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Building the evidence base for the National Carer Strategy

Rapid review of the evidence



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Overview

This paper provides a broad overview of the current evidence base on informal carers in Australia including who they are, how they are faring, and the supports available to them and how effective (or not) they are.

Key messages

- There is relatively good high-level data on unpaid carers and the care they provide. However, the definition of a carer in some key data sets is more restrictive than in the *Carer Recognition Act 2010 (Cwth)*. Aboriginal and Torres Strait Islander carers, culturally and linguistically diverse carers, and LGBTQIA+ carers are under-identified and under-recognised in the literature. Data is needed to more accurately reflect the diversity of carers' circumstances and needs, to better inform policy and practice.
- There is longstanding evidence that unpaid carers generally experience poorer wellbeing, income, employment and education outcomes relative to their non-carer peers, and these effects tend to be worse the greater the level of caregiving (hrs/week and intensity of caring). However, further research is needed to understand the specific drivers of these poorer outcomes for different types of carers and care-giving.
- Evidence on what works to support carers is critical for informing policy, but very scant. Part of the reason for this is unclear and/or conflicting policy and program objectives, which make it difficult to assess effectiveness. This underlines the importance of setting clear, measurable objectives and continuing to build the evidence base on effective carer supports.
- Many of the deficiencies and gaps in the unpaid carer support system are well known, but progress has been slow. Roles and responsibilities for some of the needed changes are unclear and/or fragmented, weakening accountability. And many of the problems needing attention are systemic and will require dedicated effort and action by multiple areas of government.
- A National Carer Strategy is an opportunity to:
 - ensure all Australian Government departments and agencies take actions – informed by the evidence – that support the vision '*for an Australian community in which all carers are recognised, valued and empowered with the support they need to participate fully in society and fulfil their caring role*'
 - clarify roles and responsibilities for key reforms and outcomes
 - implement adequate monitoring and reporting on outcomes
 - embed evaluation in carer policy-making and practice.

1. Scoping and framing matters

This report discusses the evidence base in respect of informal (or unpaid) carers – it is developed in line with the Government's direction to recognise the immense contribution of Australia's unpaid carers (Rishworth, 2023). As part of this report to DSS we are required to quantify aspects of informal carers, their experiences and outcomes. In doing so, we recognise that each number represents a person with their own lived experience, and we value the rich diversity inherent in these voices.

1.1. A national carer evidence base

A national carer evidence base refers to both data (observations and measurements) and other information (such as evaluations of policies and programs) that support decision makers to make evidence-informed choices.

An effective national carer evidence base should provide a comprehensive understanding of the carer landscape, identify the issues facing Australian carers, and inform the development of policies and programs designed to improve carer outcomes. The ultimate aim of an evidence base is to improve carers' experiences and outcomes in a cost-effective manner.

AIFS has been engaged to help build the national carer evidence base to support development of a National Carer Strategy (the Strategy) and the monitoring of progress against the objectives of the Strategy. The Strategy will be an overarching national policy framework that will guide actions towards improved coordination of carer policy across Commonwealth portfolios including health and aged care, including mental ill health and palliative care, disability, education, employment, and veteran's affairs (National Carer Strategy Advisory Committee Terms of Reference).

The last National Carer Strategy was released in 2011 and replaced in 2015 by the Integrated Plan for Carer Support Services (Standing Committee, 2024).

1.2. Project scope

Informal carers are people — both adults and children — who provide unpaid (informal) care and support to family, friends and community members who need help because of their illness, frailty, disability, a mental health problem or an addiction (box 1). The care provided extends beyond what would normally be expected within such relationships. A recipient may receive informal care from more than one person.

Informal care can also include parenting and other forms of unpaid childcare. However, this type of care is not in the scope of this work.

Informal carers are not employed as carers (although they may receive income support that is conditional on providing care) and they are non-professionals (that is, they usually have not received qualifying training to care). Carers who volunteer through an organisation are not regarded as informal carers.

Caring relationships and roles are diverse, and it is important that the evidence base (and the National Carer Strategy) captures and reflects this diversity. In addition, some people with informal caring responsibilities do not identify as carers, meaning the scale of informal care is

Box 1: Carer Recognition Act 2010 (Cwth)

Under section 5 of the Carer Recognition Act 2010 (Cwth), a carer is an individual who provides personal care, support and assistance to another individual who needs it because that other individual: (a) has a disability; or (b) has a medical condition (including a terminal or chronic illness); or (c) has a mental illness; or (d) is frail and aged.

An individual is not a carer in respect of care, support and assistance he or she provides: (a) under a contract of service or a contract for the provision of services; or (b) in the course of doing voluntary work for a charitable, welfare or community organisation; or (c) as part of the requirements of a course of education or training.

To avoid doubt, an individual is not a carer merely because he or she: (a) is the spouse, de facto partner, parent, child or other relative of an individual, or is the guardian of an individual; or (b) lives with an individual who requires care.

likely larger than available data indicate, and under identification may be especially pronounced for some groups (see section 5.1).

1.3. Our approach

The Department of Social Services engaged AIFS to undertake a rapid scoping review to identify and synthesise existing literature and knowledge on the demographics of unpaid carers in Australia, their contribution, their wellbeing and support needs, and identify key evidence gaps.

In undertaking this rapid scoping review, AIFS has focused on literature and other evidence published in the last 10 years (since 2014), with priority given to more recent information. Both quantitative and qualitative evidence has been considered, including literature that documents carers' lived experiences of being a carer in Australia.

Evidence has been drawn from national surveys, smaller surveys (such as those run by Carers Australia) and longitudinal household surveys. Key literature sources include academic journals (Australian and international), recent inquiries and royal commissions, submissions prepared by peak groups and other representative organisations, and additional material provided by members of the National Carer Strategy Advisory Committee. Given the term 'carer' is used commonly and relatively liberally, including in contexts not relevant to this work, we screened the search results to remove out-of-scope literature.

Our search strategy involved looking at descriptive data and analyses, as well as studies of policy and program effectiveness, and program evaluations. While the predominant focus was on Australia, we also considered relevant evidence from other OECD countries, including the UK, Germany, Canada and New Zealand.

2. Informal carers in Australia

This section provides an overview of caring roles and responsibilities, and summarises the existing data, literature and knowledge on the demographic characteristics of unpaid carers in Australia. It draws heavily on the Australian Bureau of Statistics' 2022 Survey of Disability, Ageing and Carers for data on the characteristics of informal carers (ABS 2024, box 2).

Box 2: Survey of Disability, Ageing and Carers

The ABS Survey of Disability, Ageing and Carers (SDAC) provides the most comprehensive profile of people receiving care and their carers in Australia. In this survey, a carer is a person who provides any informal assistance (help or supervision) to people with disability or older people (aged 65 years and over). The questions about carers are only asked of people who are living in households and providing unpaid care.

The ABS classifies carers as either:

- Primary carers — people aged 15 years and over who provide the most informal assistance with the core activities of mobility, self-care and communication.
- Secondary carers — people aged 15 years and over who provide care with at least one of the core activities, for at least one hour per week, however they do not provide the most care (that is, they are not the primary carer).
- Other carers — people of any age who provide any other informal care (that is, they are not the primary carer and not the secondary carer).

While the SDAC is widely regarded as a vital source on information on Australian carers, some of the material in this review raises concerns that the definitions used by SDAC are more restrictive than the definition in the *Carer Recognition Act 2010 (Cwth)*, and that the survey focuses on the experiences of primary carers.

2.1. Informal carers provide care in many ways

Caring by informal carers may include help and support with any of the daily activities of living of the person being cared for. For example, informal care may include:

- physical and personal care, such as dressing, lifting, showering, toileting, feeding or providing transport
- the management of medications, and organising and attending medical appointments
- emotional and social support
- household chores, property maintenance and banking
- dealing with emergencies
- service system navigation, including paperwork and making arrangements for accessing formal care services.

In 2022, of the 1.2 million primary carers in Australia, about two-thirds provided assistance with mobility tasks, 58% provided assistance with self-care, and 55% provided assistance with communication (ABS 2024).¹

In the same year, nearly all primary carers (97.5%) helped the main person they cared for with 'non-core' activities — over 80% assisted with transport, and two-thirds assisted with household chores (ABS 2024).

