary considerably.⁵²

National Carer Strategy

- 1.40 In 2011, a ten-year National Carer Strategy (2011 Strategy) was launched to give effect to the Act and to complement the National Disability Strategy 2010-2020.⁵³ The 2011 Strategy represented the Australian Government's 'recognition of the invaluable contribution of carers to the Australian community.'⁵⁴ The 2011 Strategy outlined how this contribution can be valued, supported and shared through six priority areas for action:
- recognition and respect
 - information and access
 - economic security
 - services for carers
 - education and training
 - health and wellbeing.⁵⁵
- 1.41 The states and territories committed to identifying strategies and activities that complemented the 2011 Strategy.⁵⁶
- 1.42 The 2011 Strategy was replaced in 2015 by the Integrated Plan for Carer Support Services. DSS is currently progressing work to inform a new national carer strategy.⁵⁷

⁴⁹ DSS, *Submission 70*, pages 7-8.

⁵⁰ DSS, *Submission 70*, page 7.

⁵¹ DSS, *Submission 70*, page 9.

⁵² Carers Australia, *Submission 111*, pages 18-21.

⁵³ Australia's Disability Strategy was updated in 2021.

⁵⁴ FaHCSIA, *National Carer Strategy*, 2011, page 7.

⁵⁵ FaHCSIA, *National Carer Strategy*, 2011, page 7.

⁵⁶ FaHCSIA, *National Carer Strategy*, 2011, page 8.

⁵⁷ DSS, *Submission 70*, page 10.

Carer Gateway

- 1.43 The Integrated Carer Support Service model is known as Carer Gateway.⁵⁸ Carer Gateway provides a single point of contact for a range of free in-person, online and phone-based support and services to unpaid carers. Each region in Australia has a Carer Gateway service provider who will either provide services to support carers directly or will organise support through another organisation.⁵⁹
- 1.44 Carer Gateway is currently being evaluated for its appropriateness, effectiveness and efficiency, and the evaluation report is expected in late 2023.⁶⁰

National Disability Insurance Scheme

- 1.45 The National Disability Insurance Scheme (NDIS) provides funding to support eligible people with disability. The National Disability Insurance Agency can fund short term accommodation, including respite, when a participant needs to live out of home for a short break. However, this is subject to a 'reasonable and necessary' test.⁶¹
- 1.46 The *National Disability Insurance Scheme Act 2013* was amended in 2022 to include stronger recognition of the role of carers and the relationship they have with the people with disability who they care for.⁶²
- 1.47 The design, operations and sustainability of the NDIS have been reviewed and a final report was released in December 2023. The report makes 26 recommendations with 139 corresponding actions.⁶³

Recent reviews

Senate Select Committee on Work and Care

- 1.48 The Senate Select Committee on Work and Care (Select Committee) inquired into the impact that combining work and care responsibilities has on the wellbeing of workers, carers, and those that they care for. While the inquiry examined aspects of care, much of its work involved matters beyond the scope of this inquiry, including the role, remuneration, and working conditions of paid carers⁶⁴, and issues relating to

⁵⁸ DSS, *Disability and Carers*, 'Integrated Carer Support Service', www.dss.gov.au/disability-and-carers-carers/integrated-carer-support-service-model, viewed 12 September 2023.

⁵⁹ DSS, *Carer Gateway*, 'Services and support', www.carergateway.gov.au/services-and-support, viewed 14 September 2023.

⁶⁰ DSS, *Submission 70*, page 9.

⁶¹ DSS, *Submission 70*, page 10.

⁶² DSS, *Submission 70*, page 10.

⁶³ Department of the Prime Minister and Cabinet, *Working together to deliver the NDIS: Independent Review into the National Disability Insurance Scheme Final Report*, December 2023.

⁶⁴ Senate Select Committee on Work and Care, *Interim Report*, October 2022, Chapter 3.

the care of children.⁶⁵ The Select Committee tabled an interim report in October 2022⁶⁶ and a final report in March 2023.⁶⁷

- 1.49 The key recommendation of the Select Committee was that the Australian Government should take a comprehensive and integrated approach to addressing the challenges of work and care across a range of systems, including workplace relations, early childhood education and care, paid leave, disability and aged care, and financial supports for carers. The Select Committee said:

This reform package should ensure that Australians have a right to care, alongside their right to work, and our systems and laws should provide unequivocal support for this important role through a new work and care social contract fit for the 21st century.⁶⁸

- 1.50 The Select Committee made several other recommendations relevant to this inquiry, including:

- strengthening carer leave arrangements in the *Fair Work Act 2009*
- reviewing the level of Carers Payment and Carers Allowance, in acknowledgement of the significant social and economic contribution that carers make
- abolishing the Child Care Subsidy activity test and consider abolishing all activity tests for all income support payments, noting their impact on workforce participation, particularly for women
- the inclusion of new questions in the Census and/or new regular surveys to determine the extent, nature and effects of the interaction of work and care responsibilities across Australia
- the inclusion of a statement in the employment white paper that gives an estimate of the annual financial contribution of unpaid care to the national economy and consider including a similar statement in the Budget papers⁶⁹
- developing a mental health support program tailored to carers aged 25 years and under

⁶⁵ Senate Select Committee on Work and Care, *Interim Report*, October 2022, pages 54-61.

⁶⁶ Senate Select Committee on Work and Care, *Interim Report*, October 2022.

⁶⁷ Senate Select Committee on Work and Care, *Final Report*, March 2023.

⁶⁸ Senate Select Committee on Work and Care, *Final Report*, March 2023, page 170.

⁶⁹ The 2023 employment white paper includes information about the contribution of caring responsibilities and career interruptions to the gender pay gap and estimates the total replacement value of 'unpaid care work' in 2020-21 was \$165.1 billion. While the term 'unpaid care work' is not defined in the white paper, the data source is the ABS Time Use Survey, which includes child care activities. The Treasury, *Working Future: The Australian Government's Employment White Paper on Jobs and Opportunities*, September 2023, page 65. See also: ABS, *How Australians Use Their Time*, 2020-21, www.abs.gov.au/statistics/people/people-and-communities/how-australians-use-their-time/2020-21, viewed 16 November 2023.

- developing and implementing programs and initiatives for carers from migrant and CALD backgrounds to improve access to carer support services and family support.⁷⁰

1.51 The Australian Government is currently considering the Select Committee's recommendations.

Royal Commission into Aged Care Quality and Safety

1.52 The Royal Commission into Aged Care Quality and Safety reported in March 2021 and made 148 recommendations, including establishing a new Aged Care Act. The new Act would include supports, including respite for unpaid carers of people receiving aged care, in its definition of aged care.⁷¹ The Royal Commission also recommended that:

- the Australian Government fund the engagement of a workforce of personal advisers to older people, their families and carers, called 'care finders' to assist older people seeking aged care services with information about the aged care system and case management services
- there be a single, comprehensive assessment process for older people needing aged care that includes an assessment of unpaid carers' needs
- unpaid carers of older people have access to up to 63 days of high-quality respite per calendar year
- My Aged Care and Carer Gateway should be linked to provide a single system for accessing respite care and information, training and other support services
- a community-based Carers' Hub network should be established.⁷²

1.53 The Australian Government responded to the Royal Commission's report in May 2021, and accepted many of its recommendations.⁷³

Productivity Commission Carer Leave inquiry

1.54 In February 2022, the Productivity Commission announced it would examine the economic and social impacts of allowing informal carers to take extended unpaid leave from their work to care for older people who are frail and living at home. This inquiry was established in response to one of the recommendations of the Royal Commission into Aged Care Quality and Safety.

1.55 The final report was released in September 2023. The Productivity Commission recommended a model that provides between one and 12 months of unpaid carers'

⁷⁰ Senate Select Committee on Work and Care, *Final Report*, March 2023, pages 104, 171, 178-179, 184-185, 195.

⁷¹ Royal Commission into Aged Care Quality and Safety, *Final Report*, Volume 1, page 205.

⁷² Royal Commission into Aged Care Quality and Safety, *Final Report*, Volume 1, pages 228, 231, 237-239

⁷³ Department of Health and Aged Care, *Australian Government response to the final report of the Royal Commission into Aged Care Quality and Safety*, May 2021.

leave. This leave would be available to all employees who have worked for at least 12 months for their current employer, including regular casuals.⁷⁴

- 1.56 The Australian Government has not yet responded to the Productivity Commission's report.

National Strategy for the Care and Support Economy

- 1.57 In May 2023, the draft National Care and Support Economy Strategy was released for consultation. The draft strategy focuses on paid care and support services in aged care, disability care and support, veteran's care and early childhood education and care. The strategy's vision is for a sustainable and productive care and support economy that delivers quality care and support with decent jobs.⁷⁵

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

- 1.58 The report of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability was tabled in September 2023. The Royal Commission drew on the experiences of people with disability, their families and carers in making 222 recommendations, which seek to strengthen the rights of Australians with disability.
- 1.59 The Royal Commission recommended establishing:
- a Disability Rights Act, which would require Australian Government entities to consult with people with disability, and their families and carers, in developing and evaluating policies, laws, programs and new initiatives that affect people with disability and their carers
 - a Minister for Disability Inclusion to be responsible for a disability inclusion strategy, and policies and programs that are currently the responsibility of the Minister for Social Services
 - a Department of Disability Equality and Inclusion, responsible for national disability and carers policies and programs that are currently the responsibility of DSS
 - a National Disability Commission that partners with people with disability, and their families and carers, to develop advice and key reports.⁷⁶

⁷⁴ Productivity Commission, *A case for an extended unpaid carer leave entitlement? Inquiry report*, September 2023, pages 1-2.

⁷⁵ DSS, *Submission 70*, page 11.

⁷⁶ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Final Report, Executive Summary*, September 2023, pages 177, 197-198, 211-213.

- 1.60 Other recommendations aim to improve disability rights and the right of families and carers to be consulted, informed and involved in making decisions in areas of state and territory responsibility, such as schools.⁷⁷
- 1.61 The Australian Government has not yet responded to the Royal Commission's recommendations.

Scope and conduct of the inquiry

- 1.62 The Committee adopted an inquiry into the recognition of unpaid carers on 13 June 2023, following a referral from the Minister for Social Services, the Hon. Amanda Rishworth MP.
- 1.63 The terms of reference for the inquiry are provided in the front pages of this report and are available on the inquiry webpage at www.aph.gov.au/UnpaidCarers.
- 1.64 The adequacy of payments for carers is out of scope for this inquiry. The Australian Government is currently considering the recommendations of the Senate Select Committee on Work and Care relating to this issue.
- 1.65 The Committee called for written submissions, ideally of no more than ten pages, from individuals and organisations relating to any or all of the inquiry terms of reference by Friday, 11 August 2023.
- 1.66 The Committee received 143 submissions and five exhibits and held eight public hearings. The list of submissions is provided in Appendix A. The list of public hearings and witnesses is provided in Appendix B. The list of exhibits is provided at Appendix C.
- 1.67 This inquiry has been strongly informed by the lived experiences of carers and the Committee is particularly grateful for the courage of those who came forward to tell their stories. The Committee wishes to thank all the individuals and organisations who contributed their time, experience, and expertise in making submissions and appearing at public hearings.

Report structure

- 1.68 Recognition is the first fundamental need of carers and is the foundation on which the provision of better supports for carers can be built. Chapter two considers what reforms are needed in the Act and its associated Statement to better recognise and support carers and the diversity of caring roles.
- 1.69 Chapter three considers developments in the policy landscape since the Act was established and what reforms are needed to better recognise and support carers.

⁷⁷ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Final Report, Executive Summary*, September 2023, pages 240-243.

The chapter examines the 2011 strategy, current supports provided to carers through Carer Gateway, and evidence about what a new national carer strategy should include.



2. The Carer Recognition Act

- 2.1 Carers report they are significantly under-recognised and excluded in workplaces, communities, by service providers and in the health sector.¹ This has not improved since the *Carer Recognition Act 2010* (the Act) was established. Carers describe feeling like a burden, invisible, frustrated, fatigued, isolated, overlooked, hopeless and undervalued.²
- 2.2 This chapter considers the effectiveness and limitations of the Act and its associated Statement for Australia's Carers (the Statement). It examines:
- the meaning of carer
 - the Statement
 - international recognition of carers
 - obligations on the public service and associated providers.

Box 2.1 A carer's experience of caring

Carers often live in the shadows. They can be seen in hushed meetings with schools, doctors and allied health providers. They can be heard on phone calls trying to navigate their way through the intractable medical, educational and government systems. Those who can work won't generally discuss their caring role at work. It may be perceived as a weakness ... The real caring work is done at home, day in day out, 24/7/365. We don't clock off. Our work is largely hidden, unrecognised, not discussed. It's cumulative work, made up of many small things, large things, unpredictable explosive things, all with a rich emotional overlay – over many years, leading to bone weary fatigue ... We just want our work to be recognised, respected and supported. It's the selfless glue that helps hold our families and communities together.³

¹ Carers Australia, *Submission 111.1*, page 5; Older Person's Advocacy Network (OPAN), *Submission 39*, page 7; Dementia Australia, *Submission 35*, pages 4-5; Carers NSW, *Submission 94*, page 7; HelpingMinds, *Submission 55*, page 7; Name Withheld, *Submission 18*, page 3.

² Women, Work and Policy Research Group, and ARC Centre of Excellence in Population Ageing Research, USYD, *Submission 81*, page 2; Alex, *Committee Hansard*, 24 August 2023, page 11; Lived Experience Australia Ltd (LEA), *Submission 56*, page 7; Name Withheld, *Submission 74*, page 3; Name Withheld, *Submission 6*, page 3; Kathleen Moore, *Submission 112*, page 2; Carers WA, *Submission 113*, page 6; Carers Tasmania, *Submission 57*, page 5; Name Withheld, *Submission 27*, page 2; Carers Queensland, *Submission 59*, page 4.

³ Name Withheld, *Submission 6*, pages 3-4.

An outdated and aspirational Act

- 2.3 While the Act was an important step forward at the time,⁴ it has been widely criticised because it lacks enforceability, has a narrow focus and contains weak language. Thirteen years on, the Committee heard that:
- the Act has not had a significant impact on the recognition of carers because it does not create any rights or duties
 - its obligations on public service agencies are limited, piecemeal and unenforceable (some calling it a 'box ticking' exercise)⁵
 - there are no consequences for failing to fulfill these obligations
 - there are no appeals or complaints mechanisms
 - there are not enough measures in place to support carer recognition initiatives.⁶
- 2.4 The Act is limited in its capacity to affect change because, as the Department of Social Services (DSS) noted, it only aims to create a sense of obligation on the part of public service agencies to observe its principles.⁷ This limited objective is concerning because the consequences of a lack of recognition and awareness of carers are far-reaching. Kiind said:
- If the current Act were effective in driving the changes it sought, then our organisation would not be seeing the daily and long-term impacts of the low recognition of unpaid carers and the consequences for families, including high levels of parental stress, burnout, low workforce participation, relationship breakdown, and financial hardship.⁸
- 2.5 Every state and territory in Australia have enacted their own carer recognition legislation. However, there are inconsistencies in language and obligations and varying definitions of the term carer that can create barriers for carers to self-identity and access appropriate supports in their jurisdiction.⁹
- 2.6 For instance, the Australian Capital Territory (ACT), Victorian, and Tasmanian acts explicitly recognise informal kinship carers.¹⁰ The Act and the other state and territory

⁴ Women, Work and Policy Research Group, and ARC Centre of Excellence in Population Ageing Research, USYD, *Submission 81*, page 2; Carers Victoria, *Submission 109*, page 5; HelpingMinds, *Submission 55*, page 2; Ethnic Communities' Council of Victoria, *Submission 99*, page 5.

⁵ HelpingMinds, *Submission 55*, page 3.

⁶ Carers Australia, *Submission 111.1*, page 5; Merri Health, *Submission 103*, page [3]; Dementia Australia, *Submission 35*, page 5; Suicide Prevention Australia, *Submission 22*, page 4; HelpingMinds, *Submission 55*, page 3; Kiind, *Submission 51*, page 2;

⁷ Ms Robyn Shannon, Deputy Secretary, Disability and Carers, Department of Social Services, *Committee Hansard*, 24 October 2023, page 4.

⁸ Kiind, *Submission 51*, page 2.

⁹ Carers ACT, *Submission 58*, page 3; Carers Tasmania, *Submission 57*, page 7.

¹⁰ *Carers Recognition Act 2021* (ACT), s 6; *Carers Recognition Act 2012* (Vic), s 4; *Carer Recognition Act 2023* (Tas), s 4.

acts do not specifically address this. None of the acts grant legal rights to carers, and in most cases, they explicitly state that their provisions are not legally enforceable.¹¹

- 2.7 Similarly, the obligations on the public sector, ‘public sector care agencies’ and funded providers are inconsistent across jurisdictions. New South Wales (NSW), Queensland and Western Australia (WA) have advisory bodies established under their respective acts, and all jurisdictions except Queensland and Victoria specify a review period.
- 2.8 There are disparities in the definition of carer across other federal legislation and policy relating to disability, aged care, mental health and social services. This can lead to confusion about eligibility in service settings and hamper efforts to raise awareness about the role of carers.¹²
- 2.9 The Committee heard that the Act and the Statement should be strengthened to create meaningful and practical recognition; that the Act be rights-based and more inclusive of the diversity of caring roles; and that public service agencies and associated providers should have stronger legal obligations.

Meaning of carer

- 2.10 There was considerable support for modernising the meaning of carer, under section 5 of the Act, to be more inclusive of the diversity of caring roles. There was concern that the current definition may prevent carers from self-identifying and therefore limit their awareness or opportunities to seek carer-specific supports, resources and information.¹³
- 2.11 There was strong support for reframing the definition in terms of a ‘care relationship’, as used in the *Carers Recognition Act 2012* (Vic) and *Carers Recognition Act 2021* (ACT).¹⁴ For example, Carers Victoria said the focus on the recognition of care relationships is helpful because it:

... accommodates the diversity, and sometimes multiplicity, of caring roles that a person might have. With some sectors of our society not identifying with the language of carer, such as multicultural communities, we sometimes find that the language of care relationships provides us with some additional options ...¹⁵

¹¹ Carers Australia, *Submission 111*, page 19.

¹² Carers ACT, *Submission 58*, page 3; Research Centre for Palliative Care, Death and Dying, *Submission 16*, page 4; Carers Australia, *Submission 111*, pages 25, 29-31.

¹³ Qld Alliance for Mental Health (QAMH) and Arafmi, *Submission 41*, page 4; MS Australia, *Submission 91*, page 4.

¹⁴ Carers Victoria, *Submission 109*, page 7; Ms Lisa Kelly, Chief Executive Officer, Carers ACT, *Committee Hansard*, 29 August 2023, page 24; Ms Tarishi Desai, Manager, Treatment and Supportive Care, McCabe Centre for Law and Cancer, *Committee Hansard*, 4 October 2023, pages 16-17; Carers WA, *Submission 113.1*, page 1.

¹⁵ Ms Judith Abbott, Chief Executive Officer, Carers Victoria, *Committee Hansard*, 4 October 2023, page 23.

- 2.12 Carers WA said that any addition of a 'care relationship' in the Act should be clarified to avoid confusion and supported the inclusion of examples, such as those used in the ACT *Carers Recognition Act 2021*.¹⁶ Carers NSW suggested instead that the Statement is a better place to address care relationships. Carers NSW was concerned that 'moving towards a more relational definition in the Federal legislation might water down the ultimate intent of the Act'.¹⁷
- 2.13 The Committee heard that the current meaning of carer assumes that there is a single primary carer and does not consider that an individual may be receiving care and support from multiple carers. In situations where families care for children with disability or a chronic and terminal illness such as cancer, there may be 'a network of family carers' contributing different aspects of care.¹⁸ In First Nations communities, caring responsibilities are generally shared among several family and community members through kinship structures.¹⁹
- 2.14 The meaning of carer in the Act may not fully reflect the range of assistance and support carers provide to the people they care for, or the challenges carers experience. Merri Health and MS Australia, among others, noted that the caring role can be varied and may include life administration, emotional support and transport.²⁰ Merri Health said that caring can also include:
- ... navigation of the health and welfare system, and can often be likened to a case management and support coordination role. A carer often also plays a strong advocacy role for the care recipient, which is not currently captured within the definition.²¹
- 2.15 There was support for updating some of the terminology in section 5 of the Act. The Committee heard that the term 'frail and aged' assumes that all care recipients who are aged are also frail and does not consider that older people may need ongoing care before they might be recognised as frail.²² Merri Health suggested that the term is reworded to 'frail and/or aged'.²³
- 2.16 There are concerns the term 'mental illness' is outdated. Carers Tasmania supported the use of the term 'mental ill health' in the Tasmanian *Carer Recognition Act 2023*.²⁴ Queensland Alliance for Mental Health (QAMH) and Arafmi advocated for the use of

¹⁶ Carers WA, *Submission 113.1*, pages 1-2.

¹⁷ Carers NSW, *Submission 94.1*, page 2.

¹⁸ Kiind, *Submission 51*, page 7; Name Withheld, *Submission 27*, page 8; Research Centre for Palliative Care, Death and Dying - Flinders University, *Submission 16*, page 4.

¹⁹ Gayaa Dhuwi (Proud Spirit) Australia, *Submission 31*, page 3; Australian Human Rights Commission, *Submission 32*, page [5]; Carers NSW, *Submission 94*, page 5.

²⁰ Merri Health, *Submission 103*, page 2; MS Australia, *Submission 91*, page 3; QAMH and Arafmi, *Submission 41*, page 4.

²¹ Merri Health, *Submission 103*, page 2.

²² Merri Health, *Submission 103*, page 2; Women, Work and Policy Research Group and ARC Centre of Excellence in Population Ageing Research, USYD, *Submission 81*, page 6.

²³ Merri Health, *Submission 103*, page 2.

²⁴ Carers Tasmania, *Submission 57*, page 7.

strength-based language such as 'people facing mental health challenges' or 'people experiencing or recovering from mental health challenges'.²⁵

- 2.17 Carers NSW and Carers WA proposed that the meaning of carer should include clarification that individuals receiving carer concession payments are regarded as unpaid carers, ensuring that individuals are not discouraged from self-identifying as carers.²⁶ The ACT and Victorian acts include provisions to this effect.
- 2.18 Stakeholders emphasised the importance of ensuring that any amended definition is consistently applied across all state and territory carer recognition legislation, as well as across other federal legislation and services relating to carers.²⁷ However, DSS noted that 'it is within the remit of states and territories to construct the legislation as they wish' and the Commonwealth does not have 'clear levers to drive consistency with the states'.²⁸
- 2.19 There was support for the meaning of carer in the Act to be amended so that it values and recognises the contributions of all carers regardless of their relationship to the person they care for.²⁹ The current meaning of carer does not explicitly recognise the diversity of carers such as:
- young carers and sibling carers
 - First Nations collective kinship care
 - culturally and linguistically diverse (CALD) carers
 - carers who identify as lesbian, gay, bisexual, transgender, intersex, queer/questioning, asexual and other sexually or gender diverse identities (LGBTIQA+)
 - carers of those with an alcohol or other drug dependence.

