

Policy Platform: Updated March 2019

Caring Fairly is a national campaigning coalition led by unpaid carers, and specialist organisations and peak bodies that support and advocate for carers' rights. Established in August 2018, *Caring Fairly* is made up of over 25 organisations, spanning all states and territories of Australia. A full list of coalition members can be found at caringfairly.org.au.

Caring Fairly has a human rights-based agenda for social and policy change. We are leading a political advocacy and public awareness raising campaign focused on improving and realising the economic, social, and cultural rights of all unpaid carers in Australia. In practical terms, we are especially focused on improving workforce participation and workplace conditions for unpaid carers, improving the long-term economic security of all unpaid carers, and improving social outcomes for young carers.

We have invested in leading edge new research - and produced evidence-based policies - that we believe promote fairer and more inclusive outcomes for all unpaid carers in Australia - at home, in the workplace, and in society.

Caring Fairly is a movement that wants to lead a new public conversation about the value of those who care. *Caring Fairly* is coordinated by Mind Australia, and is supported by a growing coalition of allies and grassroots supporters from across Australia.

Please visit caringfairly.org.au for more information about our activities, evidence base, policy agenda, supporters, and impact.

Our Theory of Change

Caring Fairly wants:

To shape and positively change public policy and public attitudes to structural systems of unpaid care in Australia, and sustainably advance the realisation of the economic, social and cultural rights of unpaid carers.

To achieve this we will:

- build a unified national social movement, focused on strategically and sustainably advancing the realisation of economic, social and cultural rights of unpaid carers in Australia
- invest in research and evidence-based policy development, and use the research to influence and improve legislation and public policy arrangements for unpaid carers
- trial, test and evaluate innovative policy solutions
- influence and sustainably improve employer practices and workplace cultures positively for all unpaid carers, including through targeted approaches for mental health carers
- raise public awareness on why these concerns should matter to all Australians how the value of unpaid carers can be recognised.

Our use of language

Carer

A carer is any person, such as a family member, friend or neighbour who provides regular, ongoing help and support to another person due to a disability or long-term health condition, without receiving a salary, wage or fee. The terms 'carer', 'informal carer' and 'unpaid carer' are often used interchangeably, and there are ongoing debates about the appropriate term. *Caring Fairly* uses 'unpaid carer'.

There are an estimated 2.7 million unpaid carers in Australia. Approximately 856,000 carers are 'primary carers', who provide the most informal assistance to the person with care needs¹.

Mental Health Carer

A mental health carer is an unpaid carer who provides regular and sustained care to a friend or family member whose main health condition requiring support is a mental illness².

There are at least 240,000 mental health carers in Australia. Around 54,000 people are 'primary mental health carers', who provide the most unpaid assistance to the person with care needs.

A 'hidden workforce'

Unpaid carers provide invaluable care and support to hundreds of thousands of Australians. They also provide a vast and irreplaceable structural support to the Australian economy. We believe that what they do should be properly recognised as 'work'.

In 2015, the replacement value of care in Australia, including care provided by volunteers, family, and friends, was \$60.3 billion - over \$1 billion per week³. Mental health carers provide at least \$14.3 billion⁴ of services to the economy every year, and serve as a critical and irreplaceable structural support to a vast and growing mental health economy, valued at \$60 billion⁵.

Consistent evidence has shown that unpaid carers routinely forego their own economic security, employment, and health and wellbeing.

¹ Australian Bureau of Statistics (2015) Survey of Disability, Ageing and Carers. See also *Carers Australia*, Statistics, accessible at: <http://www.carersaustralia.com.au/about-carers/statistics/>

² Diminic S, Hielscher E, Lee YY, Harris M, Schess J, Kealton J & Whiteford H. The economic value of informal mental health caring in Australia: technical report. Brisbane: The University of Queensland; 2016.

³ Deloitte Access Economics, *The Economic Value of Informal Care in Australia*, 2015

⁴ Diminic S, Hielscher E, Lee YY, Harris M, Schess J, Kealton J & Whiteford H. The economic value of informal mental health caring in Australia: technical report. Brisbane: The University of Queensland; 2016.

⁵ Australian Government, National Mental Health Commission, 'Economics of Mental Health in Australia', 8 December 2016, see: <http://www.mentalhealthcommission.gov.au/media-centre/news/economics-of-mental-health-in-australia.aspx>

Evidence based policy: A snapshot of *Caring Fairly's* key data

Caring Fairly's policies are underpinned by a growing body of national and international research, including government statistical data and other data sets. Key recent Australian research reports and data sets that *Caring Fairly* has drawn upon include:

- *The Survey of Disability, Ageing and Carers (SDAC)*, 2012 and 2015, Australian Bureau of Statistics
- *The Household, Income and Labour Dynamics in Australia Survey*, 2017, Melbourne Institute (Applied Economic & Social Research), University of Melbourne
- *Growing Up In Australia – The Longitudinal Study of Australian Children, Annual Statistical Report 2017*, Melbourne, Australian Institute of Family Studies
- *The economic value of informal care in Australia in 2015*, Carers Australia & Deloitte Access Economic, 2015;
- *The economic value of informal mental health caring in Australia* Diminic S, Hielscher E, Lee YY, Harris M, Schess J, Kealton J & Whiteford H., Brisbane: The University of Queensland; 2016; and
- *Understanding factors associated with Australian mental health carers' employment* Diminic S, Hielscher E, Harris M., Brisbane: The University of Queensland; 2018