2.2. The circumstances of carers can vary considerably

The characteristics and circumstances of carers can vary significantly. Some of the key points of difference amongst carers include:

- The age at which they become a carer – some carers start caring when they are relatively young, others when they are middle-aged or approaching retirement, and others older.
- The nature, duration and intensity of the caring role — caring can be short term and episodic, or life-long and 'more than' a full-time job; some caring responsibilities are predictable, others less so.
- The other roles and responsibilities they have, such as paid work or caring responsibilities for other family members or others in the community. Some carers provide care to more than one person at the same time, and some carers are 'double-duty' caregivers (that is, juggling employment in a caregiving role and informal caregiving).
- How much support they have available to them (and the person they care for) – for example, whether they have family and friends who can help with caring, the income and wealth of the carer and care recipient, and access to services. Some carers can also be receiving care themselves.

While some carers actively choose to take on a caring role, many fall into caring through circumstance and feel they have no choice about their role.

In the 2022 SDAC, around 2 in 5 people (39%) caring for their child² said they had no other choice; 19% of those caring for their parent and 16% of those caring for a spouse or partner also reported that they have no choice about being a carer (ABS 2024).

Although some carers report caring to be a rewarding and fulfilling experience, the reality for many is that caring can feel more like an obligation (or even burden) with no end-date, and can have adverse consequences for the carers' health, quality of life, and social and financial wellbeing (see section 3).

In 2022, nearly two-thirds of primary carers in Australia cited 'a sense of family responsibility' as a reason for taking on a caring role. Nearly half of primary carers also nominated 'emotional obligation' (47%) and 'an ability to provide better care than anybody else' (46%) as key reasons for becoming carers (ABS 2024).

The relationship between the primary carer and care recipient is also a factor in the decision to take on a caring role — for example, 82% of those caring for a parent felt *it was the responsibility of a family member to provide the care*, compared with 63% of parents caring for a child and 59% of those caring for a spouse or partner (ABS 2024).

¹ Proportions can exceed 100% as one person can provide multiple forms of assistance.

² Only people providing care to a child with a disability are regarded as carers in the SDAC.

2.3. Caring responsibilities can change over time

The nature and intensity of caring responsibilities can change over time.

For some people, their role as a carer remains much the same for a long time — for example, if the person they care for has a condition, such as a physical disability, that neither improves nor deteriorates much over time. For others, the role can change gradually or dramatically with the changing needs of the person they care for (or with changes in the carers own circumstances).

These changes do not always follow a set course. In some cases, carers may move in and out of different stages of caring. Their role might intensify for a time and then ease off because the person they are caring for goes through a period of improvement.

For example, the Productivity Commission's 2020 inquiry into mental health observed that the episodic nature of mental illness has implications for the caring role.

Fluctuations in the duration and intensity of needs can make the caring role more unpredictable . . . When they are not actively providing care, mental health carers often remain on-call, in case support is required.

Similarly, some carers (eg, of children with a disability or mental illness) can end up in the role for much longer than other types of carers (such as those caring for elderly parents):

Mental illness typically has an earlier age of onset than many physical health conditions). The toll on a mental health carer's life can be significant given that many are in this role for many years and often from a relatively young age.

A caring role can be established very quickly, without warning, or emerge gradually over a long period. The caring role can also end abruptly and unexpectedly, and the loss of a caring role can also have a significant impact on a carer's life. Granaheim, Johansson and Lindgren (2014) investigated the experiences of carers of people with dementia once they relinquished care to a nursing home and found that the period after relinquishing care was characterised by contradictory feelings: grief and loss, mixed with feelings of relief that the family member was safe. Many also noted their increased freedom.

2.4. At least 3 million Australians provide informal care

In 2022, there were 3 million carers, representing nearly 12% of all Australians living in households (up from 2.6 million and 10.8% in 2018; ABS, 2024). This means around one in eight Australians provided unpaid care to people with disability and older people.

Around 1.2 million people (or 4.5% of all Australians) were primary carers — an increase from 861,600 people (or 3.5%) in 2018 (ABS 2024). A large amount of informal care is provided to supplement that provided by primary carers — in 2022, there were 383,600 secondary carers and almost 1.5 million other carers.

In 2022, primary carers most commonly provided care to:

- a spouse or partner (37.4%)
- their child (29.1%)
- a parent (24.7%) (ABS 2024).

2.5. Informal caregiving can be (more than) a full-time job

Some Australians spend a significant amount of their time providing informal care — about 30% of primary carers spend an average of 40 hours or more per week caring and a further 19% spend an average of 20-39 hours per week caring (ABS 2024).

Carers Australia commissioned Deloitte Access Economics to estimate the economic value of Australia's informal carers in 2020. Using data from the 2018 SDAC, Deloitte Access Economics estimated that informal carers in Australia provided nearly 2.2 billion hours of care in that year (Deloitte Access Economics, 2020).

To estimate the value of this informal care, Deloitte Access Economics used both the replacement cost and opportunity cost methodologies. Using the former, which considers the cost of replacing each hour of informal care with a formal sector equivalent, informal care was valued at \$77.9 billion in 2020. But it is also known that many informal carers will have to partially or fully withdraw from the labour force to provide their care. The lost earnings — or opportunity cost — from this reduced employment was valued at \$15.2 billion. Opportunity cost valuations tend to be lower than the replacement cost as it considers only those carers who would have otherwise been employed.

2.6. Carers are a diverse group

Age and gender

In 2022, the average age of a carer in Australia was 50 years, and the average age of a primary carer was 54 years (ABS 2024). However, around 13% of all carers (391,300 people) were under the age of 25 (young carers) — young carers make up a growing share of total carers (an increase from 8.9% or 235,300 people in 2018).

Overall, females were more likely to be carers than males, with 13% of all females in Australia providing care in 2022 (similar to 2018) compared with 11% of males (up from 9% in 2018; ABS, 2024). Two-thirds of primary carers were female.

Disability

Of the 3 million carers in Australia, almost two in five (39%) had disability, an increase from 2018 (32.1%; ABS, 2024). Incidence of disability was higher among primary carers than other carers — 44% of primary carers had disability in 2022 (ABS, 2024).

Young people with disability were far more likely to be carers than young people without disability — around 6% of Australians aged 0-14 years with disability were carers in 2022, compared with 1.7% of people in this age group without disability (ABS, 2024).

First Nations

The ABS Census of Population and Housing found 15% of First Nations people (76,600 people) aged 15 and over provided unpaid assistance to a person with disability, long-term health condition or problems related to ageing in 2021. After adjusting for differences in age structures, the proportion of First Nations people providing unpaid care was 1.3 times the proportion of non-Indigenous Australians (AIHW, 2023).

Evidence also suggests First Nations carers are more likely than non-Indigenous carers to support multiple people in need of care. In particular, older First Nations people often have multigenerational caring roles. The 2022 National Carer Survey found that 43% of First Nations carer respondents cared for more than one person, and 17% cared for three or more people (Carers NSW, 2023).

This is partly reflective of traditional and cultural care responsibilities, with many women regarding the strength of caring to be fundamental to identification as Aboriginal and Torres Strait Islander women (Woods & McCormick, 2018).

LGBTQIA +

The 2022 SDAC was the first cycle of this survey to ask carers their LGB+ status³. Around 3% of primary carers described their sexual orientation as gay or lesbian, bisexual or who used a different term such as asexual, pansexual or queer (LGB+).

The 2022 National Carer Survey found that the average age of LGBTQ+ carers⁴ was 47 years, which was significantly younger than other carers in the sample, and just under 1 in 3 young carers in the survey (29%) identified as LGBTQ+ (Carers NSW, 2023). Similar to First Nations carers, around 2 in 5 surveyed LGBTQ+ carers were caring for more than one person.

Other demographic characteristics

In 2022, most primary carers (>80%) resided in the same household as the person for whom they provided the most care. Of primary carers who did not live with their main recipient of care, 70% were caring for a parent, and almost two-thirds were aged 45-64 years (ABS 2024).

Of primary carers living in households:

- 4.4% had served in the Australian Defence Force
- 12.7% primarily spoke a language other than English at home
- 29.9% were born overseas
- 24.2% lived in an area of greater socio-economic disadvantage
- 31.8% owned their house outright
- 3.7% lived in a lone person household (ABS 2024).

It is estimated that between 25 and 30% of all Australian carers are from Culturally and Linguistically Diverse (CALD) backgrounds (Standing Committee, 2024). However, this figure is likely to be an underestimate due to the lack of reporting or identification of the caring role within CALD groups (Carers Australia, Unpublished 2024a).

2.7. Carers access a range of assistance measures, but satisfaction has declined

Some carers receive help to assist with their caring role. This assistance may be informal, from family and friends, or formal, from organised services (carer support groups, counselling, respite care, home support services).

³ The ABS SDAC uses the term LGB+ to represent people who described their sexual orientation as gay or lesbian, bisexual, or who used a different term such as asexual, pansexual or queer.