Young carers

Box 2.2 Young carers' experiences of caring

I'm a 13-year-old young carer to my 10-year-old brother, Sawyer. Sawyer has spent over a year in hospital, has had 21 brain surgeries and has nearly died three times. He has cerebral palsy, with both physical and intellectual disabilities, but these do not define who he is ... I'm a passionate young carer dedicated to making sure that his dreams come true. To me, a carer is someone who sacrifices time, energy and effort towards physically

²⁵ QAMH and Arafmi, *Submission 41*, page 6.

²⁶ Carers NSW, *Submission 94*, page 5; Carers WA, *Submission 113*, page 4.

²⁷ Carers WA, *Submission 113*, page 4; Mrs Jane Bacot-Kilpatrick, Chief Executive Officer, Carers Australia, *Committee Hansard*, 17 October 2023, page 6.

²⁸ Ms Robyn Shannon, Deputy Secretary, Disability and Carers, Department of Social Services, *Committee Hansard*, 24 October 2023, page 6.

²⁹ National Disability Services, *Submission 79*, page 4; Carers Australia, *Submission 111*, page 30.

and/or emotionally supporting family member. I identify as a young carer and require support myself because this responsibility has impacted my development.³⁰

I am an unpaid young carer to my adult brother, who was diagnosed with classic autism and an intellectual disability at 3 and 1/2 years old ... I have grown up in a world different to my peers and my parents; in a world where my brother constantly requires additional love, care, and support.³¹

I am 23 years old and I grew up as a carer for my Dad, who was diagnosed with a form of Motor Neurone Disease in 2002, and my younger brother who is autistic and has an intellectual disability and epilepsy ... I was providing some kind of support from at least age 6. This could include helping him [my brother] get dressed, hygiene, eating, and entertainment.³²

I have been a carer my whole life and didn't know it until I was in my early 20s. My struggles through education, employment and my own mental health were all directly impacted by my caring role. I had nobody in my life who could identify or support me as a young carer.³³

I was an informal carer to my mother from the ages of 12 years to early adulthood ... The caring responsibilities, and feeling overwhelmed and isolated, took a heavy toll on my ability to be a normal child. I felt responsible for keeping my mother alive. It adversely affected my education by having a high non-attendance rate, and as well I was not afforded the space or privacy after school hours to complete homework as my mother's needs were always the priority.³⁴

- 2.20 Young carers are children and young people under the age of 25 who currently provide, or intend to provide, unpaid care, assistance or support to a family member with mental illness, chronic illness, disability, substance dependency or conditions related to aging.³⁵ It is estimated that there are 246,000 young carers in Australia, with approximately 50,000 under the age of 15.³⁶ These numbers are likely to be an underestimate due to the invisible nature of caring by young people and 'low rates of self-identification'.³⁷
- 2.21 Young carers experience unique challenges as one of Australia's most at-risk groups of young people.³⁸ Little Dreamers Australia, a peak body established to improve the quality of life of young carers, stated that:

³⁰ Hudson Langan-Stark, Young Carer Participant, Little Dreamers Australia, *Committee Hansard*, 4 October 2023, page 2.

³¹ Name Withheld, *Submission 66*, page 2.

³² Ms Mary Pilkinton, *Submission 87*, pages 1, 3.

³³ Mr Kyle Hayes, *Submission 100*, page 2.

³⁴ Suicide Prevention Australia, *Submission 22*, pages 6-7.

³⁵ Little Dreamers Australia, *Submission 54*, page 1.

³⁶ Australian Research Alliance for Children and Youth, *Submission 129*, page 2.

³⁷ ARACY, *Submission 129*, page 2; The Centre for Excellence in Child and Family Welfare, *Submission 121*, page 2.

³⁸ Little Dreamers Australia, *Submission 54*, page 4.

Young carers are required to work alongside the demands of their caring role whilst attempting to navigate their way through adolescence, often significantly impacting their ability to connect with other young people and gain pivotal space to form their sense of identity.³⁹

- 2.22 Young carers are largely under-recognised because they see their caring roles as a normal part of family life.⁴⁰ A lack of a consistent, formal definition of the term ‘young carer’ across legislation and policies in Australia creates confusion and hinders young carers’ ability to self-identify. Little Dreamers Australia said this results in funding issues, unequal access to support services, fragmented service and can have psychological and emotional impacts on young carers, such as stigmatisation and isolation.⁴¹
- 2.23 Young carers face many barriers preventing them from seeking help. Most services, legislation and policies are designed for adult carers, which means that young carers can miss out on accessing services such as Carer Gateway and Centrelink.⁴² Other barriers include a lack of awareness and understanding of how to access services, family fear of children being removed, issues with accessibility due to transport and cost, and consistency of service delivery.⁴³
- 2.24 There was support for amending the Act to better define and specifically identify young carers.⁴⁴ Little Dreamers Australia argued that a universal definition of young carers should be developed to identify and support ‘potential young carers at an early stage, which can have several benefits related to early intervention.’⁴⁵
- 2.25 Ms Jacqueline de Mamiel, a Young Carer Participant at Little Dreamers Australia, noted that having a label of ‘young carer’ encouraged her school and extracurricular activities to accommodate the supports she needed. Ms de Mamiel stated that ‘it’s really helpful to have a label that articulates that this is an ongoing role for me and a proper responsibility’.⁴⁶
- 2.26 Internationally, the United Kingdom (UK) provides advanced recognition of young carers through various legislation and policy and service frameworks that acknowledges, recognises and assists young carers.⁴⁷ For example, the *Children and*

³⁹ Little Dreamers Australia, *Submission 54*, page 15.

⁴⁰ Ms Ludmila Fleitas Alfonzo and Associate Professor Tania King, *Submission 83*, page 2; Women, Work and Policy Research Group and ARC Centre of Excellence in Population Ageing Research, USYD, *Submission 81*, page 4.

⁴¹ Little Dreamers Australia, *Submission 54*, page 5.

⁴² Ms Madeleine Buchner, Founder and Chief Executive Officer, Little Dreamers Australia, *Committee Hansard*, 4 October 2023, page 6.

⁴³ ARACY, *Submission 129*, page 3; Little Dreamers Australia, *Submission 54*, page 11.

⁴⁴ Mental Health Carers Australia, *Submission 116*, page 8; Name Withheld, *Submission 66*, page 4; Ms Ludmila Fleitas Alfonzo and Associate Professor Tania King, *Submission 83*, page 2; ARACY, *Submission 129*, page 4; Name Withheld, *Submission 118*, page 2; Merri Health, *Submission 103*, page 4; Mental Health Carers Australia, *Submission 116*, page 4; Carers Tasmania, *Submission 57*, pages 7-8.

⁴⁵ Little Dreamers Australia, *Submission 54*, page 5.

⁴⁶ Ms Jacqueline de Mamiel, Young Carer Participant, Little Dreamers Australia, *Committee Hansard*, 4 October 2023, page 4.

⁴⁷ Little Dreamers Australia, *Submission 54*, page 8.

Families Act 2014 (UK) includes provisions that require 'local authorities to identify and support young carers' and to promote 'cooperation between education, health and social care services' to meet their needs. Further, the *Care Act 2014* (UK) includes rights to 'assess and support children and young people from taking on excessive or inappropriate amounts of care'.⁴⁸

- 2.27 Little Dreamers Australia noted that, in addition to these laws, there is broad 'awareness and recognition of young carers amongst public, policy makers and professionals' in the UK and multiple services and interventions dedicated to young carers nationwide.⁴⁹ Little Dreamers Australia argued that similar legal recognition in Australia would safeguard young carers' 'rights, wellbeing and future prospects'⁵⁰, and ensure that their needs are acknowledged. Recognition may also ensure that appropriate support mechanisms are in place to prevent potential negative consequences on young carers' education, health and overall development.⁵¹

Impact of caring on young people

- 2.28 Caring significantly impacts a young carer's education. Young carers have lower attendance at school than non-carers and are less likely to complete Year 12.⁵² Young carers may come to the attention of the school due to challenges and behaviours such as:
- poor attendance or truancy and failure to stay on top of school assessments
 - victims of bullying
 - a strong desire to have mobile phones handy
 - being unkempt
 - anxiety and/or depression, suicidal ideation or self-harming
 - financial constraints and being unable to attend school outings, purchase school uniforms or appropriate footwear
 - feeling anxious about their family members at home
 - social isolation.⁵³
- 2.29 Young carers who care for family members with mental illness or alcohol or drug use have significantly lower educational engagement.⁵⁴ The stigma associated with mental illness prevents many young people from disclosing what is going on at home.⁵⁵

⁴⁸ Little Dreamers Australia, *Submission 54*, page 8.

⁴⁹ Little Dreamers Australia, *Submission 54*, page 18.

⁵⁰ Little Dreamers Australia, *Submission 54*, page 6.

⁵¹ Little Dreamers Australia, *Submission 54*, page 6.

⁵² ARACY, *Submission 129*, page 2.

⁵³ Ms Dee-ann Riley, *Submission 62*, pages 1-2; ARACY, *Submission 129*, page 2.

⁵⁴ ARACY, *Submission 129*, page 2.

⁵⁵ Suicide Prevention Australia, *Submission 22*, page 7.

- 2.30 Siblings of young people with a disability, medical condition or mental illness find that there are very few psychosocial supports or other services that recognise their unique experiences.⁵⁶ Siblings are often overlooked in young carer policies and programs and need better access to appropriate respite and bereavement support services.⁵⁷ In addition, siblings rarely get a break from their caring roles as the needs of their sibling often come first.⁵⁸
- 2.31 Redkite reported that siblings of a child diagnosed with cancer often face considerable unmet needs. For example, the sibling may no longer have constant access to their usual primary carer, travel to treatment centres cause siblings to face extended periods of school disruptions and loss of contacts, and siblings may be withheld from school and have reduced social interactions if the sick child is immunocompromised.⁵⁹

First Nations collective kinship care

Box 2.3 First Nations' experience of care

Informal systems of care aren't recognised, but they have been keeping our kids and vulnerable ones safe and connected to culture and community, this needs to be recognised, we been doing it all along. [Elder of community]⁶⁰

- 2.32 Understandings of care in First Nations communities are holistic, complex and intersectional and are shaped by culture, kinship relationships and historical context.⁶¹
- 2.33 The term 'carer' may not fully represent what First Nations people do for family.⁶² The Australian Human Rights Commission (AHRC) uses the term 'collective care' to describe First Nations conceptions of care and support. It said:

The term 'collective care' is used to describe the shared responsibility of caring for family, community, and Country, and signifies that the act of care is a means to transfer knowledge and culture intergenerationally. In this way, care and support do not only exist within the formal paid economy, but also encompass culturally grounded practices and customs that enable communities to be safe, happy and connected through kinship and Country. In many ways, 'care' is treated as an ethic or value that is held by community to give and receive love, kindness and support, rather than an obligation or occupation.⁶³

⁵⁶ Kiind, *Submission 51*, page 6; Redkite, *Submission 53*, page 6.

⁵⁷ Childhood Dementia Initiative, *Submission 133*, page 10.

⁵⁸ Kiind, *Submission 51*, page 6.

⁵⁹ Redkite, *Submission 53*, page 6.

⁶⁰ National Aboriginal Torres Strait Islander Women's Alliance (NATSIWA), *Submission 127*, page 9.

⁶¹ Victorian Aboriginal Child Care Agency, *Submission 73*, page 2; Australian Human Rights Commission (AHRC), *Submission 32*, page [5]; Gayaa Dhuwi (Proud Spirit) Australia, *Submission 31*, page 3.

⁶² Department of Health and Aged Care, *Submission 140*, page 15.

⁶³ AHRC, *Submission 32*, page [5].

- 2.34 First Nations people are often invisible, unrecognised and experience a lack of understanding and responsiveness from formal and mainstream services.⁶⁴ Generations of cultural differences, discrimination, accessibility issues and historical mistrust are barriers to First Nations people accessing supports, employment and services, which can lead to poor health and wellbeing outcomes, mental health and addiction challenges, and unemployment.⁶⁵ Gayaa Dhuwi (Proud Spirit) Australia said that ‘these factors contribute significantly to the health, life expectancy, disability, and need for care in First Nations communities’.⁶⁶
- 2.35 While the proportion of First Nations people providing unpaid care is 1.3 times the proportion of non-Indigenous Australians, this figure is likely to be an under-representation due to First Nations people not identifying as carers, and the Australian Census not recognising kinship care.⁶⁷ More First Nations women (18 per cent) than men (12 per cent) are carers.⁶⁸
- 2.36 The AHRC warned that First Nations women and their families are at risk of experiencing a ‘poverty trap’ as insufficient income for their caring roles ‘creates the risk of further harm to health and wellbeing, which redoubles the load of care’.⁶⁹ The National Aboriginal Torres Strait Islander Women's Alliance (NATSIWA) argued that the current definition of carer in the Act ‘does not recognise the important contributions that Grandmothers, Mothers, Aunties and Sisters have always played in looking after children and community’.⁷⁰
- 2.37 The AHRC, among others, argued that the definition should be broadened to ‘recognise the full spectrum of care’ provided by First Nations people, including ‘collective care models, and unpaid and informal caring duties, including domestic work and duties performed by paid carers that go beyond their formal responsibilities’.⁷¹
- 2.38 The AHRC added that the Act should:
- ... broaden its definition of the roles and responsibilities of carers to acknowledge their right to provide and receive care aligning with cultural practices and knowledge, and that supports culture, language, identity and self-determination as dictated by the United Nations Declaration on the Rights of Indigenous Peoples.⁷²

⁶⁴ Department of Social Services, *Submission 70*, page 6; AHRC, *Submission 32*, page [5]; Victorian Aboriginal Child Care Agency, *Submission 73*, page 3.

⁶⁵ Gayaa Dhuwi (Proud Spirit) Australia, *Submission 31*, page 3; AHRC, *Submission 32*, pages [5]-[6].

⁶⁶ Gayaa Dhuwi (Proud Spirit) Australia, *Submission 31*, page 3.

⁶⁷ Department of Health and Aged Care, *Submission 140*, page 15; NATSIWA, *Submission 127*, page 8.

⁶⁸ NATSIWA, *Submission 127*, page 2.

⁶⁹ AHRC, *Submission 32*, page [5].

⁷⁰ NATSIWA, *Submission 127*, page 7.

⁷¹ AHRC, *Submission 32*, page 3; NATSIWA, *Submission 127*, page 10; Gayaa Dhuwi (Proud Spirit) Australia, *Submission 31*, page 5.

⁷² AHRC, *Submission 32*, pages 3-4.

Culturally and linguistically diverse carers

- 2.39 Carers from CALD backgrounds face unique and significant challenges in Australia primarily due to members of these communities not identifying with the term 'carer', resulting in many CALD carers being hidden and unrecognised.⁷³ The Ethnic Communities' Council of Victoria (ECCV) said:

In many non-Western cultures, looking after one's relatives is commonly seen simply as one of life's responsibilities, and not something for which special assistance or financial compensation should be sought. Many languages do not have a word that translates as 'carer', since caring for family members is presumed to be part of the family role.⁷⁴

- 2.40 CALD carers comprise between 25 and 30 per cent (roughly 500,000) of all carers in Australia.⁷⁵ As well as language, religious and gender barriers, CALD carers often face:

- Stigma and shame, including stigma associated with disclosing certain disabilities or health conditions. For example, some parents may not wish to disclose that their child has a disability, and adult children may not want to tell their community that their parents have dementia.⁷⁶
- Apprehensions about how personal data will be collected and used, due to past experiences of discrimination or trauma, cultural beliefs, or an unwillingness before rapport has been built.⁷⁷
- Increased isolation, loneliness, and poor mental health outcomes.⁷⁸
- Cultural rules or obligations relating to how someone with a disability or an older person is cared for, who performs a caring role, and what it entails.⁷⁹
- Lack of information and educational materials on support services available in different languages and lack of access to interpreters.⁸⁰
- Limited access to culturally appropriate services and avoidance of carer support groups due to differences in understanding or not wanting to discuss family business.⁸¹
- Implicit and explicit racism and prejudice in care settings leading to lack of cultural safety.⁸²

⁷³ Ethnic Communities' Council of Victoria (ECCV), *Submission 99*, pages 3, 5; Department of Health and Aged Care, *Submission 140*, page 14; Carers Victoria, *Submission 109*, page 10.

⁷⁴ ECCV, *Submission 99*, page 3.

⁷⁵ Department of Health and Aged Care, *Submission 140*, page 14.

⁷⁶ ECCV, *Submission 99*, pages 3, 8; Department of Health and Aged Care, *Submission 140*, page 14.

⁷⁷ ECCV, *Submission 99*, page 8.

⁷⁸ GenWest, *Submission 65*, page 10.

⁷⁹ Department of Health and Aged Care, *Submission 140*, page 14.

⁸⁰ GenWest, *Submission 65*, page 11.

⁸¹ GenWest, *Submission 65*, page 11; ECCV, *Submission 99*, page 6; Department of Health and Aged Care, *Submission 140*, page 14.

⁸² GenWest, *Submission 65*, page 11.

- Lack of services for small or emerging communities in regional, rural, and remote areas.⁸³

2.41 Carers from CALD backgrounds may be expected to take on additional advocacy roles, such as acting as an interpreter or translator with clinicians and health care workers.⁸⁴ This requires carers to understand and interpret complex, personal and often distressing health information, such as details about prognoses or whether a treatment is working, and can impose difficult ethical, cultural and emotional pressures on carers.⁸⁵ These additional responsibilities can result in burnout and a lack of appropriate care being provided.⁸⁶ Furthermore, if carers have low language or digital literacy skills themselves, they may not be aware of existing support services and respite options and how to apply for them.⁸⁷

Carers who identify as LGBTIQA+

2.42 For some carers who identify as LGBTIQA+, their caring role, identity, experiences and relationships are met with stigma and discrimination when attempting to access services.⁸⁸ It is estimated that between 15 to 30 per cent of people who identify as lesbian, gay, bisexual or transgender (LGBT) are currently in caring roles.⁸⁹ Around one-third say that being LGBTIQA+ 'affects how and when they access support services'.⁹⁰ A lack of consistent population-level data on LGBTIQA+ carers prevents the development of evidence-based policy and services that address their specific needs.⁹¹

2.43 Additional concerns and challenges for carers who identify as LGBTIQA+ include:

- increased risk of experiencing moderate to high levels of psychological distress (60.3 per cent) compared to other carers (48.1 per cent) in 2022⁹²
- increased social isolation and lack of access to appropriate LGBTIQA+ specific carer support groups and services
- a fear and distrust of accessing formal health support services as they do not feel accepted or respected (only 66 per cent of LGBTIQA+ people have a regular general practitioner [GP] compared to 81 per cent of the general population) leading to reduced disclosures of full mental health and wellbeing circumstances

⁸³ Department of Health and Aged Care, *Submission 140*, page 15.

⁸⁴ McCabe Centre for Law and Cancer, *Submission 80*, page 5; The University of Melbourne Graduate Student Association, *Submission 34*, page 6.

⁸⁵ McCabe Centre for Law and Cancer, *Submission 80*, page 5.

⁸⁶ ECCV, *Submission 99*, page 6.

⁸⁷ ECCV, *Submission 99*, page 6.

⁸⁸ Queensland Nurses and Midwives' Union, *Submission 72*, page 7; Department of Health and Aged Care, *Submission 140*, page 14.

⁸⁹ Carers Victoria, 'LGBTI Carer Facts', January 2017, www.carersvictoria.org.au/media/1107/lgbti-carer-facts-infographic.pdf.

⁹⁰ Department of Health and Aged Care, *Submission 140*, page 13.

⁹¹ GenWest, *Submission 65*, page 9; Carers Australia, *Submission 111*, page 8.

⁹² Carers Australia and the University of Canberra, *Caring for Others and Yourself: 2022 Carer Wellbeing Survey*, October 2022, page 8.

- limited access to affordable and inclusive services
 - invisibility of their carer role within some LGBTIQ+ communities
 - financial disadvantage and limited job opportunities.⁹³
- 2.44 GenWest, among others, reported that discrimination and stigma can arise when LGBTIQ+ carers and same-sex family members rely on their ‘family of choice’ as their primary source of support, but they are not legally authorised as the next of kin to make decisions.⁹⁴
- 2.45 The Queensland Nurses and Midwives’ Union suggested ‘ensuring there is an option on paperwork where LGBTIQ+ related questions are asked’ and more training for staff who provide services and supports, can enhance inclusion.⁹⁵

Carers who support a person experiencing alcohol or other drug dependence

- 2.46 There was support for the meaning of carer in the Act to be expanded to formally recognise carers who care for a person experiencing alcohol or other drug dependence, consistent with the *Carer Recognition Act 2023* (Tas).⁹⁶
- 2.47 Families and carers can often face stigma and isolation⁹⁷, and the inadequacy of services for those with a dependence may lead their carers to believe that they too are ineligible for support.⁹⁸
- 2.48 Family Drug Support said carers who care for a person with alcohol or other drug dependence are ‘not very well understood by the health system in general’, and many ‘feel responsible and to blame for their family member’s drug dependence, which presents barriers to their ability to seek help and engage in both informal and informal support systems’.⁹⁹
- 2.49 Carers Australia noted this cohort have particularly low wellbeing and the person they care for is ‘least likely to access help of a medical or other support service’.¹⁰⁰
- 2.50 Carers Tasmania said that including this cohort in the meaning of carer can ‘reduce stigma and ensure that as many carers as possible can access support’.¹⁰¹

⁹³ GenWest, *Submission 65*, page 10; Department of Health and Aged Care, *Submission 140*, pages 13-14.

⁹⁴ GenWest, *Submission 65*, page 10; Carers Australia, *Submission 111*, page 8; Department of Health and Aged Care, *Submission 140*, page 13.

⁹⁵ Queensland Nurses and Midwives’ Union, *Submission 72*, page 7.