A more complete list of resources can be found at caringfairly.org.au

Taken together, this evidence base reveals that:

- there are at least 2.7 million unpaid carers in Australia. Of these, over 800,000 people are 'primary carers'
- there are at least 240,000 mental health carers in Australia. This latter group comprises 54,000 primary carers
- unpaid carers provided an estimated 1.9 billion hours of care in 2015. This is equivalent to each carer providing 673 hours per year, or 13 hours per week. The total annual replacement cost for all unpaid carers was \$60.3 billion, as at 2015
- mental health carers provide an estimated 208 million hours of informal care per year. The total annual replacement cost for all informal mental health carers was \$14.3 billion, as at 2015
- Australia's future demand for unpaid care is set to significantly outstrip its supply
- unpaid carers are disadvantaged in the Australian labour market. In 2015, the labour force participation rate for primary carers was 56.3%, and other carers was 77.2%. This compares to a participation rate for non-carers at 80.3%⁶
- there are no significant differences in employment rates between mental health carers and carers of people with other conditions or disability
- women who are unpaid carers are acutely disadvantaged. In 2015, women represented 68.1% of primary carers, and 55.5% of all carers. Seventy-three per cent of males who were carers were in paid

⁶ Australian Bureau of Statistics, Disability, Ageing and Carers, Australia, Summary of Findings, 2015, cat. No. 4430.0. See also: Australian Government, Department of Employment, Senate Finance and Public Administration References Committee, *Inquiry into gender segregation in the workplace and its impact on women's economic equality*, Submission of the Department of Employment, 10 February 2017

employment compared with only 60.8% of females⁷. More female than male carers are working part-time or not employed at all

- the disadvantage faced by women who are unpaid carers is mirrored by other structural patterns of economic disadvantage and inequity. On average, women retire with approximately 50% of the superannuation balance of men⁸
- forty-seven per cent of primary mental health carers who are not currently employed were in paid work before taking on their caring role. This rate is similar across primary carers for all types of conditions
- between 45 and 56% of working primary carers have reduced their hours or left employment due to caring
- unpaid carers are much less likely to be working 16 or more hours per week compared to non-carers
- primary carers who provide more hours of support each week have a much greater chance of not being employed
- based on what we know, over half (54.3%) of employed primary mental health carers aged 15-64 years may need more employment related support to maintain, improve or re-enter paid work
- over half (57.1%) of primary mental health carers who are not employed have a possible need for employment related support based on having left employment to commence caring, or wanting to work while caring
- young mental health carers may have lower participation in education and employment compared to other young people of the same age. School attendance for mental health carers aged 5-14 years is much lower (87.2%) than for other carers.

What are the problems, and what needs to change?

- Carers can face multiple barriers to entering or remaining in the labour market.
- Some of the employment barriers faced by carers are a feature of the income support system.
- Many employers do not understand the needs of carers, or how carers can be supported at work.
- Many carers have low retirement incomes/savings due to absences from paid employment, and/or from sustained periods in part time or casual employment.
- There are demographic characteristics of carers that indicate likely disadvantage, including that:
 - young carers typically have lower educational attainment due to their caring role and this has lifelong employment consequences.
 - financial outcomes for women, and consequences in retirement, are particularly poor, contributing to entrenched gender inequality.
- Employment barriers and gaps in government services distinctly affect mental health carers, mainly due to:
 - lack of understanding of the unpredictability of episodic illness in workplaces.
 - the structure and availability of government payments and services to support people with mental illness – particularly episodic illness – and their carers.

⁷ Ibid.

⁸ 12th Annual Statistical Report of the Household, Income and Labour Dynamics in Australia (HILDA) Survey, Commonwealth of Australia, 2017

Why should this matter to government, and to all Australians?

As Australia's population profile changes, more Australians will either need, or take on, some form of intensive unpaid caring responsibility in their lifetime.⁹ For many Australians, this will limit their ability to engage fairly with the world of paid work.

This dynamic is already shaping the contours of Australia's economy, society, and families, with intergenerational economic, moral, and social implications.

The shift, over many decades, away from the provision of health and community services in institutional settings towards care in the home and community has been positive. However, this move has led to an incremental and structural reliance on systems of unpaid care. This reliance has now reached a tipping point, and a fundamental reassessment of the economic and social value placed on unpaid carers is needed.

The public policy implications of Australia's changing demographics around the need for care are enormous. Between 2011 and 2016, more new jobs were created in the paid care sector than in any other industry.¹⁰ In parallel, the demands of intensive and complex care are increasingly absorbed within the family home. Individuals, families, and even young children routinely provide complex and intensive care where formal care services do not exist (or are inadequate or simply inappropriate). They routinely do so at the expense of their own careers, education, and long-term economic security.¹¹ Since the scale of care provided is vast and effectively irreplaceable, solutions must be found to better support them.

There are an estimated 2.7 million unpaid carers in Australia. Approximately 10% of Australians now have intensive caring responsibilities, while over 850,000 Australians have 'primary care' responsibilities that extend far beyond traditional familial and community norms.¹² Increasing numbers of Australians face the challenge of balancing work, careers, and intensive care for loved ones at home.