⁴ Throughout this report different terms are used to reflect the differences in scope across data collections and literature for LGBTQIA+ people.

Assistance may be provided directly to the recipient of care or may be provided to the carer, to support them in their caring role.

In 2022, the SDAC (ABS, 2024) found that 38% of primary carers reported having received assistance from organised services in the last 6 months (a similar result to 2018). Female primary carers were more likely to report receiving assistance from organised services than male primary carers (41% compared with 28%).

Of primary carers who received assistance from organised services, two-thirds reported being satisfied with the quality of assistance received (down from 71.3% in 2018), while 12% reported being dissatisfied with the quality of assistance (compared to 10% in 2018).

Of primary carers who answered the satisfaction questions, 32% reported being satisfied with the range of services available (down from 36% in 2018), 12% reported being dissatisfied (similar to 2018), and 30% reported they did not know the range of services available.

More recently, the 2023 Carer Wellbeing Survey found some evidence that access to formal support reduced between 2022 and 2023. The report notes that ‘this may in part reflect the significant proportion of carers who reported reducing use of services due to cost-of-living challenges in the last year’ (Mylek & Schirmer, 2023).

Respite care is a service which gives carers a short-term break by providing alternative care arrangements for elderly people, or people with disability. In 2022, the SDAC (ABS 2024) found that 9% of primary carers (103,800 people) reported using respite care. This represented a decrease from 12% in 2018, despite the proportion of primary carers needing respite care remaining similar (around 14% in both 2018 and 2022). Around 12% of primary carers said they did not use respite care because they were unaware of respite entitlements and services (compared to 8.6% in 2018) — a similar number reported that they did not access respite care because the care recipient did not want the service.

The Carer Wellbeing Survey also reported a decline in the use of respite care (and psychological support) between 2021 and 2023 (Mylek & Schirmer, 2023). In regard to informal help with caring, the report found that — in 2023 — 28% of carers reported having no access to help from family or friends, while about half of carers reported that some friends and family can help, but that it is difficult to organise.

3. Evidence on informal carers' wellbeing

Some carers report that caring can be a rewarding experience, and many derive a sense of pride and accomplishment from their caring role. In some circumstances, relationships between family members can be strengthened when they are able to cooperate to overcome difficult circumstances. And carers can contribute enormously to the wellbeing of the person they are caring for.

There is evidence that many unpaid carers find being a carer satisfying (Mylek & Schirmer, 2023). And international research shows that carers often report positive aspects of their roles such as feelings of gratitude; fulfilment; personal growth; maturity; resilience; learning new skills and a sense of mastery; meaningfulness; and a closer and stronger relationship with the person they are caring for (Allen and Clarke, Unpublished 2023).

However, for many carers they feel they have no choice about being a carer, and caring can have costs — it affects some people's mental and physical health, social participation, career trajectory, educational attainment and financial security.

This section describes how well (or not) carers are faring in terms of health and wellbeing, and on economic and social measures. It also describes the (fairly limited) literature and evidence on how caregiving impacts on the health, wellbeing and financial security of carers.

3.1. Health and wellbeing

While not all informal carers suffer adverse health impacts because of caregiving, the evidence indicates that informal carers are at a greater risk of experiencing poor physical and mental health, psychological distress, and low wellbeing than the average Australian.

Carers consistently report lower wellbeing than non-carers

Data on carers and non-carers are not directly comparable but do provide some indication of differences in wellbeing. The 2023 Carer Wellbeing Survey (Mylek & Schirmer, 2023) reports on the wellbeing of carers aged 14 and over and presents comparison data from the Regional Wellbeing Survey which relates to adults 18 and over in the general population across Australia. Broad comparisons can be made, bearing in mind that carer experiences are different for younger carers and may impact the results given the slight difference in the scope of age group included.

The 2023 Carer Wellbeing Survey reported that carers are almost twice as likely to have low wellbeing compared to Australian adults, and almost three times *less* likely to have high wellbeing. Carers also report higher than average rates of psychological distress and loneliness compared to the general population.

- While 23% of adult Australians had high levels of psychological distress in the first half of 2023, 31% of carers were experiencing high levels of distress.
- About 19% of adult Australian's reported feeling lonely often or always in 2023, while 39% of carers reported that they often or always feel lonely.

The 2023 Carer Wellbeing Survey also revealed that many carers feel worried or overwhelmed by their carer role.

- 66% feared for the future of the people they cared for
- 59% reported they did not have enough time for themselves
- 49% felt they have more responsibilities than they could cope with.

While a lot of the available literature is cross-sectional and compares the mental and physical health of care givers with non-caregivers, recent work by Lacey et. al (2024) measures health and wellbeing before and after the onset of caregiving. It finds that:

- the transition to caregiving leads to substantial increases in psychological distress
- this distress continues for several years after the onset of caregiving
- the increase in distress is especially pronounced for caregivers under 50 years of age.

The authors observe that caregiving is less normative in younger people and has the potential to interfere with other social roles such as parenting, education and employment.

Carers have also reported experiencing poorer physical health relative to their non-carer peers. In 2023, only 19% of carers reported being in very good or excellent health, 31% in 'good' health, and 50% in fair or poor health. This is significantly lower than the Australian adult population, with 48% reporting being in very good or excellent health, 32% in 'good' health, and 20% in fair or poor health (Mylek & Schirmer, 2023). Kenny, King and Hall (2014) found that females providing 20 or more hours of care per week had poorer physical functioning after two years as a carer relative to non-carers in an otherwise similar life situation.

The Productivity Commission inquiry into an extended unpaid carer leave entitlement noted the Australian Psychological Society submission that stated the 'prevalence of depression and anxiety is higher for carers' when compared with non-carers, and that physical health is affected as well, with carers found to be 'at risk for a variety of stress-related diseases and some reports of higher mortality' (PC 2023).

Research by Harris-Roxas et al (2023) considered the effect of carer status on the health status, health risks, health service use and mortality in people aged 45 years and over. It found that — compared with non-carers — carers in central and eastern Sydney had higher rates of self-reported smoking, anxiety, psychological distress, heart disease, and self-rated poor quality of life. Carers also had higher rates of general practitioner use than non-carers.

The extent to which carers experience adverse health and wellbeing outcomes depends in part on the care requirements. The more hours of care provided each week, and the longer the duration of care, the higher the levels of carer distress and the greater the risk of burnout and social isolation (PC 2023). The circumstances of the care-recipient can also impact on carers — for example, providing care to veterans or refugees that have experienced trauma is likely to present unique and complex challenges for carers, and there is evidence that carers of veterans tend to put their own physical and psychological well-being needs behind the needs of the person they are caring for and often do not seek assistance for their own physical and psychological well-being (Post et al, 2021). That said, carers of veterans are generally under-recognised in the literature.

Access to support can also be related to carers' wellbeing. The 2023 Carer Wellbeing Survey (Mylek & Schirmer, 2023) found that:

Consistent with previous years, carers in 2023 who had good access to support from friends and family were significantly more likely to have healthy levels of wellbeing compared to those who had no or limited access to support from friends or family. A total of 75.4% of carers with no access to help from friends and family reported low wellbeing, compared to 32.3% of those who had easy access to help from friends and family.

The 2022 National Carer Survey (Carers NSW, 2023) found that Aboriginal and Torres Strait Islander carers reported significantly lower wellbeing than the survey average, and the majority

reported being socially isolated and experiencing high to very high psychological distress. Nearly 1 in 5 Aboriginal and Torres Strait Islander carers reported that no culturally appropriate services were available for the person they care for. Research noted in Woods & McCormick (2018) found little quality evidence around Aboriginal and Torres Strait Islander carer functioning and the need for further research.

A survey of 16 LGBT women carers in WA found that all respondents, regardless of identity group, reported that caring had impacted their mental health (GRAI 2023). Lesbian women were more likely than other LGBT women to 'strongly agree'. This may be due in part to another survey finding, that lesbian women who were in a same sex relationship experienced additional strain due to experiencing discrimination in health and social service settings, a finding supported in research on older lesbian women and gay men providing care for an LGBTI person (Alba et.al., 2019).

Some carers experience social isolation and stigma

Some of the negative wellbeing outcomes experienced by carers are related to the social isolation and stigma commonly associated with caring responsibilities.

In particular, the time-consuming responsibilities of caring can lead to social isolation, reducing the time carers spend with friends, family, and even the person they care for. Carers may also feel isolated from their peers due to the stigma or lack of understanding surrounding their responsibilities, leading to feelings of loneliness and alienation.