⁹⁶ Family Drug Support, *Submission 82*, page 2; Carers WA, *Submission 113*, page 4; ARACY, *Submission 129*, page 4; Carers NSW, *Submission 94*, page 5; Department of Premier and Cabinet, Tasmania, *Submission 5*, page 1; Carers Tasmania, *Submission 57*, pages 6-7.

⁹⁷ Family Drug Support, *Submission 82*, page 2; Carers Australia, *Submission 111.1*, page 6.

⁹⁸ Carers Australia, *Submission 111.1*, page 6.

⁹⁹ Family Drug Support, *Submission 82*, page 2.

¹⁰⁰ Carers Australia, *Submission 111.1*, page 6.

¹⁰¹ Carers Tasmania, *Submission 57*, pages 6-7.

Care that goes beyond what would typically be expected in a relationship

- 2.51 While there was some support for the caring of children to be recognised as care work in the Act¹⁰², there was broad agreement that the definition of carer should be limited to care that goes beyond what would typically be expected in a familial relationship.¹⁰³ Carers Australia noted that there is already ‘a lot of legislation and programs out there covering families.’¹⁰⁴
- 2.52 Some stakeholders also proposed that informal kinship carers and foster carers should be explicitly recognised in the Act. Informal kinship carers are family-based carers within a child’s extended family or close friends of the family known to the child. Informal kinship carers do not provide care under statutory orders of the state and territory child protection services and are not eligible to receive carer payments.¹⁰⁵ Foster carers provide temporary housing and care for children who are unable to live safely with their parents and receive little or no carer payments for doing so.¹⁰⁶
- 2.53 Informal kinship carers and foster carers are not explicitly recognised in the Act but are covered by the definition if the child they care for has a disability, medical condition or mental illness.¹⁰⁷
- 2.54 While ‘a large proportion of kinship care in Australia is informal’¹⁰⁸, this cohort is a ‘little-recognised group with significant unmet needs for support’ and are predominantly women and around 50 per cent are grandparents.¹⁰⁹
- 2.55 Carers Tasmania and Kin Raising Kids Tasmania Inc., among others, recommended that the definition of carer in the Act be amended to specifically recognise informal kinship carers.¹¹⁰
- 2.56 Carers Australia and Carers NSW noted, however, that care provided by informal kinship and foster carers should not be considered as care that goes beyond what would typically be expected in a relationship and did not support their inclusion in the Act.¹¹¹ Carers NSW added that ‘these groups would be more appropriately recognised and supported through their own legislative or policy instruments’.¹¹²

¹⁰² GenWest, *Submission 65*, page 5; Ms Rosie Goethel, *Committee Hansard*, 5 September 2023, page 6.

¹⁰³ Carers NSW, *Submission 94.1*, page 2; Ms Sue Elderton, Senior Policy Officer, Carers Australia, *Committee Hansard*, 17 October 2023, page 8.

¹⁰⁴ Ms Sue Elderton, Senior Policy Officer, Carers Australia, *Committee Hansard*, 17 October 2023, page 8.

¹⁰⁵ Dr Meredith Kiraly, *Submission 122*, page 1.

¹⁰⁶ The Centre for Excellence in Child and Family Welfare, *Submission 121*, page 3; Connecting Foster and Kinship Carers – SA, *Submission 93*, page 3.

¹⁰⁷ Kin Raising Kids Tasmania Inc., *Submission 20*, page 2; Carers Tasmania, *Submission 57*, page 7.

¹⁰⁸ The Centre for Excellence in Child and Family Welfare, *Submission 121*, page 3.

¹⁰⁹ Dr Meredith Kiraly, *Submission 122*, page 1.

¹¹⁰ Carers Tasmania, *Submission 57*, page 10; Kin Raising Kids Tasmania Inc., *Submission 20*, page 1; Dr Meredith Kiraly, *Submission 122*, page 5; Wellways Australia, *Submission 117*, page 8.

¹¹¹ Ms Sue Elderton, Senior Policy Officer, Carers Australia, *Committee Hansard*, 17 October 2023, page 8; Carers NSW, *Submission 94*, pages 4-5.

¹¹² Carers NSW, *Submission 94*, pages 4-5.

The Statement for Australia's Carers

- 2.57 Schedule 1 of the Act provides the Statement, which is described by DSS as 'ten key principles for how carers should be treated and considered in policy, program and service delivery settings'.¹¹³
- 2.58 Many consider the Statement to be vague and abstract, containing no call to action and far from being realised.¹¹⁴ Lived Experience Australia Ltd (LEA) described the Statement as 'a toothless piece of aspirational legislation with little or no impact on achieving the intent of raising recognition and awareness of the unpaid caring role'.¹¹⁵
- 2.59 There was general agreement that the Statement does not capture the genuine experiences of carers, primarily because many carers do not receive the supports and services they need, and it lacks clarity and practical actions that improve carers' lives.¹¹⁶ For example, a former carer said:
- The key principles should be more specific and provide detailed expectations of how those principles can be achieved. Without this, the government and other accountable agencies can all too quickly ignore. They would also be more meaningful and memorable if more specific.¹¹⁷
- 2.60 All state and territory carer recognition legislation feature similar principles as the Statement. The Northern Territory, Tasmania, NSW, South Australia, Queensland and WA have carers' charters. Victoria and the ACT's legislation have 'care relationship principles' aligned with their use of the term 'care relationship'.

A human rights-based approach

- 2.61 There was considerable support for strengthening the Statement to incorporate a human rights-based approach, in a similar way that Australians receive rights through anti-discrimination and employment legislation.¹¹⁸
- 2.62 The Committee heard that human rights in Australia are currently legislated in an inconsistent and piecemeal way. This complicates the recognition of carers' rights

¹¹³ Department of Social Services, *Submission 70*, page 4.

¹¹⁴ Kiind, *Submission 51*, page 2; QAMH and Arafmi, *Submission 41*, page 4; Dementia Australia, *Submission 35*, page [6]; ANU Humanities Research Centre, *Submission 63*, page 3.

¹¹⁵ Lived Experience Australia Ltd, *Submission 56*, page 5.

¹¹⁶ ermha365, *Submission 71*, page 3; Dementia Australia, *Submission 35*, page [6]; QAMH and Arafmi, *Submission 41*, page 5; Wellways Australia, *Submission 117*, page 6; Mental Health Carers Australia, *Submission 116*, page 5; Dementia Australia, *Submission 35*, page [6]; Australian Healthcare and Hospitals Association, *Submission 8.1*, page 2.

¹¹⁷ Dementia Australia, *Submission 35*, page [6].

¹¹⁸ Carers Australia, *Submission 111.1*, page 6; OPAN, *Submission 39*, pages 2-3; McCabe Centre for Law and Cancer, *Submission 80*, pages 9-10; Carers Tasmania, *Submission 57*, page 57; AHRC, *Submission 32*, page 3; Carers Queensland, *Submission 59*, page 7; Carers SA, *Submission 61*, page 3; Inner South Family and Friends, *Submission 107*, page 8; Wellways Australia, *Submission 117*, page 6; Australian Healthcare and Hospitals Association, *Submission 8.1*, pages 2-3; Research Centre for Palliative Care, Death and Dying - Flinders University, *Submission 16*, page 7; Lived Experience Australia Ltd, *Submission 56*, page 3.

and efforts to overcome the other difficulties, marginalisation, and discrimination that carers face. The Parliamentary Joint Committee on Human Rights is currently inquiring into Australia's human rights framework and a report is expected in March 2024.¹¹⁹

2.63 The McCabe Centre for Law and Cancer emphasised that a human rights-based approach 'centres the dignity of a person'¹²⁰ and added that it 'leads to better decision-making because it provides a way for lawmakers, policymakers and those involved in service delivery to think upfront about what the needs of carers are'.¹²¹

2.64 Many stakeholders provided examples of what a modernised and rights-based Statement should include. For example, LEA shared the discussions it had with a young carer who described what human rights, to them, looked like:

... the right to have a childhood and not to be the parent to a mother or a younger sibling all the time; the right to education, peer relationships, future employment aspirations, career choices and other identities; the right to ask for help and know where to go; that services should reach out and not just expect family to always be the one reaching out for help; the right to dignity and privacy and how the various agencies and schools, for example, involve work with the young carer; the right not to be a passenger captured by systems; and the right to be taken seriously for their lived experience, once services step in.¹²²

2.65 Other suggestions to improve and strengthen the Statement included:

- a statement that reflects the intersectionality of carer identities and recognition that discrimination, racism, ageism, ableism and sexism can contribute to poor health outcomes among carers¹²³
- a statement that requires the consideration of the wellbeing of young carers in developing policy and practice¹²⁴
- greater inclusivity of gender identity and sexual orientation (for example, replacing 'sex' with 'gender identification' in Statement 1)¹²⁵
- a statement that includes improved accessibility and affordability of self-care services and respite care¹²⁶

¹¹⁹ McCabe Centre for Law and Cancer, *Submission 80*, page 9; Lived Experience Australia Ltd, *Submission 56*, page 3.

¹²⁰ Ms Tarishi Desai, Manager, Treatment and Supportive Care, McCabe Centre for Law and Cancer, *Committee Hansard*, 4 October 2023, page 16.

¹²¹ Ms Tarishi Desai, Manager, Treatment and Supportive Care, McCabe Centre for Law and Cancer, *Committee Hansard*, 4 October 2023, page 16.

¹²² Professor Sharon Lawn, Chair and Executive Director, Lived Experience Australia, *Committee Hansard*, 29 August 2023, page 1.

¹²³ Suicide Prevention Australia, *Submission 22*, page 5; GenWest, *Submission 65*, page 7.

¹²⁴ ARACY, *Submission 129*, page 4; Little Dreamers, *Submission 54*, page 4.

¹²⁵ Carers NSW, *Submission 94*, page 8; Carers Australia, *Submission 111.1*, page 8.

¹²⁶ MS Australia, *Submission 91*, page 4.

- the right to contribute to and participate in the development of health and social care policy¹²⁷
- rights for carers at the service delivery level, including ‘requirements to identify, include, assess and support carers in the delivery of care and support services for carers and the people they care for’¹²⁸
- the right for children and young people who are carers to participate fully in education and be supported to do this¹²⁹
- the right to engage in education, employment and social and cultural life should be taken into account in any assessment of their needs.¹³⁰

2.66 The Committee heard there may be legal issues associated with including human rights in federal legislation. For example, Carers Australia said:

... in the absence of a Human Rights Act which could confer specific rights on carers, the Commonwealth Government must rely on its ‘external affairs power’ provided in s51 (xxix) of the Constitution and the ratification of international treaties to insert human rights into its legislation.¹³¹

2.67 Carers Australia suggested that, to amend the Statement to make it rights-based, any individual statement that includes the words ‘have the right’ would need to correspond to an international instrument.¹³² In the statements where there is no corresponding instrument, then the word ‘should’ is used.¹³³

2.68 The McCabe Centre for Law and Cancer and Carers Australia both identified that rights for carers can be found in various international human rights instruments, including the International Covenant on Economic, Social and Cultural Rights, which includes rights ‘relating to health, social security, job security, workplace protections and non-discrimination’¹³⁴; the Convention on the Rights of People with Disability; and the Convention on the Rights of the Child.¹³⁵

2.69 The McCabe Centre for Law and Cancer added that there ‘are a number of different human rights instruments as well as guidance documents from the International Labor Organisation which would be relevant’.¹³⁶ For example, a number of

¹²⁷ OPAN, *Submission 39*, page 3.

¹²⁸ Carers NSW, *Submission 94.1*, page 2.

¹²⁹ Carers Australia, *Submission 111.1*, page 8.

¹³⁰ Carers Australia, *Submission 111.1*, page 8.

¹³¹ Carers Australia, *Submission 111.1*, page 6.

¹³² For example: United Nations, *International Convention on Economic, Social and Cultural Rights*, 1966.

¹³³ Carers Australia, *Submission 111.1*, page 7.

¹³⁴ Ms Tarishi Desai, Manager, Treatment and Supportive Care, McCabe Centre for Law and Cancer, *Committee Hansard*, 4 October 2023, page 17.

¹³⁵ Ms Tarishi Desai, Manager, Treatment and Supportive Care, McCabe Centre for Law and Cancer, *Committee Hansard*, 4 October 2023, page 17; Carers Australia, *Submission 111.1*, page 6.

¹³⁶ Ms Tarishi Desai, Manager, Treatment and Supportive Care, McCabe Centre for Law and Cancer, *Committee Hansard*, 4 October 2023, page 17.

International Labour Organisation Standards and Protocols recognise the rights of people in employment to care for people important to them.¹³⁷

- 2.70 Likewise, the AHRC observed that ‘although Australia is a party to human rights architecture, these rights may be limited to be respected in principle rather than in Australian law.’¹³⁸ Instead, it recommended that to ensure rights are fully realised, the Act should ‘strengthen understanding of the full spectrum of care, its importance to the functioning of society, and to promote equitable access to care and support services, facilities, and goods that are culturally safe and appropriate’.¹³⁹ The AHRC emphasised that:

Without the provision of adequate care and support services and goods, these rights are unable to be realised for population groups facing barriers through disability, age, language or other circumstances.¹⁴⁰

- 2.71 DSS suggested that a way to strengthen the Act would be to cross-reference to rights that already exist in other legislation, such as the *Work Act 2009*, *Sex Discrimination Act 1984* and *Disability Discrimination Act 1992*, as opposed to creating ‘a separate act with its own unique set of rights’.¹⁴¹

International recognition of care

- 2.72 The UK has well-developed laws establishing entitlements and rights for carers. Some European countries, Canada and the United States (US) have also implemented legislation for carers.
- 2.73 New Zealand does not have legislation recognising carers; rather it has a Carers’ Strategy (2008) and a Carers’ Strategy Action Plan 2019-2023.¹⁴²

United Kingdom

- 2.74 The UK has four acts that establish entitlements and rights for carers. The *Carers (Recognition and Services) Act 1995* (UK) gives carers the right to request that their capacity to provide care be assessed for eligibility for community care services.¹⁴³
- 2.75 The *Carers (Equal Opportunity) Act 2004* (UK) places a duty on local authorities to inform carers of their right to a Carer Assessment for support including in employment, training, and leisure, as part of the needs assessment process. It also

¹³⁷ See for example International Labour Organisation, *Convention on Workers with Family Responsibilities*, C156, 1981.

¹³⁸ AHRC, *Submission 32*, page [4].

¹³⁹ AHRC, *Submission 32*, page [4].

¹⁴⁰ AHRC, *Submission 32*, pages [4]-[5].

¹⁴¹ Ms Robyn Shannon, Deputy Secretary, Disability and Carers, Department of Social Services, *Committee Hansard*, 24 October 2023, page 4.

¹⁴² Carers Australia, *Submission 111*, page 28.

¹⁴³ Women, Work and Policy Research Group and ARC Centre of Excellence in Population Ageing Research, USYD, *Submission 81*, page 2.

grants local authorities more power to collaborate with departments such as housing, health and education to provide comprehensive support to carers.¹⁴⁴

2.76 The *Care Act 2014* (UK) combined various existing legislation to put ‘carers on an equal footing with the people they care for’¹⁴⁵, by mandating responsible local authorities to conduct separate assessments for both adults in need of care and their carers.¹⁴⁶ The *Care Act 2014* (UK) also introduced:

- a focus on promoting wellbeing¹⁴⁷
- the right to a carer assessment which ‘considers the sustainability of the caring role and the carer’s future needs for support as well as their ability and willingness to provide care now and in the future’¹⁴⁸
- a duty on local authorities to provide information and advice to carers in relation to their caregiving responsibilities and their own needs.¹⁴⁹

2.77 Most recently, the *Health and Care Act 2022* (UK) requires health care settings to identify carers to support admission and discharge.¹⁵⁰

2.78 Mental Health Carers Australia proposed that Australia should adopt a model similar to the UK and mandate a carer’s assessment in all government-funded programs, enforce carers’ rights to access information and ensure the ‘involvement of carers in decision making in public policy and in the governance of associated providers’.¹⁵¹ Similarly, the McCabe Centre for Law and Cancer said that establishing a right to a needs assessment ‘is likely to improve the reach of Australia’s current Carer Gateway model.’¹⁵²

2.79 Little Dreamers reported there have been challenges in effectively implementing and maintaining the UK’s Carer Act and that funding issues were a significant obstacle.¹⁵³

Europe

2.80 Portugal, Italy and Belgium have carer laws that establish certain rights for carers. Carers Australia said that Portugal introduced a Statute for Informal Carers which ‘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.’¹⁵⁴

¹⁴⁴ Carers Australia, *Submission 111*, page 26; Mental Health Carers Australia, *Submission 116*, page 6.

¹⁴⁵ Carers Australia, *Submission 111*, page 26.

¹⁴⁶ McCabe Centre for Law and Cancer, *Submission 80.1*, page 5.

¹⁴⁷ Mental Health Carers Australia, *Submission 116*, page 6.

¹⁴⁸ McCabe Centre for Law and Cancer, *Submission 80.1*, page 5.

¹⁴⁹ Mental Health Carers Australia, *Submission 116*, page 6.

¹⁵⁰ Carers NSW, *Submission 94.1*, page 3.

¹⁵¹ Mental Health Carers Australia, *Submission 116*, page 6.

¹⁵² McCabe Centre for Law and Cancer, *Submission 80.1*, page 5.

¹⁵³ Ms Madeleine Buchner, Founder and Chief Executive Officer, Little Dreamers Australia, *Committee Hansard*, 4 October 2023, page 6.

¹⁵⁴ Carers Australia, *Submission 111*, page 27.

- 2.81 Carers in Italy have access to a support network of social workers, nurses, general practitioners, and voluntary organisations. The support is designed to encompass not only services and care allowances but also psychological and 'relational' assistance, including self-help. The provisions also promote early retirement for carers, particularly those facing challenges in balancing work and caregiving responsibilities.¹⁵⁵
- 2.82 Carers in Belgium have access to paid carers' leave and flexible work arrangements, subject to satisfying criteria regarding the relationship between the carer and care recipient.¹⁵⁶

North America

- 2.83 The Canadian Human Rights Act establishes a right for people who need to provide care to family members to participate fully in the labour force and provides protections for carers' leave and flexible work.¹⁵⁷
- 2.84 In the US, hospitals are required to identify and provide information to carers under the *Caregiver Advise, Record, Enable (CARE) Act*, which has been implemented in 44 states.¹⁵⁸ A separate act, the *RAISE Family Caregivers Act*, sets out the requirements for a national family caregiving strategy,¹⁵⁹ that is supported by a family carers' advisory council.¹⁶⁰

Obligations on the public service and associated providers

- 2.85 Part 3 of the Act details the responsibilities and obligations of all Australian public service agencies, public service care agencies and associated providers. The Act is supplemented by a set of guidelines developed by DSS in 2016 to assist agencies in implementing their obligations and reporting where applicable.¹⁶¹

Public service agencies and public service care agencies

- 2.86 Obligations on all public service agencies (including a department, an executive agency or a statutory agency within the meaning of 'Agency' in the *Public Service Act*

¹⁵⁵ Carers Australia, *Submission 111*, page 27.

¹⁵⁶ Carers Australia, *Submission 111*, pages 27-28.

¹⁵⁷ McCabe Centre for Law and Cancer, *Submission 80.1*, page 6. Australia ranks well behind Canada in the difference between the number of unpaid caring hours provided by women compared to men, see: KPMG, *Towards a new and improved era in women's equality: valuing unpaid work*, November 2022, page 10.

¹⁵⁸ Carers NSW, *Submission 94.1*, page 3.

¹⁵⁹ Administration for Community Living, United States Government, *RAISE Family Caregiving Advisory Council*, May 2023, www.acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council.

¹⁶⁰ Suicide Prevention Australia, *Submission 22.1*, page 2.

¹⁶¹ 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.

1999)¹⁶² are limited to awareness and understanding of the Act, and that human resources policies are developed having regard to the Statement. There are no reporting requirements for these obligations.¹⁶³

- 2.87 Public service agencies that identify as ‘care agencies’ do have reporting obligations. Currently, it is up to each public service agency to self-assess whether they are a public service care agency, namely, ‘a public service agency that is responsible for the development, implementation, provision or evaluation of care supports’.¹⁶⁴ The Act defines ‘care supports’ as ‘policies, programs or services directed to carers or the persons for whom they care.’¹⁶⁵
- 2.88 Carers Australia found that there were ‘several ... agencies that should be considered public service care agencies’ but that did not report under the Act, highlighting an ‘ambiguity in which agencies are self-identifying and why some are not.’¹⁶⁶
- 2.89 Carers Australia identified other agencies that reported but that provided limited level of detail.¹⁶⁷ It found that the agencies that provided comprehensive statements of compliance in 2021/2022 Annual Reports were DSS, Department of Veterans’ Affairs (DVA), and the National Disability Insurance Agency (NDIA).¹⁶⁸
- 2.90 When asked about which agencies self-identify as a care agency, DSS provided the Committee with six examples of Commonwealth agencies that reported in 2021–22: DSS, DVA, NDIA, the NDIS Quality and Safeguards Commission (NDISQSC), the Department of Health, and Services Australia.¹⁶⁹ Of these agencies, only the reports from DSS, DVA and NDIA include information on what actions the agencies are taking to reflect the principles of the Statement in developing, implementing, providing or evaluating care supports, or consulting carers, or bodies that represent carers, when developing or evaluating care supports.¹⁷⁰
- 2.91 By contrast, the reports from NDISQSC, Department of Health and Services Australia focus only on those agencies’ regard for carers in their human resources policy development, including the provision of carers’ leave.¹⁷¹ There are a further six 2021-22 annual reports that were tabled in the House of Representatives that provide reports of this type.¹⁷²

¹⁶² *Carer Recognition Act 2010*, s 4.

¹⁶³ *Carer Recognition Act 2010*, s 7.

¹⁶⁴ *Carer Recognition Act 2010*, s 4; Department of Social Services (DSS), *Submission 70.1*, page 1.

¹⁶⁵ *Carer Recognition Act 2010*, s 4.

¹⁶⁶ Carers Australia, *Submission 111*, page 23.

¹⁶⁷ Carers Australia, *Submission 111*, page

¹⁶⁸ Carers Australia, *Submission 111*, page

¹⁶⁹ DSS, *Submission 70.1*, page 1.

¹⁷⁰ DSS, *Annual Report 2021-22*, pages 255-256; Department of Veterans’ Affairs, *Annual Report 2021-22*, page 207; National Disability Insurance Agency, *Annual Report 2021-22*, pages 204-205.

¹⁷¹ NDIS Quality and Safeguards Commission, *Annual Report 2021-22*, page 61; Department of Health, *Annual Report 2021-22*, page 132; Services Australia, *Annual Report 2021-22*, page 131.