Evidence on mental health carers gives detailed insight into this phenomenon. Mental health carers provide \$14.3 billion of complex and critical services each year to the Australian economy¹³ It would cost \$13.2 billion more than existing expenditure to replace their services; an unaffordable sum.

Caring Fairly's evidence base shows that there are more similarities than differences between mental health carers, and carers for people with other disabilities. In spite of their central importance to society, unpaid carers are systemically undervalued and unfairly and inadequately supported by existing public policy arrangements and workplace culture in Australia.

Many of the current systems and services in place to support the hidden workforce of unpaid carers are insufficient, inefficient, and precarious. Most crucially they can be unfair, because of the ways in which the work of unpaid caring and the related adverse life consequences fall more on some groups than others. Current arrangements do not represent foundational values of contemporary Australian society.

It is neither within the capability, nor is it the responsibility of the Australian Government to 'replace' the intensive care that this hidden workforce provides. It is, however, the government's responsibility to implement equitable and effective public policies that promote fairness and opportunity. Through its policies, governments at all levels must promote a paradigm shift in the community's understanding of, and attitudes to, unpaid care; one in which the communal benefits and burdens of social need are dispersed more fairly.

⁹ The number and proportion of older Australians is expected to continue to grow. By 2056, it is projected there will be 8.7 million older Australians (22% of the population); by 2096, 12.8 million people (25%) will be aged 65 years and over. See: Australian Institute of Health & Welfare, *Older Australia at a Glance*, Web Report (last updated 21 April 2017), accessible at: <https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/demographics-of-older-australians/australia-s-changing-age-and-gender-profile>

¹⁰ Australian Jobs 2017, Australian Government, Department of Employment

¹¹ Edwards B, Higgins D J, Gray M, Zmijewski N, Kingston M. The nature and impact of caring for family members with a disability in Australia. Research report no. 16. Australian institute of Family Studies; 2008

¹² Australian Bureau of Statistics, *Survey of Disability, Ageing and Caring*, 2015

¹³ Diminic S, Hielscher E, Lee YY, Harris M, Schess J, Kealton J & Whiteford H. The economic value of informal mental health caring in Australia: technical report. Brisbane. The University of Queensland; 2016.

It is time for a cultural change in Australia about the value attached to people who provide unpaid care. It is time for fresh thinking, and a new approach to carer support systems and services that places the fair reconciliation of 'work' and 'care' at the core.

Bringing Fairness to Care: How to achieve sustainable policy change

Australia must strengthen existing support systems for unpaid carers in order to safeguard the long-term sustainability of our public systems (including our social care, health, and mental health systems), and promote fairer and more inclusive social outcomes for unpaid carers and their families.

Current inequities and inefficiencies surrounding unpaid care in Australia are surmountable, but only if they are addressed through a multi-platform, and multi-stakeholder investment approach to social service provision. New policies are needed that place the advancement of unpaid carers' economic, social and cultural rights at the forefront, together with a nuanced approach to fairly reconciling the worlds of 'work' and 'unpaid care'. Businesses, unions, civil society, and carers themselves, all have critical roles to play in this proposed solution.

Caring Fairly has developed a range of 'step-by-step' policy solutions for government and businesses, anchored within three overarching principles:

- 1. Help people to combine unpaid care and paid work**
- 2. Provide better financial support for unpaid carers**
- 3. Invest in specialised system responses where they are needed, and take steps to address social inequalities**

This will require 'whole of government' commitments, together with the support of Australia's employers, unions and business community.

Caring Fairly believes that, if implemented, these policies will contribute to improved, equitable, and sustainable social outcomes for Australia's hidden workforce of carers, while safeguarding critical care for those who need it. These policies can also spur increased productivity and generate higher tax revenues through higher workforce participation.

These policies serve as a blueprint for wider reforms to Australia's far larger unpaid care economy.

Principle 1: Help people to combine unpaid care and paid work

To do this:

Step 1: Improve carers' participation in the workforce

What do we know?

Intensive caring responsibilities can make it extremely difficult for carers to work full-time, or sometimes at all.¹⁴ However, those carers who wish to and are able to work (whether full-time or part-time) should be supported by government to do so.

For mental health carers, this issue is already recognised by the Australian Government as a key policy aspiration. The Government's *Fifth National Mental Health and Suicide Prevention Plan (2017)* recognised the centrality of this need (indeed, mental health carers' participation in employment is codified as a central indicator for the Plan's implementation and success). Government needs to explicitly expand this policy aspiration to include *all* unpaid carers.

¹⁴ Bittman M, Hill T, Thomson C. The impact of caring on informal carers' employment, income and earnings: a longitudinal approach. *Australian Journal of Social Issues*. Vol 42 No 2. Winter 2007.

While many carers are able to combine paid work and rewarding careers with their caring role, many more are unable to do so.

They are limited by:

- the intensity or nature of their caring role
- inflexible or unsupportive workplace structures and job designs
- inadequate or inappropriate replacement care systems for the person they support
- wider federal and state carer support systems, which are not aimed (at least not widely or consistently) at helping people retain, enter, or re-enter the workforce.¹⁵

Recently published research, focused on the economic circumstances of mental health carers in Australia, provides a critical insight into the scale of this problem for unpaid carers in Australia more widely. This research, commissioned by Mind Australia and undertaken by the University of Queensland's School of Public Health from 2016-18 found no significant differences in the available data for mental health carers and carers for people with other disabilities¹⁶. As such, these research findings support public policy changes focused on *all* unpaid carers.