The SDAC collected information on the social connectedness of informal carers and found that, in 2022, of the 1.2 million primary carers in Australia:

- 72% saw family and friends living outside their household at least once per week in the last 3 months
- female primary carers were more likely than male primary carers to see family and friends living outside their household, at least once per week (75% compared to 67%)
- male primary carers were more than twice as likely to have *not* seen family or friends living outside their household in the last 3 months, compared with female primary carers (7% compared to 3%).

When asked about satisfaction with their level of social and community participation in the last 3 months:

- 61% of primary carers reported that they were satisfied all or most of the time (though younger carers were less satisfied than older primary carers)
- 7% of primary carers reported that they were not satisfied any of the time
- 48% of primary carers reported that they would like more contact with family or friends living outside their household.

Barriers to social and community participation

In 2022, when asked about their participation in social and community activities in the last 3 months:

- 70% of primary carers reported that they had experienced barriers to their participation when attending with the main recipient of their care

- younger primary carers were more likely than older primary carers to report experiencing barriers (77% of those aged 15-34 years, compared with 61% of those aged 65 years and over)
- the likelihood of experiencing barriers increased with the average weekly hours spent caring (61% of carers who spent 1-19 hours per week caring experienced barriers, compared with 81% of those who spent 40 hours or more per week caring).

The most common barriers to participation in social and community activities when attending with their main recipient of care were:

- the recipient's disability/condition/old age (56%)
- COVID-19 related reasons (40%)
- caring responsibilities (36%)
- cost (34%)
- being too busy or having no time (28%)
- problems with accessibility (24%).

The most commonly reported types of social activities where barriers were experienced included:

- socialising in someone else's home (57%)
- visiting a restaurant, café, bar or club (44%)
- participating in physical activity for sport, exercise or recreation (41%).

Carers can be subject to abuse and violence

Informal caregivers are sometimes affected by care recipient violence. However, there is limited evidence on the extent to which carers experience abuse and violence within the care giving relationship.⁵

Lucien et al. (2024) found that the lack of studies of care recipient violence against informal caregivers could 'indicate an underestimation of the problem worldwide' and could also be explained by 'the fact that ... some informal caregivers could perceive violence as normal in their relationship with care recipients or not perceive it at all'.

A UK study (Onwumere et. Al, 2018) reviewed 20 papers documenting the effects of patient-initiated violence in psychosis on carer functioning and found that:

- When a person with psychosis does engage in violence, it is their informal carers, when compared to those from the general population, who are more likely to be the targets, and violence will often occur within the family home
- Patient violence in psychosis was linked to poorer carer outcomes, including carer reports of burden, trauma, fear, and helplessness.
- There is a significant need for further studies to systematically quantify the impact and correlates of patient-initiated violence on psychosis caregivers, and improve prevention.

⁵ This is not to say that care recipients do not experience violence from carers. However, the focus for this report is the experience of the carer.

3.2. Employment, income and financial hardship

Time spent caring means less time available for employment. And health problems caused by caring can limit labour market participation – people who develop a chronic health condition are five times more likely to give up work before the traditional retirement age (Welsh et al. 2018). While the literature suggests that having caring responsibilities does not, in itself, lead to work withdrawal, having caring responsibilities that are stressful or interfering with work (creating ‘role conflicts’) is associated with work withdrawal (Constantin et al. 2022).

In 2022, the SDAC found that three-quarters of carers were in the labour force, with 70% of carers employed (compared to nearly 80% of non-carers).

- Male carers were more likely to be employed than female carers (74.8% of male carers were employed, compared with 66.5% of female carers).
- Primary carers were less likely to be in the labour force than other carers and non-carers (ABS, 2024).

The employment status of carers varies depending on how much care (hours per week) the person is providing to their main recipient of care. Less than half (45%) of primary carers providing more than 40 hours of care per week were employed in 2022, compared with 72% of those providing less than 20 hours of care per week (ABS, 2024). And the 2022 National Carers Survey (Carers NSW, 2023) suggests only a third of carers living with disability or a long-term health condition are in paid employment.

Not only does providing care reduce the probability of employment it also reduces the hours of work undertaken by carers who remain employed and can have other impacts on career progression. The 2022 National Carers Survey found that:

- 34% of carers reported having left the workforce (retired, left a paid job, or stopped looking for work) due to their caring responsibilities
- 27% reported reducing their working hours
- only 28% of respondents said that caring had not impacted their career (Carers NSW, 2023).

The lower level of participation in the paid labour force (relative to non-carers) has direct consequences for the incomes of carers. Data from the 2022 SDAC found that:

- In 2022, the median gross personal income of all carers aged 15-64 years was \$900 per week, 10% less than the median gross income for non-carers (\$1000 per week).
- 62% of carers aged 15-64 years cited employee income as their main source of income (an increase from 56.1% in 2018), while 19% of carers primarily derived income from a government pension or allowance (a decrease from 24% in 2018).
- Primary carers were more than twice as likely to receive a government pension or allowance as their main source of income (30%) than other carers (12%) and non-carers (7%) (ABS, 2024).

The impact of unpaid caring on workforce participation and the number of hours worked is most pronounced when carers are providing intensive, time-demanding care (more than 20 hours per week) (Colombo et al., 2011).

Brimblecombe et. al. (2018) also found that unpaid carers often experience difficulties re-entering employment after caring finishes, and the longer that a carer is out of paid work, the harder it is for them to return to it.

All up, these circumstances mean that many carers face financial hardship. In 2022, of primary carers aged 15-64 who reported their income:

- 47% lived in a household in the lowest two equivalised household income quintiles, almost twice that of non-carers.
- Only 10% lived in a household in the highest equivalised household income quintile, compared with 26% of non-carers (ABS, 2024).

In 2023, the Carer Wellbeing Survey found that 16% of carers reported being poor or very poor, higher than the 13% in 2021 and 12.5% in 2022. Carers were 1.6 times more likely to be poor or very poor than the average Australian.

In 2023, just over 3 in 5 carers (61%) reported that they had experienced at least one significant financial stress event in the previous 12 months, such as being unable to pay bills on time, going without meals, or having to ask for financial assistance. ... Carers consistently experience higher rates of financial stress events compared to the broader population (Mylek & Schirmer, 2023).

Furthermore, research commissioned by Carers Australia estimates that a primary carers superannuation balance at age 67 is reduced by \$17,700 for every year they provide care. 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 (Furnival & Cullen, 2024).

3.3. Younger carers

The evidence base on carer wellbeing for different demographic groups is somewhat patchy, but there is a growing understanding about the impacts for young carers having regard to their developmental needs.

A significant and growing number of Australian children and young (<25 years) adults have informal caregiving responsibilities (SDAC, 2024). Societal awareness of young carers and the potential effects of caring on their health, wellbeing, education and employment has increased.

A recent study (Alfonzo et. al., 2024) provides some important insights into these issues. This study drew on 20 years of longitudinal data from the Household, Income and Labour Dynamics in Australia (HILDA) survey to:

- assess the longitudinal changes in mental health when young people are in different caregiving categories, and
- examine whether the mental health effect of young caring varies by the extent of weekly caring activities (hours per week).

It found that mental health was poorer when caring relative to not caring, and the average mental health differences were larger when caring for 20 hours or more. The authors observed that:

One explanation for these findings relates to the caregiving role overload. Young carers, especially those providing intense caregiving, not only dedicate a considerable part of their time to these roles, but they also spend a substantial amount of time and energy living in a state of constant readiness and concern. The ongoing stress of the caregiving role might underpin the observed mental health effects. Informal care could also be isolating for young carers. Many are forced to

prioritise other obligations, such as maintaining employment and continuing their education, limiting their engagement with peers. Furthermore, although most young people are afforded an extended period of adolescence, caring responsibilities necessitate that young carers mature early, further marking them as different to their peers. These feelings of isolation and loneliness could amplify the existing mental health strains of informal care.

The authors concluded that these findings could have implications for the longer-term mental health of young carers:

Evidence shows that poor mental health in youth increases the risk of adult depression, anxiety, and suicidality, and predicts low educational attainment and unemployment. Without adequate support, the mental health differences attributed to informal care could potentially place young carers at a disadvantage relative to their non-caring peers, with possible consequences for their personal, educational, and economic development.

This study echoes findings from *Growing up in Australia: The Longitudinal Study of Australian Children*. Of the 760 adolescents (37% of adolescents in the study) who had provided some form of informal care at age 14/15, 7% provided daily care and 30% provided less than daily care. At age 18/19, mental health was worse for carers than non-carers, and these effects were greater for those providing daily care. The survey findings also reveal that bullying is a problem for young carers and up to a quarter of the mental health effects of informal care are explained by experiences of school bullying (King et. al., 2021).