¹⁷² Australian Electoral Commission, *Annual Report 2021-22*, page 70; Attorney General’s Department, *Annual Report 2021-22*, page 49; National Indigenous Australians Agency, *Annual Report 2021-22*, page 89;

- 2.92 There was general agreement that this voluntary and inconsistent reporting system, with limited oversight, accountability or consequences¹⁷³, has resulted in an Act that is not effective and has not established significant or ongoing practical opportunities for carers.¹⁷⁴
- 2.93 MND Australia said that while the NDIA claims compliancy with the Act, its members report that ‘carers are not considered “important” when developing participant plans for people with MND [motor neurone disease] — and this is an experience that is nationwide.’¹⁷⁵
- 2.94 Carers and support organisations recommended that the obligations and reporting requirements under sections 7 and 8 should be extended to all public service agencies and omit the concept of public service care agencies from the Act altogether.¹⁷⁶
- 2.95 The Committee heard that obligations should not be limited to public service care agencies, as carers are present in all aspects of society¹⁷⁷ and can experience challenges across government including transport, employment, and education.¹⁷⁸
- 2.96 Carers NSW reported that carers are continually not being ‘included in care planning and decision making’¹⁷⁹, despite public service care agencies being obligated to include carers when developing or evaluating policies, programs or services directed to carers or the persons for whom they care.

Enforceability and complaints pathways

- 2.97 Stakeholders argued that the Act’s biggest weakness is its explicit exclusion of any rights or duties that are legally enforceable (section 10).¹⁸⁰ LEA commented:

Without a legally enforceable legislative approach, the nature of these Acts remains largely as rhetorical documents. Where stigma, discrimination and human rights abuses remain rife in Australian society, it is not enough to simply state ‘this is the way the Government would like you all to consider your fellow humans.’¹⁸¹

National Mental Health Commission, *Annual Report 2021-22*, page 75; Treasury, *Annual Report 2021-22*, page 200.

¹⁷³ Carers NSW, *Submission 94*, page 6; Merri Health, *Submission 103*, page 3; Carers Australia, *Submission 111*, page 23.

¹⁷⁴ Carers Victoria, *Submission 109*, page 5; Inner South Family and Friends, *Submission 107*, page 1.

¹⁷⁵ MND Australia, *Submission 69*, page 5.

¹⁷⁶ Carers NSW, *Submission 94*, page 7; Name Withheld, *Submission 27*, page 4; Redkite, *Submission 53*, page 10; QAMH and Arafmi, *Submission 41*, page 8; Suicide Prevention Australia, *Submission 22*, page 4; Relationships Australia, *Submission 17*, page 14.

¹⁷⁷ Redkite, *Submission 53*, page 10.

¹⁷⁸ Suicide Prevention Australia, *Submission 22*, page 4.

¹⁷⁹ Carers NSW, *Submission 94*, page 7.

¹⁸⁰ Carers NSW, *Submission 94*, page 7; *Carer Recognition Act 2010*, s 10(1).

¹⁸¹ Lived Experience Australia Ltd, *Submission 56*, page 7.

- 2.98 Carers NSW emphasised that, without enforceability, ‘there is no formal way of holding a public service care agency to account if it develops or evaluates care supports without consulting with carers, or bodies that represent carers.’¹⁸²
- 2.99 Importantly, there are no appeals or complaints mechanisms if the principles in the Act are not followed.¹⁸³ According to QAMH and Arafmi, this is evident in carers’ service outcomes:
- ... there are many examples of instances where the principles in the Statement are clearly not being followed by public service agencies or associated providers. For example, carers may be routinely excluded from and marginalised in care settings, often with detrimental effects to the person being cared for as well as the efficiency and effectiveness of the service.¹⁸⁴
- 2.100 Similarly, Carers SA provided an example of a carer’s interaction with government services:
- I recently spoke to a Carer who had cared for an adult child with severe mental illness and quadriplegia for a great many years. Along the way, the Carer naturally had been in contact with health services, mental health services, Centrelink, NDIS ... support services provider and the GP ... Unfortunately, not one of these had ever offered support for the Carer, nor advised the Carer that specific support services for Carers were available.¹⁸⁵
- 2.101 There was general agreement that to achieve true carer recognition, the Act should contain stronger enforcement and accountability measures, consequences for not delivering on obligations, and opportunities or pathways for carers to make a complaint or appeal a situation where they feel they have not been recognised or where human rights breaches have occurred.¹⁸⁶
- 2.102 The McCabe Centre for Law and Cancer added that for the Act to be rights-based, it needs to include:
- ... mechanism[s] for carers to participate in decision-making that affects their lives; more effective monitoring and obligations on Public Service agencies and others that are funded by the federal government; and clearly stating that carers have rights and providing a way to empower them.¹⁸⁷

¹⁸² Carers NSW, *Submission 94*, page 8.

¹⁸³ QAMH and Arafmi, *Submission 41*, page 7; Carers NSW, *Submission 94*, page 8.

¹⁸⁴ QAMH and Arafmi, *Submission 41*, page 7.

¹⁸⁵ Carers SA, *Submission 150*, page 4.

¹⁸⁶ Carers NSW, *Submission 94*, page 8; QAMH and Arafmi, *Submission 41*, page 7; Carers ACT, *Submission 58*, page 10; Kiind, *Submission 51*, page 3; Carers SA, *Submission 150*, page 4; Professor Sharon Lawn, Chair and Executive Director, Lived Experience Australia, *Committee Hansard*, 29 August 2023, page 1.

¹⁸⁷ Ms Tarishi Desai, Manager, Treatment and Supportive Care, McCabe Centre for Law and Cancer, *Committee Hansard*, 4 October 2023, page 16.

- 2.103 DSS agreed that a rights-based approach would mean that the Act would need to contain a mechanism to monitor compliance, consequences for a failure to observe the right and a way to review decisions.¹⁸⁸
- 2.104 Carers in the ACT who believe they have not had their rights upheld can make a complaint through the ACT Human Rights Commission.¹⁸⁹ Complaints are then resolved through the ACT's *Human Rights Act 2004* as well as the *Carer Recognition Act 2021* (ACT).¹⁹⁰
- 2.105 Carers recognition legislation in WA, Northern Territory and Queensland provide that consideration must be given to complaints made by carers in relation to services that impact them.¹⁹¹

Obligations on associated providers

- 2.106 In addition to public service agencies, 'associated providers' are obligated by the Act to ensure that their officers, employees and agents have an awareness and understanding of, and take action to reflect the principles of the Statement when developing, implementing, providing or evaluating care supports.¹⁹² Associated providers are defined as people or bodies, and their immediate subcontractors, that are contracted or funded by a public service care agency to develop, implement, provide or evaluate care supports.¹⁹³ Associated providers do not have reporting obligations.
- 2.107 There was some confusion about which associated providers had obligations under the Act because, as Carers Australia noted, the onus is on the 'public sector care agency to stipulate such reporting requirements in their funding agreements'.¹⁹⁴ Mental Health Carers Australia said that it is unclear if it extends to NDIS providers because 'carers currently consider themselves "fortunate" if a provider engages them, not that it is and should be their right'.¹⁹⁵
- 2.108 As discussed earlier, First Nations carers experience a lack of understanding and responsiveness from mainstream service providers, with Gayaa Dhuwi (Proud Spirit) Australia explaining that this is 'due to cultural differences and historical mistrust'.¹⁹⁶ It recommended that 'all service providers should recognise, support, and offer

¹⁸⁸ Ms Robyn Shannon, Deputy Secretary, Disability and Carers, Department of Social Services, *Committee Hansard*, 24 October 2023, page 4.

¹⁸⁹ Ms Lisa Kelly, Chief Executive Officer, Carers ACT, *Committee Hansard*, 29 August 2023, page 24.

¹⁹⁰ Ms Lisa Kelly, Chief Executive Officer, Carers ACT, *Committee Hansard*, 29 August 2023, page 24.

¹⁹¹ *Carers Recognition Act 2004* (WA), Schedule 1 – The Western Australian Carers Charter; *Carers Recognition Act 2006* (NT), Schedule – Northern Territory Carers Charter; *Carers (Recognition) Act 2008* (Qld), Schedule – The Queensland carers charter.

¹⁹² *Carer Recognition Act 2010*, s 9.

¹⁹³ *Carer Recognition Act 2010*, s 4(2).

¹⁹⁴ Carers Australia, *Submission 111*, page 25.

¹⁹⁵ Mental Health Carers Australia, *Submission 116*, page 4.

¹⁹⁶ Gayaa Dhuwi (Proud Spirit) Australia, *Submission 31*, page 3.

First Nations concepts of SEWB [social and emotional wellbeing], mental health, and healing.’¹⁹⁷

- 2.109 Carers ACT told the Committee that the *Carer Recognition Act 2021* (ACT) requires services ‘that interact with the care relationship’ to have carer friendly policies and to operate carer friendly workplaces.¹⁹⁸ In addition, the ACT legislation ‘requires service providers who provide support to either side of the care relationship to ensure carers are provided with their rights on entry into the service and that those rights are upheld within the service’.¹⁹⁹ Carers ACT added that:

... that's given us the opportunity to effect some really pertinent changes for carers in the ACT, both at the high level in terms of policy at government but also in local changes in daily spaces. We've seen things, for example, like recognising carers is now an outcome in funding contracts that come through the territory. So, anyone who gets a contract to deliver a service as part of their performance indicators needs to be able to show how they've identified and responded to carers in that contract.²⁰⁰

Carers not recognised in health sector

- 2.110 There was considerable concern about the lack of awareness and understanding of the Act in the health sector. Carers and carer support organisations reported that principle 7 of the Statement is not consistently upheld in medical settings. In practice, carers are not recognised, often treated as an afterthought and frequently overlooked. Carers are excluded from important decisions that affect both them and the person they are caring for.²⁰¹

Box 2.4 Carers’ experiences of service providers and the health sector

Carers are not considered partners with other care providers, such as medical staff. Many times, I was left out of important decisions and at other times struggled to be heard about what my husband was suffering.²⁰²

Another thing that has helped has been the rare times that health professionals have shown care or concern for me as a carer. When this happens, I feel seen and heard, and I am grateful to those health professionals who have understood. Sadly, I can count on one hand the number of times this has actually happened in 30 years ...²⁰³

¹⁹⁷ Gayaa Dhuwi (Proud Spirit) Australia, *Submission 31*, page 3.

¹⁹⁸ Ms Lisa Kelly, Chief Executive Officer, Carers ACT, *Committee Hansard*, 29 August 2023, page 23.

¹⁹⁹ Ms Lisa Kelly, Chief Executive Officer, Carers ACT, *Committee Hansard*, 29 August 2023, page 23.

²⁰⁰ Ms Lisa Kelly, Chief Executive Officer, Carers ACT, *Committee Hansard*, 29 August 2023, page 23.

²⁰¹ Carers Australia, *Submission 111.1*, page 5; OPAN, *Submission 39*, page 7; Dementia Australia, *Submission 35*, pages 4-5; Carers NSW, *Submission 94*, page 7; HelpingMinds, *Submission 55*, page 7; Name Withheld, *Submission 18*, page 3; Carers Queensland, *Submission 59*, pages 5-6; Professor Sharon Lawn, Chair and Executive Director, Lived Experience Australia, *Committee Hansard*, 29 August 2023, page 2; OPAN, *Submission 39*, page 7.

²⁰² Dementia Australia, *Submission 35*, page 4.

²⁰³ Ms Alyssa Weirman, *Committee Hansard*, 4 October 2023, pages 11-12.

No-one—including my GP—identified me as a mental health carer, or told me about available supports for mental health carers ... None of the service providers I spoke to while getting XX care identified me as a carer either ... While I supported XX to attend a variety of appointments with clinicians and support services, I was not able to be included in care plans, nor could I contact any of these service providers to warn of impending problems. I had no recognised role in XX's care, and their privacy outweighed other considerations.²⁰⁴

... when I was caring for my mum—who ... had breast cancer—I was not included in any of the discussions around her care even though she was coming back into the home and I had to provide care for her. I was told, 'You're 15 years old; you don't need to worry about it.' But, when she was vomiting from her chemotherapy and she couldn't sleep at night, I was the one who was helping to take care of her.²⁰⁵

... carers and their relationship with service providers should also be recognised, not just as an afterthought or worse still an inconvenience in the eyes of some service providers ... if a service believes a person is good to go home and be released from hospital care back into our care, a lot of times it would have been nice if the carer could be checked to see whether they have the capacity to take back the person ...²⁰⁶

I wonder why no-one has thought to reach out to me as a carer, whether it's one of the services that I deal with from a social services point of view, or even my superannuation company. No-one has thought to reach out to me and say: 'You're a carer. Let's have a chat about how we can specifically help you. What do you need? Tell us how we can help you.' I think again it's not that no-one wants to help, I just don't think they've thought to help. They haven't recognised that there is a need that I have specific to the role that I play.²⁰⁷

2.111 Carers Queensland reported that carers are often sidelined by healthcare professionals, which can mean that important information about the patient is not being considered. Carers are then expected to take the patient home and provide care 'with little to no new knowledge as to how best to provide care and support or any discussion as to their ongoing capacity to continue to provide care'.²⁰⁸

2.112 HelpingMinds noted that even when carers identify themselves, they often go unrecognised in clinical service settings²⁰⁹, and said:

Often, carers express frustration that the caring role can be overlooked by clinicians when the focus is on the patient. It is often in these circumstances that discharge of the patient to the carer is part of the treatment plan without acknowledging the impact that is going to have on the carer.²¹⁰

²⁰⁴ Name Withheld, *Submission 18*, page 3.

²⁰⁵ Ms Madeleine Buchner, Founder and Chief Executive Officer, Little Dreamers Australia, *Committee Hansard*, 4 October 2023, page 6.

²⁰⁶ Alex, *Committee Hansard*, 24 August 2023, page 11.

²⁰⁷ Briana, *Committee Hansard*, 24 August 2023, page 11.

²⁰⁸ Carers Queensland, *Submission 59*, pages 5-6.

²⁰⁹ HelpingMinds, *Submission 55*, page 3.

²¹⁰ HelpingMinds, *Submission 55*, page 7.

- 2.113 HelpingMinds suggested that the Act be amended to oblige clinicians, and in particular psychiatrists, to involve the carer ‘because they know their loved one, they know what they’re like when they’re not in front of a clinician.’²¹¹
- 2.114 Concerns were raised that service providers may not be asking the right questions to determine whether a patient has a carer. LEA suggested that patients should be asked questions such as ‘do you have someone who supports you emotionally, someone that you trust and who looks out for you?’²¹²
- 2.115 There was strong support for the Act to be amended to require service providers to recognise carers and to promote and protect their rights.²¹³ The Older Person’s Advocacy Network (OPAN) called for carers to have access to remedies if their rights are not respected.²¹⁴
- 2.116 Alongside proposed amendments to the Act, there was emphasis on the importance of educating healthcare and other service providers to enhance awareness of carers.²¹⁵

Carer advisory council

- 2.117 Some Australian states have advisory councils established under their respective carer recognition legislation, or in Tasmania’s case, established by the relevant Minister, tasked with advancing the interests of carers. Table 2.1 outlines the membership and functions of each carer advisory council.

Table 2.1 Carer advisory councils in Australia

Jurisdiction	Membership	Functions
Western Australia ²¹⁶	10 members who have knowledge of, and experience in, matters relevant to carers.	Advance the interests of carers and promote compliance by applicable organisations with the Carers Charter. Make recommendations to the Minister on fostering compliance. Provide general advice to the Minister on matters relating to carers. Provide the Minister an annual report on its performance and compliance with the Act and Carers Charter.

²¹¹ Mrs Paula Smith, Volunteer, Mood Disorders Carers Support Group, *Committee Hansard*, 24 August 2023, page 3.

²¹² Professor Sharon Lawn, Chair and Executive Director, Lived Experience Australia, *Committee Hansard*, 29 August 2023, page 3.

²¹³ OPAN, *Submission 39*, page 3; Carers SA, *Submission 61*, page 4; Women, Work and Policy Research Group and ARC Centre of Excellence in Population Ageing Research, USYD, *Submission 81*, page 2.

²¹⁴ OPAN, *Submission 39*, page 3.

²¹⁵ See Chapter 3.

²¹⁶ *Carers Recognition Act 2004* (WA), Part 3.

Queensland ²¹⁷	10 members consisting of four public service employees, three carers and three representatives of different carers associations.	Advance the interests of carers and promote compliance with the carers charter. Make recommendations to the Minister on enhancing compliance with the carers charter. Provide general advice to the Minister on matters relating to carers.
New South Wales ²¹⁸	Persons appointed as members by the Minister who, in the opinion of the Minister, have relevant knowledge of and experience in matters relevant to carers and the majority of members must be carers.	Advance the interests of carers. Review and make recommendations to the Minister on any legislative or policy proposal, or any other matter, relating to carers referred to the Carers Advisory Council by the Minister.
Tasmania ²¹⁹	Three to five members with lived or living experience as a carer.	Provide advice to inform Tasmanian Government responses to carer issues. Provide feedback on Tasmanian Government policies, programs, services and initiatives that address and respond to carer issues. Identify issues faced by carers and the services that support carers. Provide advice and assist in monitoring the implementation of and reporting on the Tasmanian Carer Action Plan and the <i>Carer Recognition Act 2023</i> (Tas).

2.118 The McCabe Centre for Law and Cancer, among others, proposed the establishment of a similar federal advisory body to monitor compliance with the Act.²²⁰ Carers NSW said that this would ensure that carers are consulted in the ‘development of legislation, policies and programs that affect them’.²²¹

2.119 Kiind provided positive feedback on WA’s advisory council, stating that the ‘direct reporting and advisory capacity to the minister’ has worked well and as the council works across multiple sectors, there has been an increased recognition of carers.²²²

²¹⁷ *Carers (Recognition) Act 2008* (Qld), Part 3.

²¹⁸ *Carers (Recognition) Act 2010* (NSW), Part 3.

²¹⁹ Tasmanian Government, Department of Premier and Cabinet, ‘Minister’s Carer Advisory Council Terms of Reference’, November 2022, page 1, www.dpac.tas.gov.au/__data/assets/pdf_file/0019/254305/Ministers-Carer-Advisory-Council-MCAC-Terms-of-Reference.pdf.

²²⁰ McCabe Centre for Law and Cancer, *Submission 80.1*, page 5; Carers NSW, *Submission 94*, page 6; Suicide Prevention Australia, *Submission 22*, page 5; ermha365, *Submission 71*, page 7; Tandem, *Submission 123*, page 3; Carers WA, *Submission 113.1*, page 2.

²²¹ Carers NSW, *Submission 94*, page 6.

²²² Ms Carrie Clark, Chief Executive Officer, Parents of Children with Special Needs Inc, trading as Kiind, *Committee Hansard*, 29 August 2023, page 16.

Review date and regular monitoring

- 2.120 Most state and territory carer recognition legislation contain a clause that requires the relevant Minister, five years after the Act's commencement, to review the operation and effectiveness of the Act and present a report to the relevant parliament.²²³ The *Carer Recognition Act 2023* (Tas) goes further and specifies that a review should also be conducted every subsequent five years.²²⁴
- 2.121 The Committee heard that the Act should be regularly monitored and evaluated for its effectiveness to ensure it remains fit-for-purpose.²²⁵
- 2.122 Carers WA said that the review date should also apply to the National Carer Strategy.²²⁶

Committee comment

- 2.123 The *Carer Recognition Act* (the Act) has failed to provide the meaningful recognition and support that carers want and rightfully deserve. The Act contains weak and vague statements that lack clear calls to action and has a voluntary and inconsistent reporting system with no effective oversight and accountability.
- 2.124 The consequences of an ineffectual Act are that carers are ignored or unsupported by public service agencies and in healthcare settings and excluded from important decisions concerning the individuals they care for. Some LGBTIQ+ carers face stigma and discrimination, further compounding the challenges that they encounter. Young carers are often not acknowledged at school and face barriers in accessing youth-friendly support and services. First Nations and CALD carers experience a lack of understanding and responsiveness from services, as well as discrimination and difficulty accessing help when they need it.
- 2.125 While the current definition of carer in the Act may be serviceable, it is not perfect and a modern and more inclusive definition of carer could clarify the intent and scope of the Act. Carers are so much more than how the Act defines them. The term 'carer' may not translate to all CALD communities. The existing definition fails to acknowledge that an individual might receive care and support from multiple carers. The use of 'frail and aged' does not consider that some people can be frail and not aged. The definition also contributes to low rates of self-identification among young carers.

²²³ See, for example: *Carers (Recognition) Act 2010* (NSW), s 15; *Carers Recognition Act 2021* (ACT), s 15; *Carers Recognition Act 2005* (SA), s 9; *Carers Recognition Act 2006* (NT), s 9.

²²⁴ *Carer Recognition Act 2023* (Tas), s 10.

²²⁵ Carers Tasmania, *Submission 57*, page 9; HelpingMinds, *Submission 55*, page 5.

²²⁶ Carers WA, *Submission 113*, page 9.

- 2.126 The definition needs to encompass the diverse realities of the caring role. In this regard, the meaning should be reframed into a ‘care relationship’, modelled on the ACT’s *Carer Recognition Act 2021* and Victoria’s *Carers Recognition Act 2012*.
- 2.127 A ‘care relationship’ can be more flexible and inclusive of the diversity of carers, regardless of the nature of the relationship. It should explicitly acknowledge and encompass carers who support those with alcohol or other drug dependence, and young carers who care for a family member.
- 2.128 Any modernised definition of carer should also recognise relationships where multiple family members are carers. For example, where a parent or child requires constant care, there is often a network of family members who provide that, and they should also be considered carers.
- 2.129 Informal kinship carers and foster carers should not be explicitly defined as carers in the Act as their roles may not necessarily go beyond what would typically be expected from a familial relationship. Informal kinship carers and foster carers should be considered carers under the Act if they meet the definition of a ‘care relationship’—that is, that the person or people they care for have a disability, are frail and/or aged, or are experiencing mental ill health, a medical condition or alcohol or other drug dependence.
- 2.130 An amended Act should be established with urgency. The Committee considers that thirteen years is long enough for Australia’s carers to experience low recognition and its consequences on their interactions with government and the health sector.