As at 2015, 42.3% of working age mental health carers were not employed (compared to 24% for working age non-carers).¹⁷ For more than half of mental health carers, caring had a negative impact on their working hours (26.4% have stopped working altogether to care, and a further 25.8% have reduced their working hours).

In addition, many mental health carers report significant anxiety and poor health associated with caring, in turn negatively impacting work performance.¹⁸ The economic impacts of presenteeism (being less than fully productive because unwell at work) have been explored by the Productivity Commission, and include reduced labour productivity.¹⁹

Over half (57.1%) of mental health carers who are not employed either left employment to commence caring, or report that they want to work while caring²⁰. This group has an identifiable need for focused help in balancing work with their caring responsibilities, and the available data indicates a similar need for all unpaid carers.

Why does this matter?

At an individual and family level, lower workforce participation leads to lost or lower income, lower standards of living for the individual and their family, career disruption, reduced social networks, lower savings and retirement provisions, and poorer health outcomes. Some carers, including mental health carers, forego the critical respite from caring duties that the workplace can provide.

For government and society, lower workforce participation leads to lost or lower tax revenue, combined with increased costs to provide income support, and increased health system costs associated with poorer health

¹⁵ Edwards B, Higgins D J, Gray M, Zmijewski N, Kingston M. The nature and impact of caring for family members with a disability in Australia. Research report no. 16. Australian institute of Family Studies; 2008

¹⁶ Diminic S, Hielscher E, Harris M. Understanding factors associated with Australian mental health carers' employment: technical report. Brisbane: The University of Queensland; 2018

¹⁷ Diminic S, Hielscher E, Lee YY, Harris M, Schess J, Kealton J & Whiteford H. The economic value of informal mental health caring in Australia: technical report. Brisbane. The University of Queensland; 2016.

¹⁸ Edwards B, Higgins D J, Gray M, Zmijewski N, Kingston M. The nature and impact of caring for family members with a disability in Australia. Research report no. 16. Australian institute of Family Studies; 2008

¹⁹ Productivity Commission 2017, *Why a Better Health System Matters*, Shifting the Dial: 5 year Productivity Review, Supporting Paper No. 4, Canberra. In this report, the Productivity Commission noted that this evidence is partial and draws principally on data from the United States, and cites Econtech 2007; Goetzel et al. 2004; Medibank Private 2011; Schultz and Edington 2007.

²⁰ Diminic S, Hielscher E, Harris M. Understanding factors associated with Australian mental health carers' employment: technical report. Brisbane: The University of Queensland; 2018

outcomes for the carer. Businesses and employers experience lost productivity, and lower returns on training investments when skilled employees exit the workforce (or reduce working hours) due to their caring responsibilities.

What needs to change?

Caring Fairly's data reveals that many carers would like to work but are unable to find or retain a job flexible enough to allow them to continue caring, or lack support to return to paid work after a long break.²¹ As the OECD has articulated, unpaid carers are a 'cohort' in Australian society who may benefit from "*targeted labour market activation policy interventions*".²² Receiving a Carer Payment is associated with transferring to another form of income support when caring ends.²³ A coordinated Australian Government policy framework is needed to guide workplace reforms, create incentives, and address the specific needs of carers in accessing equal employment opportunities. Unpaid carers who would like to enter or re-engage in the labour market (when, for example, their caring role changes, diminishes, or ends), need tailored employment support services. While workplaces need to adapt and change in parallel, leadership and coordination must come from the Government.

Government should:

1. **Create a National Framework for Carer Inclusive Workplaces**

The Department of Social Services, together with the Department of Jobs and Small Businesses, the National Mental Health Commission and the Department of Health, should invest in and co-design, a National Framework for Carer Inclusive Workplaces.

There should be a specific focus in the Framework on further research and the workplace needs and experiences of mental health carers, and carers with other types of episodic caring responsibilities. This investment should draw specific guidance and direction from the Work and Care Initiative spearheaded by Carers Australia,²⁴ and new and emerging international initiatives from both government and civil society.²⁵

2. **Invest in, improve, and expand formal government support services available to carers wishing to work**

Government should develop a costed implementation strategy for, and subsequently commit to investing in, a renewed systemic national program that seeks to improve workforce participation by unpaid carers.

Whilst there are many potential forms that such a program of government work could take, we suggest that this can be achieved (at least in part) through reforming, extending, and promoting tailored supports to unpaid carers through the government's existing *Jobactive* program. As the recent Senate Inquiry into *Jobactive* recommended, Government should "*examine the merits of providing career counselling and support services for...people who are entering the paid workforce for the first time or returning after caring for a child or family member*".²⁶ A pool of *Jobactive* providers should be identified and trained (in partnership with specialist organisations providing support to

²¹ Ibid.