A 2020 study by Dharampal and Ani reviewed the literature on the emotional and mental health needs of young carers of parents with mental illness and the extent to which such needs are recognised and supported by professionals. They concluded that:

Young caregivers had a significantly higher dose-response mortality risk than their peers; were at increased risk of mental health difficulties, especially where the ill family member was a parent and had mental illness or misused substances; were overlooked by professionals owing to a lack of awareness; but could derive benefits from their caring role when appropriately supported.

In 2022, Lacey, Xue and McMunn undertook a systematic review of 1162 studies (mostly from the UK) related to the health of young carers (< 18 years). All the included studies, except one, were cross-sectional⁶ in design. The authors found that:

- on average, young carers have poorer mental and physical health than their non-caregiving peers.
- there is some evidence to suggest that physical and mental health might be poorest for young carers providing intense care.
- young carers (when they are primary caregivers) are most likely to be providing care for a parent and most often for a parent with mental health conditions.

⁶ Cross-sectional studies provide information on caring and health at one timepoint, but it could be that young carers have poor mental and physical health before becoming a carer. Longitudinal studies enable a researcher to disentangle the temporal ordering of care and health and therefore strengthen causal claims.

The authors concluded that:

Most studies found that young carers had poorer physical and mental health, on average, than their non-caregiving peers. However, the evidence is relatively weak and more quantitative research is needed, particularly research that is longitudinal in design and assesses physical health outcomes.

Health is not the only concern. Education and employment outcomes for young people can also be affected by caring responsibilities. For example:

- Warren and Edwards (2016) found that the difference in Year 9 NAPLAN results between young carers with significant responsibilities and other children was equivalent to more than one year of schooling.
- Hamilton and Redmond (2019) found that young carers are less likely to complete or do well in secondary school compared with young people without caring responsibilities. While school engagement of young carers of people with disability is not significantly different from that of non-carers, school engagement among young carers of people with a mental illness or using alcohol/drugs is significantly lower. Among this latter group, young carers who are themselves with disability report particularly low levels of engagement.

A roundtable of Australian young carers in May 2024 identified several reasons why engaging in education and employment can be problematic for young carers.

- Sometimes staff (or employers) do not realise that a student (employee) is a young carer and therefore do not offer them support. Some young people do not wish to identify as a carer (often out of fear of stereotyping and bias) or do not see their role in those terms.
- There can be a lack of support and understanding from educational staff and employers about what it means to be a young carer and the additional help people might need.
- Rigid attendance and/or medical certificate requirements can place significant pressure and stress on young carers (Carers Australia, Unpublished 2024b).

Disruptions to education and employment due to caregiving responsibilities can be very consequential for young carers. Not being in education and/or work at such an important time of transition and skill development is associated with increased vulnerability to their career and broader wellbeing throughout their life.

4. Support for informal carers

Various types of support are available to informal carers — health and wellbeing supports (such as counselling, peer support groups, coaching and education), financial assistance, respite care, and support to engage in education and paid work.

The 2022 National Carer Survey (Carers NSW, 2023) found that the most commonly-used types of carer support in the past two years were the Carer Gateway website (35.2%) and phone line (28.0%), followed by phone-based carer counselling (17.0%), and face-to-face carer peer support groups (16.7%).

Having access to carer supports can make a significant difference to the quality of carers' lives, and to both their wellbeing and the wellbeing of the people they care for (Mylek & Schirmer, 2023).

The Royal Commission into Aged Care Quality and Safety (2018) stated that 'early access to services is critical to supporting the wellbeing of the informal carer as well as the sustainability of the caring relationship'. In the context of the low rates of male relative to female carers, Carers Australia noted that: 'Caring is not traditionally seen as a male role and that understanding the male perspective of the caring roles presents a challenge...to better assist men who are often only reaching out assistance when at a crisis point' (Carers Australia, 2023 p.7).

This section will describe the evidence on how carers are accessing and using these services, and (based on the limited available evidence) how effective (or not) existing supports are.

4.1. Health and wellbeing support

Informal carers access a range of government-funded services aimed at supporting carers' health and wellbeing and helping carers in their caring role. Results from the 2023 Carer Wellbeing Survey found show that in the previous 12 months about 1 in 5 carers accessed carer training and skills courses, and 28% of carers accessed psychological support services (Mylek & Schirmer, 2023).

Carer Gateway services

Carer Gateway is an Australian Government program providing free services and support for carers. Services are delivered in-person, online and over the phone and include:

- In-person and online peer support groups to share stories, knowledge and experience.
- Tailored support packages, including planned respite, cleaning services, assistance with shopping and transport services.
- One-off practical support for items that support carers in their caring role or to access education or employment, such as training courses or a laptop.
- In-person and phone counselling.
- In-person and online self-guided coaching.
- Online skills courses to support carers' wellbeing, and to increase carers' understanding of their legal responsibilities relating to the caring role.
- Access to emergency respite.

Use of Carer Gateway services is growing. A submission from DSS to the Inquiry into the recognition of unpaid carers reported that the proportion of carers registered with Carer

Gateway service providers increased from 2% in 2021 to almost 5% in 2022. As of June 2023, 163,403 carers were registered with Carer Gateway service providers (Standing Committee, 2024).

However, there is little publicly-available data to assess the effectiveness of Carer Gateway, in part because the program is in its infancy — 2022-23 represented the third full year of operation for the Carer Gateway program. In its 2022-23 annual report, the Department of Social Services reported that 34% of carers registered with Carer Gateway service providers experienced improved levels of carer wellbeing since the program commenced (DSS 2023). However, this metric is based on scores provided by Carer Gateway service providers who may have a vested interest in seeing improvements in results.

The 2024 Inquiry into the recognition of unpaid carers (Standing Committee, 2024) observed that:

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. However, the Committee also heard that accessing support through Carer Gateway can be slow, time-consuming and difficult for carers. Some carers did not receive the assistance they wanted and were offered services they felt were unhelpful, while others believed it was not worth the effort seeking support from Carer Gateway.

A survey by Tandem (2023) as part of their submission to the 2024 inquiry asked carers about their experiences with the Carer Gateway. Tandem reported that of the 132 respondents:

- Views were split noting 30% either 'strongly agreed' or 'agreed' that the Gateway understands the experiences of, and is useful for, unpaid carers who support people with mental health challenges. However, a third of responses 'strongly disagreed' or 'disagreed', and the remainder were neutral.
- Most expressed concerns, such as long waitlists for resources that are inadequate, practical assistance such as in-home help or respite being largely unavailable, and carers' calls not being returned.

Respondents also found the intake and assessment process confusing and considered 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 than the challenges associated with the mental health carer role (Tandem, 2023).

The Standing Committee (2024) recommended strengthening the supports provided to carers via the Carer Gateway by (recommendation 9):

- 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.

It also recommended 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. Further, options for in-person and online training should be provided (recommendation 14).

Other wellbeing programs and supports

A variety of psychological interventions aim to improve carers' wellbeing and reduce the caring burden and related stress. Evidence on the effectiveness of wellbeing supports and interventions for unpaid carers is relatively limited, though there are some important insights.

For example, the literature tends to favour multi-component approaches to carer support. A 2018 review (Woods & McCormick, 2018) concluded that:

Multi-component or multi-dimensional interventions are more successful than single interventions at addressing carers' health and wellbeing needs. Abrahams et al. (2018), for example, suggest on the basis of a systematic review of the literature, that a combination of counselling, support groups, education, stress and mood management, and telephone support are important strategies within an effective multi-component intervention for carers of people with dementia...

Multi-component interventions may be more successful than individual interventions because carers are dealing simultaneously with 'a broad range of stressors' (Carers NSW 2017).

The PC's inquiry into an extended unpaid carer entitlement observed that there is some evidence that psychological supports — such as counselling, emotional support, behaviour management, meditation, mindfulness and acceptance-based interventions — are linked to reduced depression, caregiving burden and psychological distress among informal carers, but the evidence is not as strong for some other types of psychological interventions, such as cognitive behavioural therapy and support groups (PC, 2023).

That said, there is some evidence that peer support groups can be effective for specific groups of carers.

- Worrall et al (2018) showed a consistent pattern of evidence, generated over many years, which confirms the effectiveness of support groups for carers of people with mental illness. Professionally facilitated group work for carers of people with severe mental illness can assist them by:
 - providing education and information in order to increase knowledge and understanding of the disorder
 - encouraging an atmosphere of mutual trust through which they could explore strategies for coping, and
 - providing emotional support conducive to an open and honest sharing of feelings.
- Peer support groups were also found to be beneficial for carers of older adults with dementia living in their own home (Lauritzen et al. 2015).