Recommendation 1

- 2.131 **The Committee recommends that the meaning of carer under section 5 of the *Carer Recognition Act 2010 (the Act)* be modernised and contextualised as a ‘care relationship’ to be more inclusive of the diversity of caring roles and to make it easier for carers to self-identify.**
- 2.132 **The Committee considers that a person is in a ‘care relationship’ with another person if the first person (the carer) provides care for one or more of the following reasons:**
- **the other person has a disability**
 - **the other person is experiencing mental ill health**
 - **the other person has a medical condition, including a terminal or chronic illness**
 - **the other person is frail and/or aged**
 - **the other person is experiencing alcohol or other drug dependence.**
- 2.133 **The Committee considers the Act should specify that:**
- **a person can be in multiple care relationships**

- **children and young people under the age of 25 who provide care are young carers.**

2.134 All states and territories have carer recognition legislation but there are significant disparities in how the term 'carer' is defined. Carers who access healthcare services in a different state, or who move, may be unsure of their status as carers and what supports and services are available to them. To ensure national consistency, the Australian Government should work with the state and territories to develop a uniform and modern definition of carer across all carer recognition legislation. The Committee strongly encourages the Australian Government to consistently apply the modern definition of carer across other federal legislation relating to carers, and in data collection and reporting about the value of unpaid care.

Recommendation 2

2.135 The Committee recommends that the Australian Government works with the state and territories to harmonise the definition of carer across all carer recognition legislation, acknowledging respective Australian Government and state and territory care arrangements, and in data collection and reporting about the value of unpaid care.

Recommendation 3

2.136 The Committee recommends that the Australian Government conduct a review of all federal laws relating to carers, and make amendments where needed, to ensure consistency with the revised Act. The review should be conducted within one year of the revised Act being established.

2.137 Carers should be able to have a clear understanding of their rights and have them realised. Carers want confidence that Australia's lawmakers, policymakers and service providers place carers at the forefront when shaping health and social care laws and policy, rather than as an afterthought.

2.138 The Statement for Australia's Carers are ideals that remain far from being realised and one of the reasons for this is because the Act confers no rights on carers in the way that all Australians receive rights through anti-discrimination and employment legislation. While the Committee believes it is critical that a set of rights be established for carers, recognition legislation may not be the best way to do this.

2.139 Evidence suggests there may be legal issues associated with introducing new rights in federal legislation that do not correspond to an international treaty. The Australian Government should seek legal advice to determine how best to establish rights for carers.

Recommendation 4

2.140 The Committee recommends that, by December 2024, the Australian Government seek legal advice to determine how best to establish rights for carers. These rights should include:

- **being acknowledged as partners in care**
- **being involved in planning and policy development**
- **being provided with information regarding the person they care for in order to provide care**
- **accessing flexible work arrangements.**

2.141 Several elements of the existing Statement should be retained, including that:

- Carers should be treated with dignity and respect;
- Support for carers should be timely, responsive, appropriate and accessible; and
- Carers should be supported to enjoy optimal health and social wellbeing and to participate, in family, social community and economic life.

2.142 The Committee considers that the Statement must be strengthened to better recognise and acknowledge the diverse cohorts of carers and the gendered nature of the caring role. Again, the ACT's *Carer Recognition Act 2021* 'Care relationship principles' provides a good model for how best to present the principles in the Statement to ensure that all carers are seen and heard.

Recommendation 5

2.143 The Committee recommends that the Statement for Australia's Carers is amended to include explicit recognition of:

- **First Nations carers**
- **culturally and linguistically diverse carers**
- **lesbian, gay, bisexual, transgender, intersex, queer/questioning, asexual and other sexually or gender diverse (LGBTIQA+) carers**
- **young carers.**

2.144 The current approach of allowing public service agencies to self-assess if they are a 'care agency' is not working, and ultimately results in poor outcomes for carers, on both an individual level and in terms of policy development. Carers are present in almost all aspects of society, including but not limited to health, transport, employment, education, child protection and the family courts. All public service agencies must consider the needs of carers and become well-informed about their role in society, regardless of whether those agencies have carer-related policies, programs, or services in place.

- 2.145 The failure of associated providers to recognise or identify carers as partners in care is concerning. Carers should be involved in treatment discussions as they are the ones that are expected to take the individual home and provide care. Carers should be asked whether they have the capacity and ability to do so. There should be clarity and transparency about which associated providers have obligations under the Act.
- 2.146 The Department of Social Services, in collaboration with the Australian Public Service Commission, should be supporting all public service agencies to report on these obligations. The 2016 Carer Recognition Act 2010 Guidelines must be updated and include additional information on how agencies and associated providers can meet their obligations and reflect the principles in the Statement.

Recommendation 6

- 2.147 The Committee recommends that the definition of ‘public service care agency’ under section 4 of the Act, and any further reference to ‘public service care agency’ is omitted.**

Recommendation 7

- 2.148 The Committee recommends that Part 3 of the Act be amended to require all public service agencies and associated providers to:**
- **take all practicable measures to ensure that it and its employees and agents have an awareness of, and take action to, reflect the principles of the Statement for Australia’s Carers in developing, implementing, providing or evaluating care supports**
 - **develop internal human resources policies, so far as they may significantly affect an employee’s caring role, having due regard to the Statement for Australia’s Carers**
 - **consult carers, or bodies that represent carers, when developing or evaluating care supports.**
- 2.149 In addition, all public service agencies should be required to, in each reporting period, prepare a report that is to be included in the agency’s annual report, on:**
- **the agency’s compliance with its obligations under the Act**
 - **its associated providers’ compliance with their obligations under the Act.**
- 2.150 A modernised Act with stronger obligations must be supported by regular monitoring to ensure that it continues to remain fit-for-purpose. Like other state and territory carer recognition legislation, the Act should contain a provision requiring the relevant Minister to review the operation and effectiveness of the Act, the Statement, and the National Carer Strategy, every five years. A report on the Minister’s review should be tabled in Parliament.

Recommendation 8

- 2.151 The Committee recommends that the Act be amended to include a provision that requires the Minister, every five years, to review the operation and effectiveness of the Act, the Statement for Australia's Carers, and the National Carer Strategy. A report on the Minister's review must be tabled in Parliament.**
- 2.152 It is important that carers are aware of how to voice their concerns or appeal situations where they believe they have not been recognised or where government agencies have not met their obligations under the Act. These issues are considered further in the following chapter.



3. A national carer strategy and practical recognition

- 3.1 The Committee was concerned that the number of carers in Australia is not expected to keep pace with demand for informal care in the future.¹ This has implications for the sustainability of care provision,² and warrants careful consideration of the supports available to carers, and drivers and barriers to people becoming carers.³
- 3.2 There are many factors that influence whether a person requires informal care, such as the availability and adequacy of paid care. As chapter one noted, significant policy work and community consultation has already occurred around improving support for people with disability and people who are frail due to age.
- 3.3 The Committee examined developments in the policy landscape since the *Carer Recognition Act 2010* (the Act) was established and considered what reforms are needed to better recognise and support carers. This chapter examines:
- the National Carer Strategy 2011 (the 2011 strategy)
 - the adequacy of existing supports for carers provided through Carer Gateway
 - developments towards a new National Carer Strategy (new strategy) and evidence about what its key features should be.

National Carer Strategy 2011

- 3.4 The 2011 strategy gave effect to the principles of the Act and outlined how carers' contributions can be valued, supported and shared across six priority areas for action.⁴ Table 3.1 details the 2011 strategy's priority areas, policy directions and performance measures. The data source for performance measures was to be the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC), which is conducted every three years.⁵

¹ Department of Social Services (DSS), *Submission 70*, page 6.

² Carers Australia, *Submission 111*, page 12; Kiind, *Submission 51*, page 5; Australian Federation of Disability Organisations, *Submission 137*, pages 7 and 11.

³ Merri Health, *Submission 103*, page 5.

⁴ Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), *National Carer Strategy*, 2011, page 7.

⁵ FaHCSIA, *National Carer Strategy: Implementation Plan*, 2011, pages 29-30.

Table 3.1 National Carer Strategy 2011: priority areas, outcomes, outcome indicators and performance measures

Priority area and outcome	Outcome indicator	Performance measures
1. Recognition and respect: carers are recognised, valued, respected and have their rights protected	The recognition of carers, and understanding of the caring role, is improved	Proportion of primary carers of people with disability who feel satisfied due to their caring role
2. Information and access: carers have access to appropriate and timely information which makes it easier for them to get support	Carers' access to appropriate and timely information and services is improved	Proportion of primary carers who reported their unmet sources of support was more courses or training required
3. Economic security: carers have economic security and opportunities to participate in paid work	Increased economic security and labour force participation of carers	Proportion of all carers aged 15-24 and 25-64 years who are participating in the labour force compared to non-carers aged 15-24 and 25-64 years Proportion of all carers in households in the lowest equivalised gross household income quintile compared to non-carers
4. Services for carers: carers are supported with appropriate, timely and accessible services	An increase in carers supported with appropriate, timely and accessible services	The proportion of primary carers who report not needing assistance or further assistance to care for their main recipient of care The proportion of primary carers who report receiving assistance to care for main recipient of care
5. Education and training: carers have the skills to undertake their role and opportunities to participate in formal education and training	An increase in the percentage of carers who receive support/training in their caring role and participate in formal education and training	The proportion of all carers aged 15-24 years engaged in education Proportion of all carers aged 25-64 years engaged in education Proportion of all carers aged 18-24 years who have completed Year 12 or Certificate II or above compared to non-carers aged 18-24 years Proportion of all carers with post-school qualifications
6. Health and wellbeing: the health and wellbeing of carers and their capacity to	An increase in the reported health and wellbeing of carers and capacity to	Proportion of primary carers who do not experience negative impacts on their wellbeing due to their caring role

Priority area and outcome	Outcome indicator	Performance measures
participate in social and community life is improved	participate in the community	Proportion of primary carers who participate in social and community activities

Source: Department of Families, Housing, Community Services and Indigenous Affairs, *National Carer Strategy Implementation Plan*, 2011, pages 29-30.

- 3.5 The states and territories had input into the development of the 2011 strategy and were to work with the Australian Government on its implementation through the National Carer Strategy Working Group. The working group included Australian and state and territory government representatives with disability, mental health and carer expertise.⁶
- 3.6 The implementation of the 2011 strategy was to be structured around the following three action plans:
- short term practical actions, 2011-2014
 - longer term practical actions, 2014-2017
 - emerging practical actions, 2017-2020.⁷
- 3.7 The 2011 strategy was discontinued before the second and third actions plans were progressed. Carers Australia said that few of the actions and performance indicators identified by the 2011 Strategy were achieved, and there are neither any publicly available progress reports beyond 2011–12, nor evidence of planned evaluation activities having been undertaken.⁸
- 3.8 Carers Australia noted that, after 2014, there was a shift in focus to consumer directed care and some carer support services were lost to Aged Care and the NDIS, such as funding for mental health respite and young carers.⁹
- 3.9 The Department of Social Services (DSS) said the 2011 strategy was ‘superseded’ in 2015 by the Integrated Plan for Carer Support Services.¹⁰ The Integrated Plan for Carer Support Services model, Carer Gateway, was implemented in April 2020.¹¹

Carer Gateway

- 3.10 The target cohort for Carer Gateway services is carers as defined in Section 5 of the Act. To be eligible for support, the carer’s role must be ongoing, or likely to be

⁶ FaHCSIA, *National Carer Strategy: Implementation Plan*, 2011, page 18.

⁷ FaHCSIA, *National Carer Strategy: Implementation Plan*, 2011, page 9.

⁸ Carers Australia, *Submission 111.1*, page 3.

⁹ Ms Sue Elderton, Senior Policy Officer, Carers Australia, *Committee Hansard*, 17 October 2023, page 2.

¹⁰ DSS, *Submission 70*, page 10.

¹¹ DSS, *Carer Gateway*, ‘About’, www.carergateway.gov.au/about, viewed 12 September 2023.

ongoing, for at least six months. This expectation of six months or more does not apply to a carer of a person who needs palliative care.¹²

3.11 Carer Gateway services include:

- carer directed packages that provide a range of practical supports to assist carers in their role. The total value of the package, to which each carer is entitled, is \$3,000 (over a 12-month period) and can be used for a range of items and services including:
 - planned respite
 - cleaning services
 - assistance with shopping
 - cooking
 - assistance with transport.
- one-off practical support (up to an amount of \$1,500) for items that support carers in their caring role or to access education or employment, such as training courses or a laptop¹³
- access to emergency respite
- in-person and online peer support groups
- in-person and phone counselling
- in-person and online self-guided coaching
- online skills courses.¹⁴

3.12 The proportion of carers registered with Carer Gateway service providers increased from 2 per cent in 2021 to almost 5 per cent in 2022.¹⁵ As of June 2023, 163,403 carers were registered with Carer Gateway service providers.¹⁶

3.13 The Carer Gateway national advertising campaign commenced in October 2022 and aims to increase awareness of services and supports and assist carers to self-identify. Since the campaign's launch, the number of visitors to the Carer Gateway website increased from an average of 70,000 visitors each month (over the 12 months prior), to an average of 310,000 visitors per month between October 2022 and June 2023.¹⁷

3.14 The Australian Government has committed \$1.108 billion over five years to 2026–27 to fund Carer Gateway service providers, the national phone counselling service and

¹² DSS, Exhibit 5, *Carer Gateway Service Provider Manual V1.2*, March 2021, pages 39-40.

¹³ DSS, Exhibit 5, *Carer Gateway Service Provider Manual V1.2*, March 2021, pages 46-47.

¹⁴ DSS, *Carer Gateway*, 'Services and support', www.carergateway.gov.au/services-and-support, viewed 14 September 2023.

¹⁵ DSS, *Submission 70*, page 8.

¹⁶ DSS, *Submission 70.2, Attachment 1*, page 2.

¹⁷ DSS, *Submission 70*, page 9.

other programs, such as the Young Carer Bursary Program. Estimated annual Australian Government funding for carer support services is included in Table 3.2.

Table 3.2 Estimated annual Australian Government funding for carer support services

2022-2023	2023-24	2024-25	2025-26	2026-27	Total over 5 years
\$213,068,000	\$213,279,000	\$225,530,000	\$231,336,000	\$224,875,000	\$1,108,088,00

Source: DSS, *Submission 70.2*, page 6.

- 3.15 The Australian Government also provides financial support to carers through the Carer Payment, Carer Allowance, Carer Supplement, Child Disability Assistance Payment, and Carer Adjustment Payment, at a cost of more than \$60 billion over five years to 2026-2027.¹⁸
- 3.16 Outcome reporting for Carer Gateway is included in the DSS annual report. The sole performance measure is the extent to which carers access information, supports and services. The 2021–22 annual report notes that, from 2022–23, DSS will also report on the extent to which carers' (who are registered with Carer Gateway) wellbeing is assessed as improved.¹⁹
- 3.17 Carer Gateway is currently being evaluated for its appropriateness, effectiveness and efficiency; the evaluation report is expected in late 2023.²⁰

Feedback from carers

- 3.18 There was mixed feedback on whether Carer Gateway was providing carers with access to the support services they need. Some carers indicated the supports they received were helpful.²¹ However, the Committee also heard that that accessing support through Carer Gateway can be slow, time-consuming and difficult for carers.²² Some carers did not receive the assistance they wanted and were offered services they felt were unhelpful²³, while others believed it was not worth the effort seeking support from Carer Gateway.²⁴ For example, one carer said:

While it was easy finding the Carers Gateway, finding the space and time to call was not. By the time I did, we had been in crisis for some time. It took about a week to have an intake assessment - this is too long when people are in crisis. But then the support that was offered took even longer and there have been multiple other challenges with receiving services.²⁵

¹⁸ DSS, *Submission 70.2*, page 6.

¹⁹ DSS, *Annual Report 2021-22*, pages 95-96.

²⁰ DSS, *Submission 70*, page 9.

²¹ Name Withheld, *Submission 1*, page 1; Ms Victoria Green, *Submission 105*, page 2.

²² Name Withheld, *Submission 13*, page 4; Tandem, *Submission 123*, pages 18-19.

²³ Name Withheld, *Submission 49*, page 6; Danijela Hlis, *Submission 12*, pages 1-2.

²⁴ Name Withheld, *Submission 28*, page 5; Name Withheld, *Submission 3*, page 3; Name Withheld, *Submission 6*, page 3; Name Withheld, *Submission 143*, page 3.

²⁵ Name Withheld, *Submission 143*, page 3.

- 3.19 Another carer described a series of poor experiences with Carer Gateway and said, 'at times I have felt very judged and I have heard other similar stories. In the end it was easier to go without these services than deal with more stress.'²⁶
- 3.20 Tandem reported that most respondents to a survey it conducted expressed concerns about Carer Gateway, including 'long waitlists for resources that are inadequate, that relevant practical assistance such as in-home help or respite were largely unavailable, and the service was difficult to access as carers' calls were not returned.'²⁷
- 3.21 Carers described experiences suggesting low understanding among some Carer Gateway service provider staff about program eligibility and guidelines, and a lack of consistency in the advice given to them.²⁸ For example, one carer was initially told she needed to be 'physically incapacitated' in order to access respite, but did receive help when she told Carer Gateway she had a prescription and letter from her doctor.²⁹
- 3.22 There may be a lack of awareness among Carer Gateway staff of the needs of young carers and their eligibility to access Carer Gateway supports. Ms Mary Pilkinton reported that she was initially denied access to the service, and it took at least four phone calls for an intake assessment to be offered and support provided.³⁰
- 3.23 Ms Pilkinton noted the Carer Gateway website provides no clear way for people to make a complaint to DSS about Carer Gateway services.³¹ By contrast, DSS claimed that complaints mechanisms are clearly available on the Carer Gateway website and that people could make a complaint with the service provider or directly with the department.³² However, the Carer Gateway link that DSS provided to the Committee is about 'Speaking up for someone' – that is, advocating for the rights of the person being cared for. Ms Pilkinton observed:
- ...if you click this link, it doesn't actually have any information about making a complaint about the Carer Gateway. It is general advice about how to make a complaint on behalf of someone you care for, but it doesn't say anything about where to lodge a complaint about the Carer Gateway itself. I think this is a problem as a lot of Carer Gateway participants probably don't know that the Carer Gateway is delivered by different service providers that have their own complaints process so they are likely to look for this information on the national website. I also think a lot of people would feel uncomfortable calling the Carer

²⁶ Name Withheld, *Submission 143*, page 3.

²⁷ Tandem, *Submission 123*, page 8.

²⁸ Tandem, *Submission 123*, pages 18-19.

²⁹ Name Withheld, *Submission 2*, page 3.

³⁰ Ms Mary Pilkington, *Submission 87*, page 3.

³¹ Ms Mary Pilkington, *Submission 87*, page 3.

³² DSS, *Submission 70.3*, page 5; DSS, *Carer Gateway*, 'Speaking up for someone', www.carergateway.gov.au/speaking#a3, viewed 13 November 2023. There is a link on the Department of Social Services website (dss.gov.au) at the bottom of the home page to make a complaint directly to the department.

Gateway and asking their carer support worker directly about complaints processes.³³

Accessibility and integration with other support systems

- 3.24 Concerns were raised about the accessibility of Carer Gateway. Currently, carers can call 1800 422 737 between the hours of 8.00 am and 5.00 pm, Monday to Friday. Carers requiring emergency respite can call outside of these hours, while carers requiring phone counselling can call between 8.00 am and 6.00 pm. Carers can also request a call back via a form on the Carer Gateway website.³⁴
- 3.25 The Committee heard that the option to call during regular business hours can be particularly limiting for young carers who juggle their caring role with education and after school activities. For example, Ms Jacqueline de Mamiel said:
- When I first became engaged with Carer Gateway they needed to do a really long phone consult with me with this star system to find out what I wanted and what sort of support I needed. It was about an hour-and-a-half phone call and there needed to be a phone call in advance to set up the phone call... I often get calls from support services during the day and then, when I call back after school, I'm told, 'That person has gone home now,' or 'They're not working at the moment and they can call you back tomorrow morning.' I am like: 'I am at school again tomorrow morning. Five days a week, I'll be there.'³⁵
- 3.26 The Chamber of Commerce and Industry of Western Australia said the Carer Gateway phone service should be extended to be a dedicated after-hours crisis hotline.³⁶
- 3.27 The Committee heard that services should be designed to be inclusive for carers with low digital literacy³⁷ and limited English language skills.³⁸ Carer Gateway provides a range of materials and resources in Auslan and up to 30 languages for culturally and linguistically diverse (CALD) carers on the Carer Gateway website. The Carer Gateway advertising campaign included targeted social media, radio and out-of-home advertising and a range of in-language materials for First Nations and CALD audiences, such as carer case studies.³⁹
- 3.28 There is a need to ensure that carers can easily navigate support systems, and this requires careful consideration of the user experience.⁴⁰ Carers and those they care for may be eligible to access support from other systems such as My Aged Care and

³³ Ms Mary Pilkington, *Submission 87.1*, page 1.

³⁴ DSS, *Carer Gateway*, 'Services and support', www.carergateway.gov.au/services-and-support, viewed 14 September 2023.

³⁵ Ms Jacqueline de Mamiel, Little Dreamers, Young Carer Participant, *Committee Hansard*, 4 October 2023, page 5.

³⁶ Chamber of Commerce and Industry of Western Australia, *Submission 10*, page 3.

³⁷ Research Centre for Palliative Care, Death and Dying, Flinders University, *Submission 16*, page 5.

³⁸ Ethnic Communities' Council of Victoria (ECCV), *Submission 99*, page 6.

³⁹ DSS, *Submission 70.2*, pages 7-8.

⁴⁰ City of Newcastle, *Submission 43*, page 5.

NDIS. Where these systems operate in silos, it can be confusing for carers. Improved systems integration and the provision of one-to-one support and advocacy was recommended to assist carers to navigate services.⁴¹ For example, one carer said:

NDIS should be linked into Carer gateway, so participants do not have to explain their story again and again. Carer gateway is not that easy to navigate and you feel that you aren't supported, in fact many carers do not even bother trying to access services through carer gateway because it's all too difficult.⁴²

- 3.29 Other service systems should be providing referrals to Carer Gateway. One carer noted that she was not directed to any carer support while applying for carer payments through Centrelink.⁴³
- 3.30 Neighbourhood Houses Victoria identified areas of duplication between Carer Gateway, state-based and not-for-profit services and suggested that resources could be more efficiently and effectively deployed.⁴⁴

Carer assessments and flexibility in service provision

- 3.31 A key component of Carer Gateway is a carer assessment that is used to help understand carers' needs and to plan supports. The Carers StarTM tool was developed in the United Kingdom and covers seven key areas including the carer's health, their caring role, how they are managing at home, whether they have time for themselves, how they feel, their finances and work.⁴⁵
- 3.32 DSS said that not all carers need an assessment to access support. For example, the assessment could be skipped to receive counselling. However, carers require an assessment to access more substantive services, to ensure they meet eligibility criteria. DSS noted that the assessment also provides a pathway for prevention and support, rather than just crisis management.⁴⁶
- 3.33 Tandem reported that many responses to its survey of carers described:

... a confusing intake and assessment process, in which carers are asked '*robotic questions*' to complete a Carer Star assessment tool that is '*an inaccurate measure of the carer's individual situation*', and in which carers struggle to find out what support is available. It was suggested that these difficulties can be exacerbated for carers in rural areas, and those who require interpreters. Many respondents reflected that Carer Gateway appears designed for carers who support people with physical disability or who are aged, rather

⁴¹ Research Centre for Palliative Care, Death and Dying, Flinders University, *Submission 16*, pages 5 and 7.