²² Organisation for Economic Co-operation and Development (OECD), *Connecting people with jobs: key issues for raising labour market participation in Australia*, OECD Publishing, Paris, pp. 43

²³ Ganley R. *Carer payment recipients and workforce participation*. Department of Families, Housing, Community Services and Indigenous Affairs. Canberra. 2009

²⁴ See 'Work & Care: The Necessary Investment', Carers Australia, key information and documents accessible at: <http://www.carersaustralia.com.au/work-and-care/>

²⁵ For an example of a multi-departmental government initiative, see the UK Government's June 2018 '*Carers Action Plan 2018-2020*', accessible at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/713781/carers-action-plan-2018-2020.pdf; from the UK also, see *Employers for Carers*, led by Carers UK, accessible at <https://www.employersforcarers.org/>

²⁶ Australian Government, Senate, Education and Employment References Committee, *Jobactive: Failing those it is intended to serve*, February 2019, Recommendation 9, para. 5.93

carers) to respond to the specific workplace needs of unpaid carers. This should include a focus on the specific workplace needs of mental health carers, and carers with other types of episodic caring responsibilities, recognising some of the specific features that these 'categories' of caring share.

3. Invest in initiatives to grow the rate of volunteering as an avenue for social and economic participation for mental health carers.

The Reference Group on Welfare Reform to the Minister for Social Services (2015) previously recommended this approach, in particular for jobseekers, carers and people with a partial capacity to work.

Step 2: Enhance and promote carer inclusion in Australian workplaces

What do we know?

Australia need laws, policies, and workplace practices that will keep unpaid carers in the workplace wherever possible. Many Australian workplaces lack formal policies and practices to support carers. Supporting carers to access or retain work could yield significant economic gains for businesses, as well as improving individual economic and social outcomes.²⁷

There is a range of views on the complexity and scale of the workplace changes needed to respond to Australia's changing demographics. There are assumed costs to businesses and to the wider economy. International studies increasingly demonstrate that employers who have policies in place to support carers see improved service delivery, cost savings and increased productivity.²⁸

Mental health carers face particularly acute challenges in the workplace. Employed mental health carers often take extended leave (13.8% have taken at least 3 months, and 28.9% have taken some time off).²⁹

The right to request flexible working arrangements is codified in law, but can be refused by employers on the basis of 'reasonable business grounds'. This principle was recently affirmed by the Fair Work Commission.³⁰ Flexible working arrangements are critical to supporting carers in the workplace, but are not enough on their own. Wider cultural change is needed in Australian workplaces.

Why does this matter?

Ten per cent of Australians are unpaid carers and occupy diverse roles throughout Australian workplaces. Employers, therefore, have a large stake in building carer-friendly workplaces.³¹

²⁷ Australian Human Rights Commission. 2013. Investing in care: recognising and valuing those who care, Volume 1. Australian Human Rights Commission. Sydney.

²⁸ Carers UK for Employers for Carers/Department of Health Task and Finish Group (2013) Business Benefits of Supporting Working Carers <http://www.employersforcarers.org/resources/research/item/809-employers-business-benefits-survey>. See also: HM Government and Carers UK, 'Supporting Working Carers': The Benefits to Families, Business and the Economy,

²⁹ Diminic S, Hielscher E, Harris M. Understanding factors associated with Australian mental health carers' employment: technical report. Brisbane: The University of Queensland; 2018

³⁰ Fair Work Commission, 4 yearly review of modern awards — Family Friendly Working Arrangements, AM2015/2, Summary of Decision 26 March 2018

³¹ As at 2009, 38.2 per cent of employees are either parents of a child under 15 years or have responsibilities to care for a person with disability, chronic illness or frailty due to older age. See, Australian Bureau of Statistics, Survey of Disability, Ageing and Carers, Australia 2009, Basic CURF, Version 3, CD-Rom (2009). Findings based on SPRC's analysis of ABS CURF data; cited by the Australian Human Rights Commission in "Investing in Care: Recognising and valuing those who care, Community Guide, 2013

As well as the need for flexible working arrangements, mental health carers report a range of barriers that make it difficult to stay in, re-enter, or perform optimally within the workforce after a period spent providing unpaid care. These include a loss of skills, expertise or confidence while out of the workforce, and lack of appropriate training or re-training options.³²

What needs to change?

Through designing and implementing carer friendly workplaces, employers and businesses will yield significant quantifiable benefits. These benefits include retention of skills and experience, a higher return on training investment, improved productivity and performance outcomes as a result of increased employee resilience, improved health outcomes, and a reduction in presenteeism and absenteeism.³³

Businesses, unions and representative business bodies should:

- 1. Engage with the Department of Social Services, the Department of Jobs and Small Businesses, the National Mental Health Commission and the Department of Health in the design of a *National Framework for Carer Inclusive Workplaces*.**

The specific features of mental health caring and other types of unpredictable, episodic, and acute caring should form a critical part of this framework, with workplace policies that recognise and accommodate episodic illness, acute illness, the unpredictable nature of support, and the time required by some carers to be 'on standby'.³⁴

As part of this framework:

- a. existing initiatives to address mental health stigma in the workplace should be extended to recognise and include the impact on employees who are caring for someone with a mental illness
- b. employers should directly provide information and commit to offering or providing linkages to support services for carers within their workforce
- c. employers should be encouraged to adopt a policy for examining job redesign possibilities where caring responsibilities emerge suddenly, and encouraged to offer flexible hours, home working, and leave arrangements that reflect the specific demands of caring on their employees.
- d. employers should be encouraged to undertake job redesign to accommodate carers with intensive caring commitments that extend beyond 3 months, and/or require more than 20 hours of care provision per week.