- And an evaluation of an Australian peer-led support group for eating disorder caregivers found that overall, it had a positive contribution for caregivers (Lefkovits et. al., 2024).

A 2018 paper by Brimblecombe et al. sought to provide an overview of the international evidence on effective support for unpaid carers and concluded that:

There are significant gaps in the evidence base with regards to interventions, outcomes and types of caring situation studied, with a dearth of evidence on cost-effectiveness and few evaluations of key recent policy initiatives.

A more recent paper by Spiers et al (2024) aimed to identify and map evidence about interventions to support carers. There were 205 studies reported across 208 publications included in the evidence map. The authors found that:

The majority [of studies] evaluated the impact of therapeutic and educational interventions on carer burden and carers' mental health. Some studies reported evidence about physical exercise interventions and befriending and peer support for carers, but these considered a limited range of outcomes. Few studies evaluated interventions that focused on delivering financial information and advice, pain management, and physical skills training for carers. Evaluations rarely considered the impact of interventions on carers' physical health, quality of life, and social and financial wellbeing. Very few studies considered whether interventions delivered equitable outcomes.

Overall, the authors concluded that little research in the past ten years has considered what works best to support carers' physical and financial wellbeing.

Evaluating the effectiveness of interventions aimed at supporting carers is not straightforward. For one, it assumes a degree of clarity on the goals of the interventions. In practice, carer interventions may seek to achieve a range of aims for carers, care recipients, or both.

Education and training

Education and training programs can target the development of a range of skills and knowledge for informal carers, including those aimed at improving the health and wellbeing of the carer and care recipient, educating the carer about the care recipient's condition (such as dementia) and those relating to manual handling. Educational interventions can improve the preparedness of the person providing informal care through, for example, the provision of skills to successfully and safely carry out personal care tasks.

However, the 2024 inquiry into the recognition of unpaid carers (Standing Committee 2024) noted that many carers take on complex caring roles with no training in providing health care. It added that submitters to the inquiry '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. Specifically, there was support for 'free manual handling, wound care and medication management training, and for carers to have access to training that is equivalent to the training that paid carers receive'.

The 2023 PC inquiry into an extended unpaid carer leave entitlement found mixed evidence on the extent to which education and training programs reduce the carer burden or otherwise improve carer wellbeing (PC, 2023):

There is mixed evidence on the extent to which these programs help with carer burden, quality of life, mental health and transitions to long-term residential care for the care recipient (Jensen et al. 2014; Yesufu-Udechuku et al. 2015). A study in the United States found that education and training for carers lead to increased carer confidence over time (Avison et al. 2018, p. xi). Other studies have found little evidence that information or training programs had significant effects on carer burden, mental health or quality of life (González-Fraile et al. 2021; Treanor et al. 2020).

4.2. Financial support

Income support payments

Direct government payments to carers include the Carer Payment, Carer Allowance and Carer Supplement.

The Department of Social Services (DSS) is responsible for Australian Government carer payments.

- **Carer Payment** – 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, studying or training 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. The amount of Carer Payment depends on an individual’s personal circumstances.
- **Carer Allowance** – a supplementary payment for carers who provide a level of daily care and attention for people who need significant additional care.

In 2022-23, about 77% of primary carers in Australia were supported by Carer Payment and/or Carer Allowance (DSS 2023).

- 305,332 people received the carer payment and 634,179 people received the carer allowance (table 1.4, pg. 54).

The number of people receiving Carer Payment and Carer Allowance increased in 2022-23 by 2 per cent (relative to 2021–22).

Recipients may also be eligible for the:

- **Carer Supplement** — an annual payment to help cover costs when caring for someone with disability or a medical condition. 660,178 people received this in 2022-23.
- **Child Disability Assistance Payment** — an annual payment for carers that receive Carer Allowance and provide care for a child with disability or a severe medical condition. 168,087 people received this in 2022-23.
- **Carer Adjustment Payment** — a one-off payment for carers of a child younger than 7 years with a severe medical condition or disability following a catastrophic event.

People have raised concerns about carer payments in many forums over many years (e.g., PC, 2020; PC, 2023; Senate Inquiry, 2024). Concerns generally relate to:

- the level of income support payments
- the administrative complexity associated with applying for payments, and
- eligibility requirements that are overly restrictive or penalise working carers.

The scope and design of financial payments to carers is inherently complex and contentious. A comprehensive review of the payment system would provide an opportunity to consider the benefits and costs of any changes to existing arrangements. The PC (2023) considered some of these issues in its inquiry into an extended unpaid carer leave entitlement and found that:

The level of income support provided by the Carer Payment is in line with other pensions in Australia. In 2022, the rates of Carer Payment were just below estimated poverty lines for people who do not participate in the paid workforce (Melbourne Institute 2022, p. 1). However, many recipients of Carer Payment also receive Carer Allowance and/or rent assistance, which may bring their income to the poverty line or above it.

The PC recommended that in the next review of government income support payments, the Economic Inclusion Advisory Committee should consider the ways in which the eligibility requirements and complexity of having multiple payments may be contributing to carers' economic disadvantage (PC, 2023).

4.3. Respite care

Access to respite care is crucial for carers to take a break from their responsibilities and helps to make caring sustainable. It can benefit carers' emotional wellbeing and physical health, address social isolation and loneliness, and help carers provide better care and return to work.

Respite care can be given by family or friends or by a respite service. It can take place at home, in the community, at a centre or in a residential care facility. Respite care can be:

- for a short time (for example, for a few hours each week)
- for a longer time, including overnight (for example, a weekend)

Emergency respite care can offer support to carers who are experiencing urgent, unplanned and imminent issues that temporarily restrict their ability to continue caring.

The 2023 Carer Wellbeing Survey found that wellbeing was significantly higher for carers who accessed respite care than for those carers who did not — 47% of carers who accessed respite care reported sufficient to high levels of wellbeing compared to 40% of carers do not use respite care (Mylek & Schirmer, 2023).

However, securing fit-for-purpose respite services can be challenging. The 2022 National Carer Survey (Carers NSW, 2023) found that:

As in previous Surveys, the largest unmet need was for planned and emergency respite services. For planned respite services, the unmet need (27%) is twice as high as the rate of use among respondents (13.8%); for emergency respite, unmet need (24.4%) is four times the rate of use (6.1%).

Some common barriers that carers report facing when accessing respite care include lack of availability, difficulty arranging, and respite services that are not aligned to the carer and care recipient's preferences, care needs and cultural needs. Indeed, concerns are not limited to the amount of respite care available, but also the quality and timeliness of respite care, and the extent to which the service is fit-for-purpose given the care recipients' need.

The Standing Committee (2024) inquiry into the recognition of unpaid carers heard that:

Despite respite care being available through multiple support systems, carers still have difficulty accessing respite services when they need them. Furthermore, there are significant differences in how much respite care is available to carers through My Aged Care and NDIS, and limitations on eligibility and barriers to access for mental health carers (para 3.38).

The Committee recommended that the Australian Government build the capacity of respite care services and concluded that:

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 (para 3.119).

The Committee noted that the Royal Commission into Aged Care Quality and Safety also found that:

There are numerous barriers to respite care — services are in short supply, they need to be booked months in advance, or they are only available for periods of several weeks when people and their carers need a shorter time (RCACQS 2021b, p. 25).

Australia is not unique in encountering these challenges. The Organisation for Economic Cooperation and Development (OECD) found that ‘among OECD countries, respite care remains insufficient, with low uptake due to low compensation, low availability of services and organisational challenges’ (Rocard and Llana-Nozal, 2022 p. 5).

The PC’s inquiry into an extended unpaid carer leave entitlement noted that (PC, 2023 p.208):

There are several reasons why respite can be difficult to access in Australia. Some of these reasons relate to the functioning of residential care – including staffing shortages. ... Respite is sometimes not available in communities outside of metropolitan areas, or is not equipped to meet the care recipient’s needs (such as for dementia or palliative care, or culturally appropriate care for culturally and linguistically diverse groups).

Studies looking at the effects of respite on informal carers suggest that regular respite can improve carer wellbeing, though there is a lack of high-quality evidence. A systematic review of the common determinants of carer burden in Western countries suggested that ‘the effects of different types of respite care could be tested experimentally regarding their effectiveness in relieving care burden’ and the benefit of using longitudinal studies to enable trend analyses over time (Lindt et. al., 2020).