⁴² Name Withheld, *Submission 28*, page 5.

⁴³ Name Withheld, *Submission 143*, page 3.

⁴⁴ Neighbourhood Houses Victoria, *Submission 114*, page 3.

⁴⁵ DSS, *Carer Support Framework - Integrated Carer Support Service*, December 2019, page 3.

⁴⁶ Ms Kelly Spence, Acting Group Manager, Disability Employment and Carers, DSS, *Committee Hansard*, 24 October 2023, pages 5-6; Ms Robyn Shannon, Deputy Secretary, Disability and Carers, DSS, *Committee Hansard*, 24 October 2023, page 5.

than the challenges associated with the mental health carer role, and that there is a subsequent lack of understanding among staff.⁴⁷

- 3.34 Carers called for greater flexibility in the requirement for assessment, the support services they could access, and transparency and clarity in how much support they are eligible to receive. For carers who may only require a few hours of support, the prospect of having to undergo a lengthy assessment may deter them seeking help.⁴⁸ One carer described navigating a 'labyrinth' of phone calls to undergo an assessment and receive support and was concerned about having to go through the whole process again to access further support because it was unclear how much funding they were eligible for.⁴⁹ It was suggested that carers should be provided with their support budget so they can decide how best to spend it.⁵⁰
- 3.35 For some carers, help in the home with day-to-day tasks may be more useful than respite or self-care supports, such as social outings.⁵¹ More practical and physical supports would allow carers to focus more on providing care.⁵²
- 3.36 Support Groups Queensland Inc. called for there to be more supports available to carers at transition points, such as when people become carers, when their caring role changes significantly and when their caring role ends, including support for grief and loss. It suggested this includes 'information kits, faster intake across government systems and jointly managing the process for both the person and their carer.'⁵³

Access to quality respite care options

- 3.37 Respite care services look after people requiring care so that their carer can have a break. Respite can make a big difference to carers' experience of caring and their ability to sustain their caring role.⁵⁴ Planned respite care can be arranged through Carer Gateway during business hours. Carers may be able to access emergency respite care through Carer Gateway outside of business hours if they are sick or injured. My Aged Care and the NDIS may also support respite care for the person needing care.⁵⁵
- 3.38 The Committee heard that, despite respite care being available through multiple support systems, carers still have difficulty accessing respite services when they need them.⁵⁶ Furthermore, there are significant differences in how much respite care

⁴⁷ Tandem, *Submission 123*, page 8.

⁴⁸ Danijela Hlis, *Submission 12*, page 2.

⁴⁹ Name Withheld, *Submission 13*, page 4.

⁵⁰ Name Withheld, *Submission 11*, page 4.

⁵¹ Mr Colin Allchurch, *Submission 30*, page 2.

⁵² Carers ACT, *Submission 58*, page 8; Name Withheld, *Submission 106*, page 3.

⁵³ Support Groups Queensland Inc, *Submission 52*, page 3.

⁵⁴ Queensland Alliance for Mental Health (QAMH) and Arafmi Ltd, *Submission 41*, page 5; Name Withheld, *Submission 135*, page 4.

⁵⁵ DSS, *Carer Gateway*, 'What is respite', www.carergateway.gov.au/what-respite, viewed 1 November 2023.

⁵⁶ Name Withheld, *Submission 13*, page 3; Name Withheld, *Submission 26*, page 1; QAMH and Arafmi Ltd, *Submission 41*, page 5; Danijela Hlis, *Submission 12*, pages 1-2; Tandem, *Submission 123*, page 8; Name Withheld, *Submission 143*, page 3; Gayaa Dhuwi (Proud Spirit) Australia, *Submission 31*, page 3.

is available to carers through My Aged Care and NDIS, and limitations on eligibility and barriers to access for mental health carers.⁵⁷

- 3.39 The Committee heard that when some carers have tried to access emergency respite care via Carer Gateway, they have been told to call back during business hours, to contact My Aged Care or to take the person they care for to their local hospital emergency department.⁵⁸ Some carers have even tried to get themselves admitted to hospital emergency departments to secure some form of respite.⁵⁹
- 3.40 Carers Australia reported that ‘respite care is even more difficult, if not impossible, to access in many regional, rural, and remote locations.’⁶⁰ For 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.’⁶¹
- 3.41 The Committee heard that the need to access respite care is not limited to carers being physically incapable of continuing in their role, and that carers experiencing mental and emotional strain from caring should be eligible for support.⁶²
- 3.42 Some carers raised concerns about the quality of respite care services. For example, Carers ACT reported:
- ... the quality of care from respite and support workers was raised in almost every consultation, with an alarmingly large number of examples where care recipients were injured or hospitalised because of the poor quality of support. This led to carers feeling that there was no alternative but to perpetually take on all responsibility of care. As a carer group attendee lamented, ‘How can I rest when I have no trust in the support worker?’ Inadequate training and lack of skilled support workers result in poor quality care, often jeopardizing the safety of care recipients.⁶³
- 3.43 There is a need for improved access to appropriate respite services for people who require complex care, such as children and young people with dementia.⁶⁴

⁵⁷ Carers ACT, *Submission 58*, page 8.

⁵⁸ Older Persons Advocacy Network, *Submission 39*, page 5; Name Withheld, *Submission 2*, page 3;

⁵⁹ Carers ACT, *Submission 58*, page 8.

⁶⁰ Carers Australia, *Submission 111*, page 6.

⁶¹ Carers Australia, *Submission 111*, page 7. See also: Name Withheld, *Submission 49*, page 4.

⁶² Name Withheld, *Submission 2*, page 1.

⁶³ Carers ACT, *Submission 58*, page 8.

⁶⁴ Childhood Dementia Initiative, *Submission 133*, pages 4-5

- 3.44 There was strong support for easier access to timely, locally available, high-quality respite care services for carers⁶⁵, including culturally appropriate options for First Nation carers and carers from CALD backgrounds.⁶⁶

Access to counselling and mental health support

- 3.45 Access to free or subsidised professional counselling and mental health support services for carers when they need it is important to safeguard carers' wellbeing.⁶⁷ Carers frequently experience severe emotional distress and immediate access to counselling and other mental health supports should be prioritised.⁶⁸
- 3.46 Carers over the age of 18 years can access a total of six free phone counselling sessions through the Carer Gateway National Telephone Counselling Service from 8.00 am to 6.00 pm, Monday to Friday.⁶⁹ Carers under the age of 18 years can contact the Kids Helpline for support over the phone.⁷⁰
- 3.47 Carers of all ages are also eligible to access a total of six free in-person counselling sessions through Carer Gateway service providers. Counsellors must have previous experience in providing counselling to children and adolescents before providing individual counselling for carers aged under 18 years of age.⁷¹
- 3.48 Counselling is particularly important for mental health carers. One carer explained:

As a carer you are a support person, a guiding hand, a safety net. It is not about you but the person you support and care for. I prioritised the acute needs of XX over my family when needed. I regularly prioritised their needs over my own. XX's needs increased incrementally over time but we didn't notice. Their behaviour changed, their needs increased day by day, one episode at a time. XX's behaviour got steadily worse, but we did not see it as it we had normalised it. We were frogs in boiling water wondering how on earth we got to this point. This is one of the benefits of counselling for mental health carers. Counsellors can hold up a mirror and invite you to look at the situation from a different perspective. The counsellor at Carers ACT was instrumental in helping us to understand the risk to our safety as things were unravelling. The counsellor talked us through this and supported us to understand the risks and introduced

⁶⁵ Name Withheld, *Submission 2*, page 1. Carers WA, *Submission 113*, page 10; Research Centre for Palliative Care, Death and Dying, *Submission 16*, page 7; The University of Melbourne Graduate Student Association, *Submission 34*, page 12; Older Persons Advocacy Network, *Submission 39*, page 4.

⁶⁶ Chamber of Commerce and Industry of Western Australia, *Submission 10*, page 3; City of Newcastle, *Submission 43*, page 5.

⁶⁷ Lyndis Flynn and Margaret Shelton, *Submission 101*, page 2.

⁶⁸ Name Withheld, *Submission 48*, page 1.

⁶⁹ DSS, *Carer Gateway*, 'A guide to counselling for carers', <https://counselling.carergateway.gov.au/s/article/A-guide-to-counselling-for-carers>, viewed 1 November 2023.

⁷⁰ DSS, *Carer Gateway*, www.counselling.carergateway.gov.au/s/for-carers-details, viewed 16 October 2023; Name Withheld, *Submission 11*, page 2.

⁷¹ Arrangements can be made for access to counselling sessions provided by Carer Gateway service providers via video or telephone in certain circumstances. DSS, *Submission 70.3*, page 3.

the notion of safety planning for us. Ironically, I was very accustomed with this term as I frequently did safety planning for XX.⁷²

- 3.49 However, the Committee received concerning evidence that some carers are not receiving the counselling support they need. For example, one carer reported that, when her son attempted suicide, ‘I found myself in serious need of immediate counselling, but instead was confronted with an agonising six-week waiting period through the Carer’s Gateway. This left me feeling abandoned, isolated, and without the much-needed support.’⁷³ Another carer reported delays in access to counselling and then described being treated ‘very poorly’ by a phone counsellor which, they said, ‘exacerbated my existing distress.’⁷⁴
- 3.50 More broadly, there was support for greater investment in mental health preventative care to aid better health and wellbeing outcomes for carers.⁷⁵
- 3.51 Autism Awareness Australia called for targeted, professional mental health and counselling services for carers of people with autism who understand the unique challenges associated with that condition.⁷⁶

Targeted support for CALD and First Nations carers

- 3.52 As noted in the previous chapter, carers have diverse backgrounds, circumstances and needs, and this diversity needs to be reflected in the Act. A strengthened Act, which places obligations on Australian Government providers to support carers, will require renewed focus on reducing barriers that CALD and First Nations carers face in accessing support.
- 3.53 CALD carers are underrepresented in Carer Gateway registrations. In June 2023, only six percent of carers registered with Carer Gateway identified as CALD,⁷⁷ whereas the percentage of carers identifying as being from a multicultural background in 2018 was 30 per cent.⁷⁸
- 3.54 Supporting carers from CALD backgrounds requires knowledge of how caring is understood in different communities and the additional barriers that CALD carers face in performing their roles and accessing support.⁷⁹ Consultations conducted by Ethnic Communities’ Council of Victoria (ECCV) and Carers Victoria from 2021 to 2023 indicated that most carers from migrant and refugee backgrounds lacked any means of support and that low English language proficiency and digital literacy were key contributors to this.⁸⁰

⁷² Name Withheld, *Submission 18*, page 4.

⁷³ Name Withheld, *Submission 48*, page 1.

⁷⁴ Name Withheld, *Submission 143*, page 4.

⁷⁵ Tandem, *Submission 123*, page 4.

⁷⁶ Autism Awareness Australia, *Submission 44*, page 2.

⁷⁷ DSS, *Submission 70.2*, attachment 1, page 2.

⁷⁸ Carers Australia, *Submission 111*, page 7.

⁷⁹ ECCV, *Submission 99*, page 6.

⁸⁰ ECCV, *Submission 99*, page 9.

- 3.55 There is a need to ensure that mainstream services are culturally safe spaces and to explore collaborative partnerships that improve referral pathways and programs for CALD carers. Close links between mainstream services and community organisations would be beneficial in encouraging carers to seek support and to help carers navigate the support system.⁸¹
- 3.56 Similarly, First Nations carers require access to high quality, culturally appropriate and community-led support services.⁸² The provision of carer support services to meet the needs of First Nations carers by the Aboriginal and Torres Strait Islander community-controlled sector would be consistent with priority reform two of Closing the Gap, the United Nations Declaration on the Rights of Indigenous Peoples, and a reformed, human rights-based Act.⁸³
- 3.57 ECCV said that increased engagement with diverse communities and greater diversity amongst service users should be a Key Performance Indicator for funded carer agencies.⁸⁴

Training

- 3.58 Many carers take on complex caring roles with no training in providing health care.⁸⁵ Stakeholders argued that there is a need for more practical training for carers to help them provide better care and to ensure they minimise risks to themselves, for example when performing heavy manual lifts. There was support for:
- free manual handling, wound care and medication management training,⁸⁶ and training in suicide intervention⁸⁷
 - options for in-person and online training⁸⁸
 - carers to have access to training that is equivalent to the training that paid carers receive.⁸⁹

Development of the new strategy

- 3.59 The Australian Government announced in October 2023 that it will invest \$3.8 million through to 2025–26 to develop the new strategy. More information on the

⁸¹ ECCV, *Submission 99*, page 10.

⁸² Australian Human Rights Commission, *Submission 32*, page 4; Gayaa Dhuwi (Proud Spirit) Australia, *Submission 31*, pages 4–5.

⁸³ Australian Human Rights Commission, *Submission 32*, pages 3, 4 and 9.

⁸⁴ ECCV, *Submission 99*, page 10.

⁸⁵ Relationships Australia, *Submission 17*, page 12.

⁸⁶ Name Withheld, *Submission 6*, page 9; Mrs Frances Findley, *Submission 130*, page 3.

⁸⁷ Suicide Prevention Australia, *Submission 22*, page 7.

⁸⁸ Name Withheld, *Submission 48*, page 2.

⁸⁹ Kiind, *Submission 51*, page 7.

development and consultation process will be announced by the end of the year and the new strategy is expected to be delivered by the end of 2024.⁹⁰ DSS said:

The strategy is part of the government's commitment to delivering a coherent national agenda to support carers in their caring role while maintaining their own wellbeing. The key objective is that the strategy should provide a framework for the coordination of carer policy across Commonwealth portfolios, including aged care, disability, veterans' affairs and mental health.⁹¹

- 3.60 Providing carers with the supports they need and removing barriers to access is clearly important and should remain a key priority, particularly for vulnerable groups. However, other factors that limit people's capacity to take on caring roles also need to be addressed, to ensure carers are recognised and have their rights protected, and to raise awareness of carers.⁹² For example, Tandem recommended the new strategy addresses the social and economic conditions that 'create unviable carer roles' and progresses the rights of carers, as set out in a reformed Act.⁹³
- 3.61 There was support for the social determinants of poor health and wellbeing for carers to be addressed holistically⁹⁴ and for evidence-based supports to be delivered to carers.⁹⁵ The Australian Healthcare and Hospitals Association (AHHA) called for carers' health and wellbeing to be prioritised in the healthcare system and said this would be achievable using existing platforms and systems such as electronic medical records. AHHA noted that the addition of a Medicare-funded item for carer assessment and support would minimise additional burdens on clinicians and the healthcare system.⁹⁶
- 3.62 The Committee heard that design of the new strategy should include an emphasis on strong governance, co-design, monitoring, data and evaluation, gender equality and community education.

Governance

- 3.63 The Minister for Social Services is currently responsible for Australian Government support for carers. Prior to 2013, there was a dedicated parliamentary secretary for carers. Carers Australia said this was preferable because it meant that carers and carers' representatives 'had someone to go to who also knows who to go to within

⁹⁰ The Hon Amanda Rishworth MP, Minister for Social Services, *Media Release*, 'Investing in a National Strategy and increased supports for Australia's carers', 19 October 2023.

⁹¹ Ms Robyn Shannon, Deputy Secretary, Disability and Carers, DSS, *Committee Hansard*, 24 October 2023, page 1.

⁹² Carers Australia, *Submission 111.1*, page 11; Older Person's Advocacy Network, *Submission 39*, page 8; Carers WA, *Submission 113*, page 6.

⁹³ Tandem, *Submission 123*, page 4.

⁹⁴ GenWest, *Submission 65*, page 3; Mental Health Carers Australia, *Submission 116*, page 3; Suicide Prevention Australia, *Submission 22*, page 3.

⁹⁵ Mental Health Carers Australia, *Submission 116*, page 3; Suicide Prevention Australia, *Submission 22*, page 3.

⁹⁶ AHHA, *Submission 8*, page 2. See also: Queensland Nurses and Midwives' Union, *Submission 72*, page 4.

the executive and within parliamentary circles to explore solutions that don't fit neatly into one portfolio.⁹⁷

- 3.64 While there may be benefits in a portfolio that combines disability and carer policy and supports, the Committee heard it is important that carers are considered as their own legitimate group with their own needs.⁹⁸ Carers Australia said that it 'wouldn't want to go back to a situation where the focus was very much on what's good for people with disabilities is automatically good for carers.'⁹⁹
- 3.65 Carers Australia called for an Australian Government Minister or Assistant Minister for Carers to lead a whole-of-government approach to carer recognition, inclusion and support.¹⁰⁰
- 3.66 There was support for a national office for carers to be established to develop the new strategy and to coordinate policy, legislation and programs for carers.¹⁰¹ Carers Tasmania said this would help ensure that carer-inclusive practices are observed across all government departments, and should be led by dedicated staff who are familiar with the history of carer services and policy changes over time.¹⁰² Carers Australia said that an office for carers should focus on the needs and interests of carers, particularly those who are vulnerable, at risk or disadvantaged.¹⁰³
- 3.67 Carers Australia called for a high-level cross-departmental forum to be established to coordinate legislation, policy, programs and services impacting on carers across Australian Government portfolios.¹⁰⁴
- 3.68 There was support for an independent national carer commission to be established to progress the recognition of carers and their rights under a strengthened Act.¹⁰⁵ Tandem said the carer commissioner is needed 'to promote integrated policy development across government portfolios and robust accountability mechanisms, including throughout the implementation of the National Carer Strategy.'¹⁰⁶ Redkite suggested that compliance and advocacy should be a focus for a national carer commissioner.¹⁰⁷

⁹⁷ Ms Sue Elderton, Carers Australia, *Committee Hansard*, 17 October 2023, page 3.

⁹⁸ Mrs Jane Bacot-Kilpatrick, Chief Executive Officer, Carers Australia, *Committee Hansard*, 17 October 2023, page 3.

⁹⁹ Ms Sue Elderton, Carers Australia, *Committee Hansard*, 17 October 2023, page 3.

¹⁰⁰ Carers Australia, *Submission 111.1*, page 11.

¹⁰¹ Carers Australia, *Submission 111.1*, page 11; Suicide Prevention Australia, *Submission 22*, page 3; Carers Tasmania, *Submission 57*, page 10.

¹⁰² Carers Tasmania, *Submission 57*, page 10.

¹⁰³ Carers Australia, *Submission 111.1*, page 11.

¹⁰⁴ Carers Australia, *Submission 111.1*, page 11.

¹⁰⁵ Redkite, *Submission 53*, page 10; Tandem, *Submission 123*, page 3.

¹⁰⁶ Tandem, *Submission 123*, page 3.

¹⁰⁷ Mr Tim Rogers, National Advocacy Manager, Redkite, *Committee Hansard*, 4 October 2023, page 45.

Co-design, monitoring and evaluation

- 3.69 There was strong support for carers and carers' representatives to be involved in co-designing, implementing, monitoring and evaluating the new strategy.¹⁰⁸ This would ensure the new strategy complies with the Act's obligation to consult carers or bodies that represent carers when developing or evaluating carer supports.¹⁰⁹
- 3.70 DSS said that the new strategy will be developed in consultation with carers 'to ensure it reflects the diversity of challenges and the needs of carers' and will be informed by policy work that is already underway across Australian Government portfolios.¹¹⁰
- 3.71 The Committee heard that the strategy should instead be co-designed with carers to ensure carers are treated as genuine partners in care provision. Queensland Alliance for Mental Health (QAMH) and Arafmi Ltd argued that co-design, not consultation, should be the default way to develop and evaluate carer supports with carers and their representatives.¹¹¹
- 3.72 The McCabe Centre for Law and Cancer suggested that a carer's advisory panel should have a role in monitoring compliance with the Act.¹¹² The previous chapter noted that some states have established carer advisory councils that work to advance the interests of carers and promote compliance with their state's carer recognition legislation and carers charter.
- 3.73 For carers to meaningfully engage in consultation and co-design, there is a need to ensure the people they care for are looked after while they take time away from caring. One carer described being offered respite care to attend a carers' planning session. The session ran overtime and when the carer arrived home, the paid carer had already left. The carer was then expected to pay for the respite care.¹¹³
- 3.74 There was support for robust action plans and outcomes measurements that focus on the needs and challenges experienced by carers to be developed to implement the strategy, with annual reporting on those outcomes, and a stronger focus on evaluation to assess the impact of policy and changes.¹¹⁴

¹⁰⁸ Everymind, *Submission 77*, page 4; GenWest, *Submission 65*, page 3; MS Australia, *Submission 91*, page 5; Tandem, *Submission 123*, page 14; Relationships Australia, *Submission 17*, page 15; Carers Australia, *Submission 111.1*, page 11.

¹⁰⁹ Dementia Australia, *Submission 35*, page 7.

¹¹⁰ Ms Robyn Shannon, Deputy Secretary, Disability and Carers, DSS, *Committee Hansard*, 24 October 2023, page 1.

¹¹¹ QAMH and Arafmi Ltd, *Submission 41*, page 6. The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability similarly recommended that governments adopt the principle of co-design, co-production and peer-led design processes in national decision-making. See: Disability Royal Commission, *Final Report*, 'Executive Summary', September 2023, page 72.

¹¹² McCabe Centre for Law and Cancer, *Submission 80.1*, page 5.

¹¹³ Name Withheld, *Submission 96*, page 2.

¹¹⁴ Carers Australia, *Submission 111.1*, page 11; McCabe Centre for Law and Cancer, *Submission 80*, page 3; Merri Health, *Submission 103*, page 6; Tandem, *Submission 123*, page 14.