Step 3: Review existing policies that restrict opportunities for unpaid carers to work

What do we know?

The Carer Payment is a critical income support payment for Australia's unpaid carers. However, the criteria for qualification for Carer Payment restricts opportunities for carers to participate in paid work and education, through both the income and assets test, and by inflexibly restricting a carer's participation in work or education to 25 hours, including travel time (the '25 hour rule'). The '25 hour rule' is not prescribed by

³² Diminic S, Hielscher E, Harris M. Understanding factors associated with Australian mental health carers' employment: technical report. Brisbane: The University of Queensland; 2018

³³ Carers Australia, Work & Care: The Necessary Investment. 2014. Report No. 2 Work & Care Initiative. Canberra

³⁴ Primary mental health carers report spending large amounts of time 'on standby' so that they are available to the recipient of care in a crisis; this is estimated to be for an additional 59 hours per week. See footnote 36.

legislation. Rather it provided for by Department of Social Services' policy directions in the *Guide to Social Security*.

Why does this matter?

The '25 hour rule' can disadvantage carers seeking to engage in paid employment or education. It creates particular difficulties when carers need to transition in and out of work as the need for care intensifies or reduces. It can be especially problematic for mental health carers, and other carers, where care is unpredictable and episodic.

The rule creates particular challenges for young carers participating in primary, secondary or tertiary education when they could undertake part-time work to help support their families. It creates challenges for anyone undertaking education or training for any reason, including to enable them to return to work. It can create a disincentive for carers in education or training to engage with further study or employment, forcing them to make important life choices based on arbitrary factors such as the number of course contact hours or location of the institution. Alternatively, they can feel pressured to conceal study or employment from Centrelink to circumvent the rules.³⁵

What needs to change?

Government should:

1. Commit to reviewing the application of the '25 hour rule'

As part of the review, government should examine reports³⁶ from carers that reporting 25 hours or more of work and travel can lead to Carer Payment being immediately cancelled by Centrelink .

As part of this review, more flexible approaches to measuring the hours of care provided could be examined, considering approaches to supporting carers with episodic or unpredictable caring responsibilities. This should include exploring the possibilities for unpaid carers to 'bank' paid working hours, and/or report, offset and aggregate paid working hours over a longer period than a fortnight.

Principle 2: Provide better financial support for unpaid carers

Invest in the long-term economic security of unpaid carers

What do we know?

The economic effects of intensive caring are both immediate and cumulative, for individuals, families, and for government revenue. Time spent outside the formal economy leads to substantially reduced retirement incomes, placing a delayed but highly significant burden on the Age Pension and other related social service provisions³⁷.

The total annual replacement cost for all unpaid carers was \$60.3 billion, as at 2015. Mental health carers in Australia provide \$14.3 billion of care services each year, in exchange for a total government spend of approximately \$1.1 billion³⁸

³⁵ See: Submission by Behavioural Insights Team Australia into Try, Test and Learn Fund, December 2016, accessible at: https://engage.dss.gov.au/ttl_fund_dec16-submissions/sub-id-4881-carer-payment-25-hour-rule-behavioural-insights-team-australia/

³⁶ Carers Australia, 2019-20 Federal Budget Submission, January 2019, pp.8

³⁷ Australian Human Rights Commission. 2013. Investing in care: Recognising and valuing those who care. Volume 1 Research Report, Australian Human Rights Commission. Sydney.

³⁸ Diminic S, Hielscher E, Lee YY, Harris M, Schess J, Kealton J & Whiteford H. The economic value of informal mental health caring in Australia: technical report. Brisbane. The University of Queensland; 2016.

What appears to be in raw economic terms a significant return on social investment is highly misleading.

Poor workforce participation for carers yields significantly lower taxation returns. Intensive caring has been shown to yield a negative effect on a carer's health, including mental health.³⁹ Poor health outcomes for carers increase the burden on public health services in the short, medium, and long-term.

Why does this matter?

Many carers subsist in weak or precarious economic conditions that can extend for decades, with the longer term impact exacerbated by the absence of a mechanism in Australia's superannuation system for compensating for periods spent providing unpaid care.

What needs to change?

The current system of retirement incomes and savings, comprises the means tested Age Pension and superannuation accumulated from income subject to the super guarantee. This system should be reviewed and reformed to make retirement incomes and savings more equitable, particularly for unpaid carers, many of whom retire in poverty.

Government should:

1. **Act on the motion, passed by the Senate on 12 November 2018, to**
 - (i) ***“model the costs and benefits of providing the superannuation guarantee to carers on the Carer Payment or other carer-related benefits, including the Commonwealth Paid Parental Leave Scheme, and***
 - (ii) ***seriously consider providing the superannuation guarantee to carers on the Carer Payment or other benefit they are paid as a result of their caring responsibilities.”***⁴⁰

Principle 3: Invest in specialised system responses where they are needed, and take steps to address social inequalities

Step 1: Invest in learning more about the experiences and needs of young carers

What do we know?