4.4. Supports to engage in education and paid work

Having the opportunity to engage in education and paid employment is fundamental to carers' wellbeing and full participation in economic and social life. However, almost-two thirds of all carers (64%) surveyed in the 2023 Carer Wellbeing survey reported low satisfaction with their ability to participate in paid work, and even more (68%) reported low satisfaction with their ability to do further education or training if they want to (Mylek & Schirmer, 2023).

And while nearly a third of carers indicated that their ability to participate in paid work was getting better with time, more than half of carers (57%) reported that their ability to progress their studies/education was getting worse (Mylek & Schirmer, 2023).

Barriers to employment and education can have significant and enduring implications for carers — as discussed in section 3.2, unpaid carers typically have lower incomes and superannuation balances (and higher rates of financial hardship) than non-carers. And for younger carers, obstacles to attending school can affect academic progress, socialisation with friends, participation in extra-curricular activities, and a young persons' sense of belonging (Moore et al, 2019).

There are also consequences for broader society if unpaid carers are not able to reach their full potential. A 2021 study on carers in higher education (Andrewartha and Harvey 2021) found that student carers were highly motivated to succeed in higher education and had very relevant skills developed through their caring role. However, juggling caring and studying led to financial hardship amongst student carers and lower levels of wellbeing relative to their non-carer peers. The study found support for student carers in higher education to be limited and inconsistent.

Many carer supports — including respite care and carer payments — can indirectly help carers to engage in education and employment. There are also dedicated programs in place to encourage carers' participation in education and paid employment.

Employment supports for unpaid carers

Entitlements to **carer leave** and **flexible working arrangements** can help people with caring responsibilities to balance paid work and care. The 2023 Carer Wellbeing Survey found that:

- most carers (59%) have some level of flexibility in the timing of their work hours (with 36% reporting that they have set hours that they can change if they need to, and 24% reporting that they can change their hours easily as needed), and
- 23% of carers could work from home any time if they want to, and 38% could work from home sometimes but not always (Mylek & Schirmer, 2023).

Having an employer that understands the challenges associating with being an unpaid carer can also assist carers in accessing and maintaining paid employment. Most employed carers in the Carer Wellbeing Survey indicated that their employer was at least somewhat understanding about their caring role — however, 16% reported that their employer is not understanding of their role as a carer and that it is expected their caring duties do not interfere with any aspect of their work.

At a minimum, all employees covered by the national workplace relations system have guaranteed and enforceable entitlements under the **National Employment Standards (NES)** that can help them balance paid work and care. This includes paid and unpaid carer leave, compassionate leave, and flexible working arrangements. The Fair Work Act 2009 provides employees in the national workplace relations system with a legal right to request flexible

working arrangements. To be eligible, employees must have worked for their employer for at least 12 months on a full-time or part-time basis. Long term casual employees who have a reasonable expectation of ongoing employment are also eligible. Many employers also provide carer leave entitlements over and above those in the NES.

However, despite the importance of flexible working arrangements for carers seeking to balance paid work and caregiving, flexible employment entitlements are not generally well known or understood (PC, 2023). As part of its inquiry into the case for an extended unpaid carer leave entitlement, the Productivity Commission observed that proactively providing information to people about carers' employment rights was an important role for governments (and employer organisations and unions also have a role to play), and recommended that working carers be provided with tailored information about flexible working arrangements and how to request them (PC, 2023).

Employer attitudes toward carer employees can have a significant impact on carers' wellbeing — carers with employers who are highly supportive of their caregiving role were significantly more likely to have healthy levels of wellbeing compared to those who feel their employers who are not understanding (Mylek & Schirmer, 2023).

The Australian Government's **Carer Inclusive Workplace Initiative** (being delivered in partnership with Carers Australia) aims to create more inclusive and supportive workplaces for unpaid carers by equipping employers with the knowledge and skills to understand the needs of carers and to support carers in the workplace. This initiative was launched in 2023 and evidence on its effectiveness is not yet available. In NSW, organisations can become 'accredited carer friendly employers' by participating in the **Carers + Employers program**.

Education supports for unpaid carers

The **Young Carer Bursary Program** assists young carers aged 12-25 years to continue their education by providing financial assistance to reduce the need to undertake part-time work while studying and managing caring responsibilities. Carers Australia delivers the Young Carer Bursary Program on behalf of the Australian Government. The program offers 1,592 bursaries of \$3,768 each year to assist with education needs and resources (Young Carers Network, nd).

A 2016 evaluation of the Young Carer Bursary Program found that the program assists bursary recipients to stay in education, continue in their caring role, increase their social connections, and reduce the daily pressure/stress they experience (Inside Policy, 2017).

And more recently, a study by Moore et al (2019) analysing data from the 2017 and 2018 applications for the Young Carers Bursary Program found that 22% of young carers were unable to attend school at least once per week due to caring responsibilities, and a further 39% were unable to attend school 1-3 times per month due to caring responsibilities. The study concluded that:

For many young carers, financial support may assist them to overcome some of the barriers to them attending, achieving and participating in education by helping them to pay for educational courses, materials and extra-curricular activities. However, the analysis confirms previous findings that suggest that ultimately young carers' educational engagement may only be improved if families are provided with resources to minimise young people's caring loads, while providing supports that reduce the physical, emotional, social and educational impacts of caring.

Unpaid carers have also been supported to engage in education (and employment) through **Try, Test and Learn** -funded trial projects administered by the Department of Social Services. For example:

- under the *Carers Connect to Education and Employment* project, 100 carer participants were provided with personalised support, including coaching and mentoring, and financial assistance, to help overcome barriers to engaging in education and training and to support them through their training/studies; and
- the *Young Carers School Accreditation* program sought to raise awareness of carers in schools, reduce stigma and support young carers to complete secondary school and navigate the transition from school to the workforce.

A 2021 evaluation of the Try, Test and Learn fund documents various challenges associated with these pilot projects but also reports some evidence that TTL projects led to an improved capacity for carers to participate in work and study (University of Queensland, 2021).

4.5. Other concerns with the support system

Stakeholders have also raised concerns about the support that is available to informal carers to navigate available services; carers' awareness of these services and the role of carers (in service system design, and as partners in care).

Service system navigation

An issue affecting the wellbeing of carers — and how well they can fulfil their caring roles — is the time spent navigating government supports and services. Carers may need to access services such as Centrelink, the NDIS, My Aged Care or Veteran's support on behalf of the person/people they care for, or to access their own carer supports and entitlements.

In 2023, the Carer Wellbeing Survey revealed that more than 40% of carers spend at least an hour a week – and often more – navigating government systems, and almost 10% of carers often spend more than five hours per week navigating support systems on behalf of the people they care for (Mylek & Schirmer, 2023).

Most carers (61%) reported that they did not receive any assistance to help navigate these government systems, while 24% reported that they received assistance and that it was helpful, and 14.6% received help but reported that it was not helpful. Assistance can come from the system's own helpline or support, from Carer Gateway, from a health professional, or from a family member, friend or community organisation. It was relatively common for carers to receive assistance from more than one of these sources (Mylek & Schirmer, 2023).

And a recent survey by Tandem (2023) as part of its submission to the 2024 inquiry into the recognition of unpaid carers found that of the 132 respondents:

- Only 9% 'strongly agreed' or 'agreed' that 'the NDIS engages well with unpaid carers who support people with mental health challenges', while 61% 'strongly disagreed' or 'disagreed' (others indicated this question was not applicable to them).
- Many felt that they are not listened to or included by planners and providers; there is limited or no understanding of mental health challenges, or challenges carers experience; and limited or no support to sustain carer roles.
- Centrelink's engagement with carers and administrative processes 'can not only be grossly inadequate but can be harmful'. Only 5% of respondents either 'strongly agreed' or 'agreed' with the following statement: 'Centrelink adequately identifies, understands and interacts

with unpaid carers of people with mental health challenges' (28% disagreed, 46% strongly disagreed).

The Tandem submission stated that:

In addition to poor identification of carers, many respondents described highly excessive bureaucratic hurdles, inadequate understanding of the responsibilities carers undertake, and disrespectful staff behaviour, leading to entitlements not being accessed and experiences of distress.

Some carers may need to navigate between multiple systems which can create additional difficulties. The Royal Commission into Aged Care Quality and Safety stated that they heard that difficulty navigating between My Aged Care and the Carer Gateway was one of the issues for carers in getting access to respite services (RCACQS, 2018).

Carers' awareness of available supports

There is longstanding evidence that some carers are not aware of the supports available to help them in their caring role, or of their rights as a carer (refer to SDAC results in section 2).