Data

- 3.75 The new strategy and implementation plan will need to identify data that will be used to monitor the proposed actions and intended outcomes.¹¹⁵ More comprehensive data about carers is required to inform policies that improve carers' health and wellbeing and deliver more appropriately targeted carer supports.¹¹⁶ Several areas where data could be improved were identified during the inquiry.
- 3.76 The main source of national data about carers is ABS' SDAC. There are concerns that the definitions used by SDAC are more restrictive than the definition in the Act, and that the survey focuses on the experiences of primary carers.¹¹⁷
- 3.77 As noted earlier, many First Nations and CALD carers may not identify with the term 'carer' or may have different understandings of what the term means. This poses challenges for ensuring First Nations and CALD carers are accurately represented in carer data.¹¹⁸
- 3.78 Similarly, there is a lack of consistent, national data on lesbian, gay, bisexual, transgender, intersex, queer/questioning, asexual and other sexually or gender diverse (LGBTIQ+) people who provide care. Carers Australia said:
- 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 LGBTIQ+ people who are carers, or who need formal or informal care support, which suggests that carer supports could be better targeted.¹¹⁹
- 3.79 The Centre for Excellence in Child and Family Welfare called for more research and more frequent data collection, particularly with young and First Nations carers.¹²⁰
- 3.80 There was support for a new national survey on carers' health, wellbeing and suicide risk factors and behaviours.¹²¹ Currently, the key source of information about carers' health and wellbeing is the Carer Wellbeing Survey, which has been conducted in 2021, 2022 and 2023. This survey provides data about changes in carers' wellbeing over time but does not specifically include information about suicide risk factors. Participants are recruited through invitations sent by carer services and organisations across Australia, social media advertising targeted to carers, and invitations to previous participants. The survey was translated into simplified Chinese, Arabic,

¹¹⁵ Carers Australia, *Submission 111.1*, page 11.

¹¹⁶ Merri Health, *Submission 103*, page 6; Relationships Australia, *Submission 17*, pages 7-8; Suicide Prevention Australia, *Submission 22*, page 8; City of Newcastle, *Submission 43*, page 5.

¹¹⁷ Carers Australia, *Submission 111*, page 31.

¹¹⁸ Carers Australia, *Submission 111*, page 8.

¹¹⁹ Carers Australia, *Submission 111*, page 8.

¹²⁰ The Centre for Excellence in Child and Family Welfare, *Submission 121*, page 4.

¹²¹ Suicide Prevention Australia, *Submission 22*, page 8; Mental Health Carers Australia, *Submission 116*, page 4.

Italian and Vietnamese, which were the most common languages spoken by carers in the 2021 ABS Census.¹²²

- 3.81 The Australian Healthcare and Hospitals Association advocated for surveys of carers' health and wellbeing to be distributed nationally through the Australian Institute of Health and Wellbeing (AIHW) or the ABS 'to reach carers who are not linked in with services and organisations'.¹²³ Similarly, Mental Health Carers Australia said that the AIHW should be funded to deliver a health and wellbeing survey of carers, and that further resources should be allocated for more research and data mapping of carers.¹²⁴
- 3.82 Suicide Prevention Australia said that the states and territories should be required to 'record and report on deaths by suicide and suicide attempts among carers and former carers through their Suicide Deaths Registers and other reporting systems including the Australian Bureau of Statistics and the National Coronial Information System.'¹²⁵
- 3.83 Relationships Australia said that the new strategy requires a research plan for building the evidence base more broadly about carers, based on many of the recommendations of the Standing Committee on Family, Community, Housing and Youth's 2009 *Inquiry into Better Support for Carers*. Relationships Australia added that this should include evidence on:
- the monetary value of work undertaken by carers
 - the contemporary financial costs to households where one or more family member is a carer
 - whether, how, and how often, carers access support, and barriers to accessing supports
 - accessibility of respite care
 - kinds of support accessed by carers
 - carers' experiences of flexible employment and education
 - carers' unmet health needs, including psychosocial needs
 - the effectiveness of Australian Public Service employment practices in supporting carers
 - the types of support that carers want but cannot access
 - the availability and effectiveness of interventions to promote social inclusion of carers and those for whom they care.¹²⁶

¹²² Carers Australia and the University of Canberra, *Caring for Others and Yourself: 2023 Carer Wellbeing Survey*, October 2023, page v.

¹²³ Australian Healthcare and Hospitals Association, *Submission 8*, page 18.

¹²⁴ Mental Health Carers Australia, *Submission 116*, page 4.

¹²⁵ Suicide Prevention Australia, *Submission 22*, page 8.

¹²⁶ Relationships Australia, *Submission 17*, pages 7-8. See also: House of Representatives Standing Committee on Family, Community, Housing and Youth, *Who Cares...?: Report on the inquiry into Better Support for Carers*, May 2009, recommendations 23, 31, 32 and 36.

- 3.84 The Committee heard that there is a need to ensure carers' needs are represented in health care system data.¹²⁷ While there are frameworks to assess carers' needs in the health care system, evidence suggests these could be better implemented. AHHA said:

More data collected through standardised assessment frameworks is needed to guide government spending and allocation of resources and services for carers. Comprehensive data will identify carers' outcomes, the suitability of existing services, and clinicians' knowledge, skills and practices in conducting carer assessments.¹²⁸

Gender equality

- 3.85 Gender equality is about making sure all people have the same rights, responsibilities and opportunities. Gender inequality can be made worse by the intersectionality of other forms of exclusion or disadvantage, such as those related to a person's First Nations identity, CALD background, migrant status, disability, gender identity or sexuality, age or socio-economic status.
- 3.86 There was support for the new strategy to include a focus on gender equality in the development of policies affecting carers.¹²⁹ Since most carers are women, women unequally experience poverty and financial hardship throughout the course of their lifetimes, as well as low wellbeing and high levels of psychological distress, and social isolation as a consequence of providing care.¹³⁰ Women who provide care are more at risk of family violence and are more limited in their ability to leave violent relationships because of their caring roles and obligations, and financial insecurity.¹³¹
- 3.87 Gender norms or stereotypes shape expectations about the types of roles people perform. The idea that caring is 'women's work' or is 'just something that women do' both devalues caring and excludes and disadvantages women.¹³² It also means that men can face discrimination or feel invisible and lack support when they take on caring roles.¹³³ The Committee heard that policies and programs that counter harmful gender stereotypes,¹³⁴ and that value caring, while addressing the financial disadvantages faced by carers,¹³⁵ will help address gender inequality in Australia.
- 3.88 Mr Greg Smith highlighted that carer supports are often targeted at women, and argued there needs to be more work to recognise that men care too, and to provide

¹²⁷ McCabe Centre for Law and Cancer, *Submission 80*, page 3; AHHA, *Submission 8*, page 2.

¹²⁸ AHHA, *Submission 8*, page 2.

¹²⁹ Australian Human Rights Commission, *Submission 32*, page 2; Mrs Deborah Childs, Chief Executive Officer, Helping Minds Ltd, *Committee Hansard*, 24 August 2023, page 1.

¹³⁰ See Chapter One.

¹³¹ Ms Rosie Goethel, Manager, Evaluation and Policy, GenWest, *Committee Hansard*, 5 September 2023, page 5.

¹³² Ms Carrie Clark, Chief Executive Officer, Kiind, *Committee Hansard*, 29 August 2023, page 11.

¹³³ Mr Greg Smith, *Submission 120*, page 3; Department of Prime Minister and Cabinet, *National Strategy to Achieve Gender Equality Discussion Paper*, page 10.

¹³⁴ GenWest, *Submission 65*, page 3.

¹³⁵ GenWest, *Submission 65*, page 6; Women in Super, *Submission 50*, page 1.

supports and services that are appropriate for men.¹³⁶ Mr Smith noted that the Australian Men's Health Forum developed a ten-step guide to improving men's access to health services, which includes ways to improve promotion, and to address any structural and cultural barriers.¹³⁷

3.89 The Australian Government released *Working for Women: A Strategy for Gender Equality* in March 2024, which outlines the Australian Government's vision for making progress towards gender equality over the next 10 years. The strategy focusses on five priority areas:

- gender-based violence
- unpaid and paid care
- economic equality and security
- health
- leadership, representation and decision-making.

3.90 Key outcomes relating to unpaid care would include narrowing the unpaid work and care gap between women and men and narrowing the gap between women working part-time or flexibly.¹³⁸

Addressing financial disadvantages faced by carers

3.91 There was support for a new strategy that includes policies that address the financial disadvantages carers face over their lifetime and make it easier for carers to balance their caring responsibilities with work, which would reduce gender inequality in Australia.¹³⁹

3.92 The Senate Select Committee on Work and Care (Select Committee) considered these issues and recommended a comprehensive and integrated approach to addressing the challenges of work and care across workplace relations, early childhood education and care, paid leave, disability and aged care, and financial supports for carers.¹⁴⁰

3.93 This Committee heard similar suggestions for policy reform to those examined by the Select Committee. For example, there was strong support for policies that address the loss of superannuation by carers, such as extending superannuation guarantee payments in recognition of carers' service and time spent out of the workforce.¹⁴¹

¹³⁶ Mr Greg Smith, *Submission 120*, pages 2-3.

¹³⁷ Mr Greg Smith, *Submission 120*, attachment 2.

¹³⁸ Department of the Prime Minister and Cabinet, *Working for Women: A Strategy for Gender Equality*, March 2024, page 44.

¹³⁹ GenWest, *Submission 65*, page 6; Women in Super, *Submission 50*, page 1.

¹⁴⁰ Senate Select Committee on Work and Care, *Final Report*, March 2023, page 170.

¹⁴¹ Name Withheld, *Submission 1*, page 2; Name Withheld, *Submission 6*, page 9; Name Withheld, *Submission 11*, page 3; Carers WA, *Submission 113*, page 5; Name Withheld, *Submission 131*, page 2; Childhood Dementia Initiative, *Submission 133*, page 10; Chief Executive Women, *Submission 134*, page 2; Relationships Australia, *Submission 17*, page 7; Older Person's Advocacy Network, *Submission 39*, page 10;

- 3.94 Kiind called for a carer credit scheme that provides a pension top-up for carers. Similar schemes have been introduced in some European countries such as Germany. Kiind said carer credits could “top up” an individual’s pension contributions to the value of what they would be if the individual was working full-time.¹⁴²
- 3.95 Consideration of a carer credit scheme was recommended by the Select Committee, which said there is merit in considering a range of options to address retirement income gaps for carers.¹⁴³

Flexible work arrangements

- 3.96 The Select Committee received considerable evidence supporting carers having access to more flexible work arrangements. It recommended amending the *Fair Work Act 2009* to broaden the definition of ‘immediate family’ and to investigate whether personal and carer’s leave should be split into two separate leave entitlements.¹⁴⁴
- 3.97 This Committee heard that workplaces that provide flexible work arrangements allow carers to balance their employment with their caring role and are particularly important for women given that women are overrepresented as carers in Australia.¹⁴⁵ There was support for improved flexible work arrangements across the economy to assist carers to maintain employment.¹⁴⁶ For example, Mental Health Carers Australia said:

Flexible workplaces can have a considerable positive impact on carers’ financial and wellbeing. Flexible workplaces allow carers to adjust their hours and days of work which particularly for mental health carers allows them to provide support when the person they are supporting is unwell. There are well known and documented impacts on employment for mental health carers associated with the fluctuating and episodic nature of mental ill-health. Flexible workplaces allow primary carers to continue to engage in employment opportunities, reduce their reliance on carer payments and help to reduce the gap in their superannuation and retirement outcomes.¹⁴⁷

- 3.98 Merri Health suggested broadening the obligation for employers to provide workplaces that are supportive of carers, and increased transparency and reporting to encourage accountability.¹⁴⁸ According to one carer, ‘this could help employers in a

City of Newcastle, *Submission 43*, page 4; Women in Super, *Submission 50*, pages 1-2; Carers ACT, *Submission 58*, page 2; Neurological Alliance Australia, *Submission 68*, page 4.

¹⁴² Kiind, *Submission 51*, page 4.

¹⁴³ Senate Select Committee on Work and Care, *Final Report*, March 2023, page 197.

¹⁴⁴ Senate Select Committee on Work and Care, *Final Report*, March 2023, pages 184-185.

¹⁴⁵ Centre for Excellence in Child and Family Welfare, *Submission 121*, page 4.

¹⁴⁶ Wellways, *Submission 117*, page 10; Centre for Excellence in Child and Family Welfare, *Submission 121*, page 4.

¹⁴⁷ Mental Health Carers Australia, *Submission 116*, page 9.

¹⁴⁸ Merri Health, *Submission 103*, page 6.

tight skills market, increase workplace diversity, improve workplace culture – as well as helping carers keep their heads above water.’¹⁴⁹

- 3.99 Several Australian Government departments currently report on their obligations under the Act by outlining how their human resources policies comply with the principles contained in the Statement for Australia’s Carers, including detailing how their respective enterprise agreements include carers’ leave entitlements.¹⁵⁰ However, there is inconsistency in how agencies’ compliance with the Act is being reported.
- 3.100 Carers Australia called for reporting requirements to be strengthened and recommended the Australian Public Service Commissioner review Australian Public Service (APS) employment principles and workplace policies and practices against obligations under the Act and provide best practice examples for government and non-government employers.’¹⁵¹
- 3.101 In October 2023, the Australian Government launched the Carer Inclusive Workplace Initiative in partnership with Carers Australia. The Government has provided \$2 million over three years to 2024-25 to deliver the Carer Inclusive Workplace Initiative.¹⁵² This will help employers develop and adopt practices that support employees with caring responsibilities. Employers that are endorsed as carer inclusive workplaces can display a logo at their business and in marketing materials.¹⁵³
- 3.102 Other countries, such as Belgium, have laws providing carers with paid carers leave and flexible work arrangements.¹⁵⁴ McCabe Centre for Law and Cancer described Canada as ‘a model for a more comprehensive system of financial support for carers’ through income support, job protected leave, right to request flexible work and non-refundable tax credits for caregivers.¹⁵⁵

Carers’ Income Tax Offset

- 3.103 There was support for establishing an income tax credit for carers returning to the paid workforce.¹⁵⁶ The concept of a Carers’ Income Tax Offset (CARITO) was suggested by KPMG in 2022. KPMG proposed the CARITO as a non-refundable tax offset that takes the same general form as the Low and Middle Income Tax Offset.

¹⁴⁹ Name Withheld, *Submission 6*, page 9.

¹⁵⁰ See, for example: DSS, *Annual Report 2021-22*, pages 255-256; Department of Veterans’ Affairs, *Annual Report 2021-22*, page 207; National Disability Insurance Agency, *Annual Report 2021-22*, pages 204-205.

¹⁵¹ Carers Australia, *Submission 111.1*, pages 11-12.

¹⁵² The Hon Amanda Rishworth MP, Minister for Social Services, *Media Release*, ‘Investing in a National Strategy and increased supports for Australia’s carers’, 19 October 2023.

¹⁵³ DSS, *Submission 70*, page 9.

¹⁵⁴ Carers Australia, *Submission 111*, pages 27-28.

¹⁵⁵ McCabe Centre for Law and Cancer, *Submission 80.1*, page 6.

¹⁵⁶ ermha365, *Submission 71*, pages 6-7; GenWest, *Submission 65*, page 3; Chief Executive Women, *Submission 134*, page 7; Relationships Australia, *Submission 17*, page 7; Suicide Prevention Australia, *Submission 22*, page 6; City of Newcastle, *Submission 43*, page 4; MS Australia, *Submission 91*, page 7.

The amount would be calculated as a basic offset amount multiplied by the number of years, or part thereof, of unpaid caring work undertaken.¹⁵⁷

- 3.104 MS Australia noted that while the CARITO would not be gender-specific, it would have a substantial benefit for female carers since most carers are women.¹⁵⁸
- 3.105 Another suggestion was to allow couples to split their income to reduce the tax payable by one partner in recognition of the significant unpaid work performed by the other.¹⁵⁹

Community education campaign

- 3.106 The Committee heard there is a need for ongoing, national community education promoting recognition of carers and access to supports, given evidence of low awareness of carers and their needs.¹⁶⁰ Public education on carer awareness is required both across the community and in the systems and industries that carers use and navigate¹⁶¹ and actions are required to reduce stigma associated with caring roles.¹⁶²
- 3.107 For example, Suicide Prevention Australia said that a national office for carers should lead the development of a national community education campaign ‘in consultation with peak bodies and key organisations providing service to carers, to address stigmatisation of care, help identify the different types of caring and diversity of carers, knowledge of carer rights, and pathways to support.’¹⁶³
- 3.108 The City of Newcastle said that a community education campaign should ‘raise awareness about the diverse needs of carers, support the reduction of stigma, and drive positive workplace cultures’ and should include targeted strategies to raise awareness among CALD communities.¹⁶⁴
- 3.109 GenWest argued that a national community education campaign should address rigid gender stereotypes relating to care provision, ‘including the low status of care work, celebrate the diversity of care and carers, and increase knowledge of carer rights and supports.’¹⁶⁵

¹⁵⁷ KPMG, *Towards a new and improved era in women’s equality: valuing unpaid work*, November 2022, page 13.

¹⁵⁸ MS Australia, *Submission 91*, page 7.

¹⁵⁹ Name Withheld, *Submission 6*, page 9; Name Withheld, *Submission 67*, page 2.

¹⁶⁰ Carers WA, *Submission 113*, page 9; Relationships Australia, *Submission 17*, page 8; Everymind, *Submission 77*, page 4; Suicide Prevention Australia, *Submission 22*, page 3. City of Newcastle, *Submission 43*, page 5; GenWest, *Submission 65*, page 3; McCabe Centre for Law and Cancer, *Submission 80*, page 3.

¹⁶¹ Carers WA, *Submission 113*, page 9; Everymind, *Submission 77*, page 4.

¹⁶² Everymind, *Submission 77*, page 4; Suicide Prevention Australia, *Submission 22*, page 3; City of Newcastle, *Submission 43*, page 5.

¹⁶³ Suicide Prevention Australia, *Submission 22*, page 3.

¹⁶⁴ City of Newcastle, *Submission 43*, page 5.

¹⁶⁵ GenWest, *Submission 65*, page 3.

- 3.110 Little Dreamers Australia called for a targeted awareness campaign to inform young carers, their families, schools and the wider community about the supports available to young carers, including Carer Gateway.¹⁶⁶

Carer card

- 3.111 There was some support for improving the recognition of carers through the introduction of a carer card, which was one of the recommendations of the Australian Human Rights Commission's 2013 report *Investing in Care*.¹⁶⁷ For example, Carers ACT suggested implementing a carer card that is not means tested, easy to apply for, provides evidence that someone is recognised as a carer and enables carers to access benefits and discounts through participating businesses.¹⁶⁸
- 3.112 Victoria has a Carer Card program that provides carers with travel concessions and discounts and other benefits from local government and some community organisations and businesses.¹⁶⁹ The discounts are like those available to Seniors Card holders in Victoria and carers can search for participating organisations on the Carer Card Program website.¹⁷⁰ Evidence from Neighbourhood Houses Victoria suggests that there may be low awareness of the program by Victorian businesses.¹⁷¹

Committee comment

- 3.113 The Committee was concerned by carers' negative experiences of Carer Gateway, particularly evidence that some carers believe it is not worth their time engaging with the system, that it is too slow to deliver support, and that the supports provided do not meet carers' needs. There was evidence suggesting some providers and staff may have low awareness of program guidelines, particularly carer eligibility for support. The current evaluation of Carer Gateway may indicate other areas in which carers' experience of the program can be improved. In responding to the findings of the evaluation, the Australian Government should carefully consider the experiences of carers who use the service.
- 3.114 The current operating hours of Carer Gateway call centres are too restrictive, particularly for those who combine caring with education and work and should be reconsidered. As a minimum, Carer Gateway should provide a 24-hour crisis hotline with access to emergency supports such as respite and phone counselling.
- 3.115 Carer Gateway should be better integrated with other key services that carers interact with and rely on. Protocols should be established to ensure that referrals are made to Carer Gateway from My Aged Care, NDIS and Centrelink, and vice versa.

¹⁶⁶ Little Dreamers Australia, *Submission 54*, page 12.

¹⁶⁷ Women, Work and Policy Research Group, and ARC Centre of Excellence in Population Ageing Research, The University of Sydney, *Submission 81*, pages 2-3.

¹⁶⁸ Carers ACT, *Submission 58*, pages 4-5.

¹⁶⁹ Victorian Government, *Carer Card Program*, FAQs, www.carercard.vic.gov.au/faqs, viewed 6 October 2023.

¹⁷⁰ Victorian Government, *Carer Card Program*, www.carercard.vic.gov.au, viewed 6 October 2023.

¹⁷¹ Neighbourhood Houses Victoria, *Submission 114*, page 3.

Again, the Australian Government should carefully consider the user experience of accessing these services in co-design with carers.

- 3.116 The timeliness, flexibility and transparency of support provided to carers are of significant concern. Many carers are not receiving the help they need, when they need it, and are unsure about what support they are eligible for. Details about how much support carers are eligible for are currently not easily available on the Carer Gateway website. While the Committee sees benefit in the use of carer assessments to access tailored support packages, it must be remembered that carers are time poor. It makes little sense for a one-hour assessment to be required to access a few hours of support, and in most cases, carers shouldn't have to undergo more than one assessment each year. Carers should be provided with an annual support budget so they can decide how best to spend it.

Recommendation 9

- 3.117 The Committee recommends that, in the next funding agreement, the Australian Government ensure there is a simple process for carers to gain support when it is most needed and strengthen the supports provided to carers via Carer Gateway by:**
- **improving the quality and consistency of advice and client service by Carer Gateway support providers through enhanced training and performance monitoring**
 - **expanding the operating hours of the helpline, including providing access to 24-hour crisis support**
 - **better integrating Carer Gateway with other key services that carers interact with, such as My Aged Care, the National Disability Insurance Scheme and Centrelink**
 - **relaxing requirements for carer assessments to be conducted in order to access support and ensuring that, under normal circumstances, carers receive no more than one assessment each year**
 - **allowing carers more flexibility to access supports that meet their needs such as practical and physical help at home**
 - **providing transparency around what supports carers are eligible to access, and more agency to carers to decide how to spend their support budgets.**
- 3.118 These reforms should be co-designed with carers and carers representatives.**
- 3.119 The Committee was concerned by evidence of a lack of quality, local respite care options that are appropriate for a diverse range of carers. Carers should not need to admit the person they care for or themselves to a hospital emergency department to have a break from caring if they are unable to continue in their role due to the mental and emotional toll of providing care, or if they are injured or otherwise unwell. Similarly, carers should not need to perpetually take on all responsibility for care because they do not trust the quality of the respite care services that are available.

There is a need for more complex care respite options and services tailored to diverse groups including First Nations and CALD carers. Carers engaged in policy work such as strategy co-design and monitoring should be able to access free respite care.