Young carers tend to leave school earlier and are less likely to be in the labour force or employed, compared to their non-carer peers.⁴¹ The impacts on their lives may be substantial, and long-term. For example, some evidence suggests that young carers are more likely to receive income support at some stage after exiting Carer Payment.⁴² Young mental health carers face specific and acute disadvantage.⁴³

Mental health caring is often taken up by people at a broader range of ages and life stages, including children, than caring for other conditions. This is because mental illnesses have a younger age of onset than many other conditions, such as cardiovascular, musculoskeletal and neurological disorders. As a result,

Emerging data suggests that fewer children with mental health caring responsibility have regular school attendance compared to other carers⁴⁴. Recent research and analysis, drawn from the government's *Survey of*

³⁹ OECD, *Help Wanted? Providing and Paying for Long-Term Care*, 2011, pp.85-103

⁴⁰ Senate Official Hansard, No. 13, 2018, 12 November 2018

⁴¹ Department of Social Services, *Young Carers Research Project: Final Report*, September 2002. For data relating specifically to 14 and 15 year old carers, see Australian Institute of Family Studies. 2017. *The Longitudinal Study of Australian Children Annual Statistical Report 2016*. Melbourne.

⁴² See Carers Australia New South Wales, *The Carer Payment: a double-edged sword for young carers*, Freya Saich and Timothy Broady, accessible at: https://www.carersnsw.org.au/Assets/Files/Carer_Payment_Young_Carers_presentation.pdf

⁴³ Diminic S, Hielscher E, Harris M. *Understanding factors associated with Australian mental health carers' employment: technical report*. Brisbane: The University of Queensland; 2018

⁴⁴ Ibid.

Disability, Ageing and Caring 2015 (SDAC 2015), indicates that, of those surveyed, almost 13% of children with mental health caring responsibility aged 5-14 years old are missing school. This compares to 95.7% school attendance for children in this age group who do not have caring responsibilities. The relatively small sample size surveyed in the SDAC 2015 limits our ability to extrapolate wider conclusions at this point. From 2019, *Caring Fairly* is investing in further research to understand the parameters of this problem. This commitment from the community sector, to more deeply exploring and understanding the public policy implications of this apparent public policy problem, should be matched by a similar commitment from government.

Why does this matter?

Without the right level of support, young carers face poor outcomes over their lifetimes and there are adverse effects for the whole of society.

Young primary carers, who provide the most substantial care, aged 20–24 were less likely to have completed Year 12 or equivalent (32%) than both non-primary carers (72%) and non-carers (80%) of the same age.⁴⁵

Research conducted by Price Waterhouse Coopers for the Department of Social Services suggests that young carers aged 24 and under are particularly vulnerable to the risk of long-term welfare dependency. Department of Social Services analysis indicates that the number of young carers in the welfare system trebled in the decade to 2014-15 and projected that 60 per cent would be receiving income support payments in 10 years and about 50 per cent would be receiving income support payments in 20 years

Young mental health carers are vulnerable to entrenched stigma attached to mental health problems, meaning that some may steer away from social activities and reduce opportunities for normal social and professional development. In addition to mental health stigma, fear of unwanted intervention from social services has been identified in Australian and UK research as a key reason behind many young mental health carers' reluctance to seek support or assistance.⁴⁶

The data point to the need for urgent government attention, and a robust policy response.

What needs to change?

Government should:

1. Commit to a cross-portfolio approach to ensure that young carers receive appropriate support (in the home, in schools, and in workplaces) and are not economically and socially disadvantaged relative to their peers.
2. Invest in learning more about the experiences and needs of young carers. Ensure that Australian datasets, especially longitudinal studies, routinely collect information about the condition of people with care needs (including more information on education and employment histories, attendance and performance) to allow more detailed analyses and comparisons between carers of different conditions.

Step 2: Take proactive steps to recognise, mitigate, and overcome gender inequality among carers

What do we know?

Caring responsibilities can emerge for anyone, but data show that the effects of unpaid care on employment are experienced more acutely by women than men.

⁴⁵ Australian Institute of Health and Welfare, 2017, Australia's Welfare, <https://www.aihw.gov.au/getmedia/affa1332-0df7-4865-9590-0c60a8aad9e0/aihw-australias-welfare-2017-chapter8-3.pdf.aspx>

⁴⁶ Eurofund. 2015. Working and caring: reconciliation measures in times of demographic change. Publication Office of the European Union. Luxembourg. See also, Diminic S, Hielscher E, Harris M. Understanding factors associated with Australian mental health carers' employment: technical report. Brisbane: The University of Queensland; 2018

- In 2015, women represented 68.1% of primary carers.
- 73% of males who were carers were employed compared with only 60.8% of females.⁴⁷
- More female than male carers are working part-time or not employed at all.
- More female than male mental health carers are working part-time (29.4%, compared to 19.5% for men), or not employed at all (51.9%, compared to 31.9% for men).⁴⁸

In contrast to male mental health carers, whether or not the person with care needs receives formal support services does not affect employment prospects for female mental health carers.⁴⁹ That is to say, policy solutions should be targeted to female unpaid carers, rather than the person with care needs. Data indicate that there are no significant differences between factors associated with employment for female mental health carers and those found for female unpaid carers of other conditions.

Why does this matter?