In some cases, this is because carers have low English language or digital literacy skills, making it difficult to find out about existing support services or apply for them. Awareness about available supports can be especially poor amongst younger carers.

The problem of low awareness is compounded by the under-identification of informal carers in the community. Many people providing informal care do not consider themselves a carer, or do not wish to formally identify themselves in this way. This under-identification can mean people are not made aware of — or do not have access to — the available supports. Section 6 provides further information on hidden carers.

The Standing Committee (2023) inquiry state that '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'. Other stakeholders have called for targeted campaigns to reach children and young carers, including those who do not identify with the term 'carer', such as through the education system (submissions to the Standing Committee inquiry).

As noted in section 4.4, a PC (2023) inquiry found that information about employment entitlements to flexible work are not generally well known or understood. And in their submission to the PC inquiry, Carers NSW stated:

Carers may be unaware of their entitlements or have limited understanding of the redress pathways available to them where they are unable to access these entitlements or feel discriminated against for doing so. Currently, there is no central place carers can access to fully understand their rights or redress pathways within the employment context. (sub. 20, pp. 9–10)

Feedback from carers is that information about carer rights and supports is needed at the start of the caring journey, and that governments, employers and schools need to be more proactive at making carers aware of the entitlements and supports available to them.

The role and recognition of carers

Community awareness of the role and contribution of informal carers is essential. However, while many agree that the *Carer Recognition Act 2010 (Cwth)* was a key development, there is widespread concern that the Act has not had a significant impact on the recognition of carers (Standing Committee, 2024).

There are also ongoing concerns about the role of carers in supporting the health care of the care recipient. While many carers want to be seen as 'partners in care', carers continue to report that their perspective or knowledge is sometimes not valued or respected (e.g., Lavers et al., 2022 for caregivers of people who have attempted suicide or experienced suicidal ideation).

Research suggests that engaging carers as partners in care and decision-making works best when professionals identify and welcome carer expertise, and when provider-carer partnerships include strong levels of collaboration from the start (Woods & McCormick, 2018).

Some groups have pointed to the UK 'Triangle of Care' model as an example of a better approach (for example, Mind Australia, nd). The Triangle of Care aims to recognise carers as important partners in care and brings together service users; their carers, families and friends; and professionals who help service users (Carers Trust, nd). To date it has been used predominately in the area of mental health care and support.

The inquiry into the recognition of unpaid carers (Standing Committee, 2024) found that:

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.

The reviewer of the *Carer Recognition Act 2005 (SA)* in 2024 stated that 'more needs to be done to acknowledge the value of carers, both in relation to service delivery and in taking their views into account in connection with service design' (Dennis, Unpublished 2024 p.13).

Transitions in caring

Research shows that carers have concerns in relation to the supports available to them as they transition through different caring roles. For example, when the care recipient moves from their care to formal care, or when the care recipient passes away. In some cases, the carer may be caring for multiple people.

Research based on analysis of free-text responses to a question in the 2020 National Carer Survey found that many carers consider life after caring to be profoundly difficult and to feature a mix of loss, isolation and precarity (Kirby et al., 2022). The authors argue that much greater improvements are required to support the transition of carers out of particular caring situations.

Similarly, a synthesis of evidence from 19 systematic reviews found that more information may be needed on how best to support carers as different trajectories to end-of-life and different diseases may require different supports (palliAGED, 2021).

5. Counting carers

5.1. Hidden carers

People providing care do not always identify themselves as carers. This is in part because providing care and support can be viewed as something that is expected of family members or because of concerns that adopting the 'carer' label would threaten the identity of the care recipient (Knowles et al., 2015). And often becoming an informal carer happens over time rather than being a decision at a particular point in time (PC 2023). In addition, some people providing informal care may not be formally recognised as carers by service providers (Standing Committee, 2024).

This means that existing data on informal carers may significantly underestimate the size of the cohort. It can also mean that some carers are not aware of, and/or do not have access to, available support services.

Certain types of carers are more likely to be hidden from service systems and miss out on support. For example, the PC's inquiry into mental health (PC 2020) noted that:

Aboriginal and Torres Strait Islander carers and culturally and linguistically diverse carers may not access services because of a lack of culturally capable services or awareness of services (DSS 2016c; Hill et al. 2016). In these communities, the caring role may be shared with many in the community, and this makes it difficult to identify who is a carer (Mind Australia et al. 2016; Northern Territory Mental Health Coalition, sub. 741). Cultural norms about family responsibilities and stigma about mental illness also contributes to lower rates of service use among people from culturally diverse backgrounds (Carers Victoria 2013; Diminic et al. 2017; MHFFTs, sub. 391).

In their submission to the PC's mental health inquiry, Carers Victoria (2020) highlighted that LGBTQIA+ carers can experience additional difficulties in the healthcare system if staff do not recognise or support their relationship. Research also indicates that LGBTQIA + carers may view their caring role as a form of love for the recipient, and therefore not feeling it should be financed. An Australian survey of 16 older lesbian women and gay men found this, with very few participants taking up the opportunity of financial support (Waling et.al., 2022).

And several submitters observed that some young carers may not identify as carers, or conceal their caring role, because they (PC 2020):

- do not realise that what they do is different to what occurs in other families
- are not taken seriously by service providers because of their age
- fear stigma and bullying
- are concerned about intervention from child protection services.

The Australian Human Rights Commission has also suggested that First Nations carers may be less likely to identify as a carer (and seek assistance) relative to non-Indigenous people (AHRC, 2020). The term 'disability' is not used in some First Nations communities, resulting in the term 'carer' often being associated with other types of relationships, such as foster and kinship care. This is further supported by research suggesting that Aboriginal and Torres Strait Islander people view the caring they do as accepted part of their normal kinship roles (Woods & McCormick, 2018).

5.2. Data on informal carers

There is reasonable high-level data on informal carers. This is mainly in relation to broad sociodemographic characteristics and some carer' outcomes and experiences (see sections 2 and 3). However, there are also significant evidence gaps.

The Standing Committee (2024) inquiry into unpaid carers found that:

- More comprehensive data about carers is required to inform policies that improve carers' health and wellbeing and deliver more appropriately targeted carer supports.
- 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.
- 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.
- 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.

6. Discussion

Robust data and other forms of high-quality evidence (such as program evaluations and qualitative research) are crucial to inform governments about what matters to unpaid carers and how best to support them. Importantly, each piece of evidence represents a person with their own lived experiences, and the insights these people provide must be recognised and valued. Ultimately, the purpose of developing an evidence base is to improve individual carers' experiences and outcomes in a cost-effective manner.

This rapid scoping review demonstrates that there is a broad body of evidence on unpaid carers in Australia. Much of this relates to who carers are and what they do, providing a comprehensive understanding of the profile of unpaid carers and the scale and nature of their care-giving. However, some of this data is high level and doesn't reflect the diversity of carers' circumstances and needs. In other cases, restrictive definitions and scope can lead to an under-identification of unpaid carers (which is especially pronounced for some groups).

Evidence about carers' wellbeing and economic and social outcomes is also well documented and typically shows that carers experience poorer outcomes relative to their non-caring peers. That said, there is also evidence that many unpaid carers find being a carer satisfying, and carers can contribute enormously to the wellbeing of the person they are caring for.

There is less evidence about the *causes* of poorer carer outcomes, and how (and why) these causal pathways vary for different types of carers and care-giving. For example, poor mental health among young carers will likely have different drivers (and require different responses) to poor mental health experienced by older carers. Building this evidence will help governments to design targeted, tailored and effective carer supports.

Evaluation of existing policies and programs aimed at supporting carers is critical for improving those programs and designing new ones. However, evaluative evidence is very scant. Several factors are behind this — where program objectives are ambiguous or conflicting, assessing effectiveness is fraught, and unclear or fragmented roles and responsibilities for carer supports further weaken accountability. Measurable objectives, transparency about outcomes, and a culture of evaluation and learning are fundamental to implementing programs that meaningfully support carers (and ceasing or amending programs that do not).

A National Carer Strategy is a key opportunity to embed an evidence-based approach to the design and implementation of carer policies and supports. Australia's 3 million unpaid carers make an enormous contribution to our society and economy, and to the wellbeing of the people they care for. However, caregiving can significantly impact on all aspects of a carer's life, and these impacts can be ongoing. This underscores the importance of all areas of government working collaboratively — guided by the evidence — to achieve the vision *'for an Australian community in which all carers are recognised, valued and empowered with the support they need to participate fully in society and fulfil their caring role.'*

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