- 3.120 The Committee notes that the Select Committee called for a review of the accessibility, availability, and flexibility of respite care.¹⁷² While it is important that the provision of respite care is carefully considered, the issue is too serious to wait for a review before any action is taken. The Committee urges the Australian Government to invest now in high quality respite care options that are appropriate for diverse needs.

Recommendation 10

- 3.121 The Committee recommends that the Australian Government work with the carer sector to identify capacity building for high-quality, respite care options that are appropriate for a diverse range of carers and the people they care for, including those that require complex care.**

- 3.122 The Committee was concerned by evidence that the counselling and mental health support provided by Carer Gateway is not meeting carers needs. Providing carers who are in distress with immediate access to counselling and other mental health supports should be prioritised.

Recommendation 11

- 3.123 The Committee recommends that the Australian Government examine how to increase access to high-quality counselling and mental health support options for a diverse range of carers.**

- 3.124 Further work is required in cooperation with the Minister for Health and the states and territories to ensure that carers' health and wellbeing is supported holistically with evidence-based treatments and that carers are prioritised in the healthcare system and other settings. This includes the implementation of standardised assessment frameworks for carers, training for practitioners and other workers who interact with carers in identifying and supporting carers, and consistent reporting of carer suicides and suicidality. These actions will support carers' health and wellbeing now and will generate important new data to guide carer policy in the future.

Recommendation 12

- 3.125 The Committee recommends that the new National Carer Strategy prioritise carers' health and wellbeing, including through:**

¹⁷² Senate Select Committee on Work and Care, *Final Report*, March 2023, page 178.

- **the implementation of standardised assessment frameworks for carers in healthcare settings**
 - **training for practitioners and other workers who interact with carers in identifying and supporting carers**
 - **consistent reporting of carer suicides and suicidality.**
- 3.126 While there was limited evidence supporting the introduction of a Medicare funded item for carer assessment and support, the Committee considers it is an idea worth investigating further because it would prioritise carers' health by incentivising practitioners to consider carers' needs.
- 3.127 There is a need to ensure that mainstream Carer Gateway services are culturally safe spaces for First Nations and CALD carers, and to explore collaborative partnerships that improve referral pathways and programs for diverse carers. Funding to establish close links between mainstream services and community organisations would be beneficial in encouraging carers to seek support and to help carers navigate the support system. Priority should be given to funding Aboriginal and Torres Strait Islander community-controlled organisations and CALD community groups in the delivery of services in their communities. Mainstream Carer Gateway service providers should be required to meet diversity targets to encourage greater engagement with diverse communities and more diversity in service users.

Recommendation 13

- 3.128 The Committee recommends that the new National Carer Strategy include targeted support for First Nations and culturally and linguistically diverse (CALD) carers, including:**
- **enhanced training and guidelines to encourage cultural safety and appropriate support for diverse communities for Carer Gateway service providers**
 - **fostering collaborative links between Carer Gateway service providers and First Nations and CALD community organisations to encourage culturally diverse carers to seek support and to help them navigate the support system**
 - **funding for First Nations and CALD community organisations to deliver Carer Gateway services**
 - **establishing diversity targets to encourage greater engagement by Carer Gateway service providers with diverse communities and more diversity in service users.**
- 3.129 There is a need for Carer Gateway to provide better access to training to help carers provide care safely, including manual handling, first aid, medication management and wound care, mental health first aid and suicide intervention. Training should be available in person as well as online.

Recommendation 14

- 3.130 The Committee recommends that, by December 2024, the suite of available training options offered by Carer Gateway be expanded to include manual handling, first aid, medication management and wound care, mental health first aid and suicide intervention. Options for in-person and online training should be provided.**
- 3.131 The Committee welcomes the Australian Government's commitment to delivering a new national carer strategy by 2024. It is important that the new strategy outlines how governments will work to implement the Act, to address the reasons why caring may be unviable for carers and to ensure that carers can access the supports they need. One of the goals of the strategy should be to ensure that there are enough carers to meet demand for care in the future. To do this, we must minimise the negative impacts that caring has on carers' financial security, their mental and physical wellbeing, and their social relationships.
- 3.132 The 2011 strategy was intended to give effect to the principles of the Act and guide carer policy for a decade. Instead, it was replaced with an approach that focuses on the provision of carer supports through Carer Gateway, which was just one of the six priority areas of the 2011 strategy. The Committee considers that all the priority areas identified by the 2011 strategy remain important areas of concern for carers and should be addressed in the new strategy.
- 3.133 There is currently inadequate guidance provided to carers about how to raise a complaint about Carer Gateway services. Complaints about Carer Gateway should be clearly directed towards service providers and the Australian Government in the first instance. A process should be developed to address breaches of the Act using existing mechanisms such as the Commonwealth Ombudsman.

Recommendation 15

- 3.134 The Committee recommends that the Australian Government establish a process to handle complaints and address breaches of the *Carer Recognition Act 2010*.**
- 3.135 In keeping with the recommendations of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, the strategy should be co-designed with and monitored by carers and carers representatives to ensure carers are treated as genuine partners in care provision. The new strategy should have robust action plans, outcomes measurement and reporting and evaluation frameworks. The previous chapter recommended that a revised Act include a requirement for the strategy to be reviewed every five years.

Recommendation 16

3.136 The Committee recommends that the new National Carer Strategy:

- **gives effect to the principles of the Act**
- **includes actions to address the negative impacts that caring has on carers' financial security, their mental and physical wellbeing, and their social relationships**
- **is co-designed and monitored by carers and their representatives**
- **has robust action plans, outcomes measurement and reporting and evaluation frameworks.**

3.137 There is a need for more comprehensive data to inform policy and to track outcomes for carers. The key source of national information about carers, the SDAC, is focussed on primary carers and is not representative of the experience of all carers. The SDAC should be broadened so that the definition of carer used in data collection is the same as the definition of carer in the revised Act. Further work is needed to ensure that First Nations, CALD and LGBTIQ+ carers are accurately represented in national surveys and other data.

Recommendation 17

3.138 **The Committee recommends that the Australian Bureau of Statistics' (ABS) Survey of Disability and Carers (SDAC) be redesigned prior to the conduct of the 2025 survey to be representative of all carers as defined in a revised Act.**

3.139 **The ABS should develop actions to ensure that First Nations carers, CALD carers and LGBTIQ+ carers are accurately represented in the SDAC.**

3.140 There are concerns that there is a lack of evidence about carers' health, wellbeing, and suicide risk factors. Currently, the annual Carer Wellbeing Survey is the key source of information about carers' health and wellbeing but does not include information about suicidality. It may not adequately represent carers who are not already linked into services or advocacy organisations. There may be benefits in the survey being distributed nationally through the AIHW or the ABS. Further funding for research and data mapping of carers is needed.

Recommendation 18

3.141 The Committee recommends that the Australian Government:

- **fund research and data mapping of carers**
- **review the scope and design of the Carer Wellbeing Survey to ensure that it is representative of all carers, is longitudinal and collects sufficient evidence about carers' health, wellbeing, and suicide risk factors.**

- 3.142 The Committee notes that the previous strategy was silent on gender equality. While many men are carers, most of Australia's carers are women and this has significant implications for the lives of women, the gender pay and superannuation earnings gaps, and the representation of women in leadership roles. The new strategy should include gender equality as a key priority area.
- 3.143 Achieving gender equality will require overcoming gender norms that mean that the burden of care mostly falls on women's shoulders.

Recommendation 19

3.144 The Committee recommends that gender equality be included as a key priority of the new National Carer Strategy, to be addressed by actions that:

- **overcome harmful gender norms that devalue caring roles and disadvantage women**
- **encourage more men to become carers and improve access to the types of supports men need**
- **address the financial disadvantages carers experience over their lifetime.**

- 3.145 While the adequacy of carer payments is out of scope for this inquiry, the Committee recognises that many carers experience significant financial hardship because of the demands of their caring role and a lack of opportunities to work. This is a key driver of financial inequalities between men and women. Many individuals voiced their concerns that the current level of income support for carers was too low, and that the income test was too restrictive and a disincentive to work. Similarly, there is a need to ensure that carers are not disadvantaged in retirement because of their service as carers. These issues were considered by the Select Committee and the Australian Government is currently considering its response to the Select Committee's recommendations. Evidence to this inquiry strongly supports many of the Select Committee's recommendations, including the proposal to adopt a carer credit scheme to help address the loss of superannuation by carers.
- 3.146 The Committee supports providing carers with access to programs of financial support such as superannuation accrued during caring, tax offsets and other incentives.
- 3.147 Flexible work arrangements are a key determinant of carers being able to balance work and care. The Select Committee's recommendations to strengthen flexible work provisions in the *Fair Work Act 2009* may, if enacted, create more carer-friendly workplaces in Australia. However, it is important that the Australian Government lead by example in creating workplaces that support employees to combine work with care. The Australian Public Service Commission (APSC) should review APS employment principles and workplace policies and practices against the obligations in the Act and provide best practice examples for government and non-government employers.

Recommendation 20

3.148 The Committee recommends that the Australian Public Service Commission (APSC) review Australian Public Service employment principles and workplace policies and practices for compliance with a revised Act and provide best practice guidance and examples. The APSC should commence the review one year after a revised Act has been established.

3.149 There is merit in implementing a non-refundable tax credit scheme for carers. This would recognise and value the time carers spend dedicated to unpaid care work and would represent affirmative action in addressing gender inequality in the provision of care. Further options to incentivise caring and address gender inequality in care provision through the income tax system should be considered.

Recommendation 21

3.150 The Committee recommends that the Australian Government introduce an income tax credit for carers returning to the paid workforce and consider other options to incentivise and recognise the impact of caring through the income tax and superannuation systems.

3.151 A community education campaign is needed to promote recognition and awareness of carers in their diversity, to address harmful gender stereotypes and reduce stigma, and to drive positive workplace cultures for carers. The campaign should inform the public, and the services and industries that carers rely on, about carers' needs and how to better support them. Targeted strategies for First Nations and CALD communities will be required.

Recommendation 22

3.152 The Committee recommends that an ongoing community education campaign form part of the new National Carer Strategy. The campaign should:

- **promote recognition and awareness of carers' rights and the diversity of carers**
- **address harmful gender stereotypes and reduce stigma associated with caring roles**
- **drive positive workplace cultures for carers**
- **aim to inform the public, and the services and industries that carers rely on, about carers' needs and how to better support them**
- **include targeted information and strategies appropriate for First Nations and CALD communities.**

Ms Susan Templeman MP
Chair
21 March 2024



A. Submissions

- 1 *Name Withheld*
- 2 *Name Withheld*
- 3 *Name Withheld*
- 4 *Name Withheld*
- 5 Department of Premier and Cabinet, Tasmania
- 6 *Name Withheld*
- 7 Mood Disorders Carers Support Group
- 8 Australian Healthcare and Hospitals Association
 - 8.1 Supplementary to submission 8
- 9 *Name Withheld*
- 10 Chamber of Commerce and Industry of Western Australia
- 11 *Name Withheld*
- 12 Danijela Hlis
- 13 *Name Withheld*
- 14 *Name Withheld*
- 15 *Name Withheld*
- 16 Research Centre for Palliative Care, Death & Dying - Flinders University
- 17 Relationships Australia
- 18 *Name Withheld*
- 19 *Name Withheld*
- 20 Kin Raising Kids Tasmania Inc.
- 21 *Name Withheld*

- 22** Suicide Prevention Australia
- 22.1 Supplementary to submission 22
- 23** *Name Withheld*
- 24** *Name Withheld*
- 25** *Name Withheld*
- 26** *Name Withheld*
- 27** *Name Withheld*
- 28** *Name Withheld*
- 29** *Name Withheld*
- 30** Mr Colin Allchurch
- 31** Gayaa Dhuwi (Proud Spirit) Australia
- 32** Australian Human Rights Commission
- 33** *Name Withheld*
- 34** The University of Melbourne Graduate Student Association
- 35** Dementia Australia
- 35.1 Supplementary to submission 35
- 36** NSW Carers Advisory Council
- 37** *Name Withheld*
- 38** *Name Withheld*
- 39** Older Person's Advocacy Network
- 40** *Name Withheld*
- 41** Qld Alliance for Mental Health and Arafmi
- 42** Council on the Ageing (COTA) NSW
- 43** City of Newcastle
- 44** Autism Awareness Australia
- 45** *Name Withheld*

- 46** Karna O'Dea
- 47** *Name Withheld*
- 48** *Name Withheld*
- 49** *Name Withheld*
- 50** Women in Super
- 51** Kiind
- 52** Support Groups Queensland Inc
- 53** Redkite
- 54** Little Dreamers Australia
- 55** HelpingMinds
- 56** Lived Experience Australia Ltd
- 57** Carers Tasmania
- 58** Carers ACT
- 59** Carers Queensland
- 60** Arafmi Ltd
- 61** Carers SA
- 62** Ms Dee-ann Riley
- 63** ANU Humanities Research Centre
- 64** *Name Withheld*
- 65** GenWest
- 66** *Name Withheld*
- 67** *Name Withheld*
- 68** Neurological Alliance Australia
- 69** MND Australia
- 70** Department of Social Services
 - 70.1 Supplementary to submission 70

- 70.2 Supplementary to submission 70
 - Attachment 1
 - 70.3 Supplementary to submission 70
- 71** ermha365
- 72** Queensland Nurses and Midwives' Union
- 73** Victorian Aboriginal Child Care Agency
- 74** *Name Withheld*
- 75** *Name Withheld*
- 76** *Name Withheld*
- 77** Everymind
- 78** Eating Disorders Families Australia
- 79** National Disability Services
- 80** McCabe Centre For Law & Cancer
- 80.1 Supplementary to submission 80
- 81** Women, Work and Policy Research Group, and ARC Centre of Excellence in Population Ageing Research, USYD
- 82** Family Drug Support
- 83** Ms Ludmila Fleitas Alfonzo and Associate Professor Tania King
- 84** Commissioner for Children and Young People South Australia
- 85** *Name Withheld*
- 86** Ms Cathy Duncan
- Attachment 1
 - Attachment 2
- 87** Ms Mary Pilkinton
- 87.1 Supplementary to submission 87
- 88** Health Consumers' Council WA
- 89** Confidential
- 90** Mr Karl Schaal

- 90.1 Supplementary to submission 90
- 91** MS Australia
- 91.1 Supplementary to submission 91
- 92** Carer and Community Support
- 93** Connecting Foster & Kinship Carers - SA
- 94** Carers NSW
- 94.1 Supplementary to submission 94
- 94.2 Supplementary to submission 94
- 95** *Name Withheld*
- 96** *Name Withheld*
- 97** *Name Withheld*
- 98** *Name Withheld*
- 99** Ethnic Communities' Council of Victoria
- 99.1 Supplementary to submission 99
- 100** Mr Kyle Hayes
- 101** Lyndis Flynn and Margaret Shelton
- 102** Health Care Consumers' Association
- 103** Merri Health
- 104** Royal Australian and New Zealand College of Psychiatrists (RANZCP)
- 105** Ms Victoria Green
- 106** *Name Withheld*
- 107** Inner South Family and Friends
- 108** Mr George Helon
- 109** Carers Victoria
- 109.1 Supplementary to submission 109
- 110** Australian Social Prescribing Institute of Research and Education (ASPIRE)
- 111** Carers Australia

- 111.1 Supplementary to submission 111
- 111.2 Supplementary to submission 111
- 112** Ms Kathleen Moore
- 113** Carers WA
 - 113.1 Supplementary to submission 113
- 114** Neighbourhood Houses Victoria
- 115** PS My Family Matters
- 116** Mental Health Carers Australia
- 117** Wellways Australia
- 118** *Name Withheld*
- 119** Judith Rafferty
- 120** Mr Greg Smith
 - Attachment 1
 - Attachment 2
- 121** The Centre for Excellence in Child & Family Welfare
- 122** Dr Meredith Kiraly
- 123** Tandem
- 124** *Name Withheld*
- 125** *Name Withheld*
- 126** *Name Withheld*
- 127** National Aboriginal Torres Strait Islander Women's Alliance
- 128** Penny Lewisohn
- 129** Australian Research Alliance for Children and Youth (ARACY)
- 130** Mrs Frances Findley
- 131** *Name Withheld*
- 132** *Name Withheld*
- 133** Childhood Dementia Initiative

- 134** Chief Executive Women
- 135** *Name Withheld*
- 136** *Name Withheld*
- 137** Australian Federation of Disability Organisations
- 138** *Name Withheld*
- 139** *Name Withheld*
- 140** Department of Health and Aged Care
- 141** Government of South Australia
- 142** Antipoverty Centre
- 143** *Name Withheld*



B. Public hearings

Tuesday, 8 August 2023

Canberra

Carers Australia

- Ms Alison Brook, Chief Executive Officer

Carers Australia

- Ms Sue Elderton, Senior Policy Officer

Individual carers

- David
- Helen

Thursday, 24 August 2023

Canberra

Mood Disorders Carers Support Group

- Mrs Paula Smith, Volunteer

HelpingMinds

- Mrs Deborah Childs, Chief Executive Officer

Australian Healthcare and Hospitals Association

- Adjunct Associate Professor Rebecca Haddock, Executive Director, Knowledge Exchange
- Dr Natalie Winter, Deeble Scholar

Private capacity

- Alex
- Briana
- Kylie

Kin Raising Kids Tasmania

- Mr John Flack, Board Secretary
- Mrs Jan Savage, Board Member

- Mr Frank Tyers, Management Committee

Gayaa Dhuwi (Proud Spirit) Australia

- Ms Rachel Fishlock, Chief Operations Officer
- Professor Helen Milroy AM, Chairperson, Gayaa Dhuwi Board

Suicide Prevention Australia

- Ms Caitlin Bambridge, Policy and Government Relations Manager
- Ms Tracey Monigatti, Lived Experience Panel Member

Tuesday, 29 August 2023

Canberra

Lived Experience Australia

- Professor Sharon Lawn, Chair and Executive Director

Dementia Australia

- Mrs Kylie Miskovski, General Manager Policy and Advocacy
- Mr Vernon Marshall, Dementia Advocate

Kiind

- Ms Carrie Clark, Chief Executive Officer
- Ms Renée Darbyshir, Systemic Advocacy Lead

Queensland Alliance for Mental Health

- Ms Jennifer Black, Chief Executive Officer

Arafmi Ltd

- Ms Irene Clelland, Chief Executive Officer

Carers SA

- Mr David Militz, Chief Executive Officer
- Ms Marianne Lewis, Manager Strategic Policy

Carers Tasmania

- Dr Samantha Fox, Chief Executive Officer
- Mrs Julie Ryan, Executive Policy Officer

Carers ACT

- Ms Lisa Kelly, Chief Executive Officer
- Mrs Kamla Brisbane, Policy and Advocacy Lead

Carers Queensland

- Ms Sarah Walbank, Manager, Quality and Assurance
- Ms Louise Houston, Quality and Evaluation Officer

Tuesday, 5 September 2023

Canberra

The Australian Human Rights Commission

- Ms June Oscar AO, Aboriginal and Torres Strait Islander Social Justice Commissioner

GenWest

- Ms Rosie Goethel, Manager, Evaluation and Policy

Tuesday, 12 September 2023

Canberra

Ethnic Communities' Council of Victoria

- Mr Eddie Micallef, Chairperson
- Ms Victoria Kyriakopoulos, Acting Chief Executive Officer
- Ms Hayat Doughan, Ageing Well Project Coordinator

Wednesday, 4 October 2023

Canberra

Little Dreamers Australia

- Ms Madeleine Buchner OAM, Founder and Chief Executive Officer
- Mr Hudson Langan-Stark, Young Carer Participant
- Ms Jacqueline de Mamiel, Young Carer Participant

Roundtable - individual unpaid carers

- Kathleen Moore
- Belinda
- Mrs Marlene McClelland
- Ms Alyssa Weirman

McCabe Centre For Law & Cancer

- Ms Megan Varlow, Director, Cancer Control Policy
- Ms Tarishi Desai, Manager, Treatment and Supportive Care

Carers WA

- Mr Richard Newman, Chief Executive Officer
- Mrs Carissa Gautam, Systemic Policy Officer
- Mr Stuart Jenkinson, Systemic Policy & Strategy Officer

Carers Victoria

- Ms Judith Abbott, Chief Executive Officer
- Ms Margaret Boulos, Senior Policy and Research Advisor

Carers NSW

- Ms Elena Katrakis, Chief Executive Officer
- Ms Sarah Judd-Lam, Executive Manager, Policy, Development and Research

Women, Work and Policy Research Group and ARC Centre of Excellence in Population Ageing Research, University of Sydney

- Associate Professor Myra Hamilton, Co-Director, Women Work and Policy Research Group, University of Sydney; and Principal Research Fellow, Centre of Excellence in Population Ageing Research, University of Sydney
- Dr Hugh Bainbridge, Associate Professor, School of Management and Governance, University of New South Wales; and Associate Investigator, Centre of Excellence in Population Ageing Research

MS Australia

- Mr Rohan Greenland, Chief Executive Officer
- Ms Sarah Clifton, Senior Policy Officer

Redkite

- Mrs Monique Keighery, Chief Executive Officer
- Mr Tim Rogers, National Advocacy Manager.

Tuesday, 17 October 2023

Canberra

Carers Australia

- Mrs Jane Bacot-Kilpatrick, Chief Executive Officer
- Ms Sue Elderton, Senior Policy Officer

Tuesday, 24 October 2023

Canberra

Department of Social Services

- Ms Robyn Shannon, Deputy Secretary, Disability and Carers
- Ms Kellie Spence, A/g Group Manager, Disability Employment and Carers
- Ms Anna Lutz, Branch Manager, Disability Employment and Carers



C. Exhibits

- 1 Tony Gartland, 'Nowhere else to go: Why Australia's health system results in people with mental illness getting 'stuck' in emergency departments', Duggan M, Harris B, Chislett WK & Calder R. 2020, Mitchell Institute Commissioned report, Victoria University.
- 2 South Australian Commissioner for Children and Young People, 'Take Care: What can be done at school to support children and young people with caring responsibilities at home', June 2020.
- 3 McCabe Centre for Law and Cancer, Submission to the Parliamentary Joint Committee on Human Rights' Inquiry into Australia's Human Rights Framework, Cancer Council Australia and McCabe Centre for Law and Cancer, June 2023.
- 4 Ethnic Communities' Council of Victoria, Elder abuse in care relationships: Key learnings from the Recognising and Respecting Carers from CALD Backgrounds project, September 2023.
- 5 Department of Social Services, Carer Gateway Service Provider Operating Manual V1.2, March 2021.