Providing unpaid care is more likely to result in lower workforce participation, lower income, lower standards of living, career disruption, reduced social networks, lower savings and retirement provisions, and poorer health outcomes for women than for men.⁵⁰

The impact is greatest during peak earning ages. Data shows that there is a 40.7% unemployment rate for female mental health carers aged 35-54 years (compared with 24% for male mental health carers).⁵¹ Again, data indicate overwhelming similarities between mental health carers and carers of other conditions.

What needs to change?

Recognising and articulating that the unpaid caring roles are disproportionately taken up by women is a critical first step. This acknowledgement must inform a renewed gendered approach to policy design by the Australian Government, within the domains of carer support services and workforce participation.

1. Reinstate a formal government commitment to producing annual gendered budget analyses.
2. All policy initiatives proposed by Caring Fairly, most importantly those relating to workplace reform, should have oversight by the Workplace Gender Equality Agency.

Step 3: Respond to the distinct features of mental health and episodic caring, and invest in tailored support

What do we know?

While all intensive caring can be profoundly difficult, and each condition has unique challenges, those associated with episodic conditions, including mental health conditions, need particular attention.⁵²

Unpaid mental health care has an intrinsic focus on emotional support, managing crises, and supervision of behaviour⁵³. Mental illness has a younger age of onset than many other conditions that lead to unpaid caring.;

⁴⁷ Ibid.

⁴⁸ Diminic S, Hielscher E, Harris M. Understanding factors associated with Australian mental health carers' employment: technical report. Brisbane: The University of Queensland; 2018

⁴⁹ Diminic S, Hielscher E, Harris M. Understanding factors associated with Australian mental health carers' employment: technical report. Brisbane: The University of Queensland; 2018

⁵⁰ Ibid.

⁵¹ Ibid.

⁵² The Network for carer of people with a mental illness. 2001. Differences and similarities in experiences of carer of people with mental illness and other carers. Arafmi Victoria. Melbourne.

Therefore, the economic impact on mental health carers can be experienced for longer. Stigma associated with the caring role can affect a person's help seeking in public, which can result in the need for more (and more costly) support than they would have with earlier services. Primary carers of people with mental health conditions provide, on average around 36 hours of care a week, with nearly 40 per cent providing 40 hours a week or more care. This does not include time on 'standby', when a carer is available to the person in case of a crisis.ⁱ can preclude the taking up stable and predictable employment⁵⁴.

Why does this matter?

Rationalising, mainstreaming, and simplifying government service delivery models (including the Integrated Carer Support Service (ICSS)) increases the likelihood that the unique support needs of mental health carers will be overlooked. Unmet support needs exacerbate the short and long term social and economic effects of unpaid caring.

What needs to change?

1. An independent review should be conducted of the performance of the new Integrated Carer Support Service in 2021, two years after its anticipated rollout in October 2019.
2. The Department of Social Services should coordinate the proposed rollout of the ICSS with (among other agencies and bodies) the National Disability Insurance Agency and state and territory governments, and produce a clear strategy for identifying and mitigating gaps in carer support services.

Step 4: A whole of government response is needed to address growing support service gaps for mental health carers

What do we know?

The transition to the National Disability Insurance Scheme (NDIS) has dominated recent policy conversations about disability and mental health, across Australia. While the NDIS provides much needed long term support for people with significant disability, it does not replace state funded services providing support to a wider range of people with mental health issues, including people with mental illness who are not eligible for the NDIS (noting that others who may be eligible do not apply).⁵⁵ In these cases, carers are vulnerable to being left without any support⁵⁶. Chronic state and territory underfunding, and withdrawal of funding for critical carer support services, have exacerbated the unmet support needs of unpaid carers across many parts of Australia.⁵⁷

Importantly, the primary focus of the NDIS is on the needs of the person with disability, not the needs of the carer. Yet successful mental health carer support services (including Mental Health Respite: Carer Support and Personal Helpers and Mentors (PHaMs) are being discontinued, with funding absorbed into the NDIS. The carer/NDIS interface is highly problematic, and is exacerbating support gaps for unpaid carers.

Why does this matter?

Unpaid carers cannot directly access services through NDIS, as a product of its fundamental design and its focus on the individual. Mental health carers who previously used effective carer support services are not eligible for NDIS in their own right.⁵⁸ State and territory services for carers have largely been withdrawn, and there is no clear process for their reformulation under the NDIS.

⁵³ Diminic S, Hielscher E, Lee YY, Harris M, Schess J, Kealton J & Whiteford H. The economic value of informal mental health caring in Australia: technical report. Brisbane. The University of Queensland; 2016.

⁵⁴ Ibid.

⁵⁵ David McGrath Consulting, for Mental Health Australia. 2016. The implementation and operation of the psychiatric disability elements of the National Disability Insurance Scheme: a recommended set of approaches. Mental Health Australia. Canberra.

⁵⁶ Ibid.

⁵⁷ Carers Australia. 2016. Submission to the draft Service Concept: Designing the new integrated carer support service. Canberra

⁵⁸ Tandem Inc. 2018. Victorian mental health carers in the NDIS: issues and recommendations. Briefing paper. Melbourne.

What needs to change?

The NDIS should:

1. Through all its processes, ensure that the application of the principle “reasonable and necessary” supports should not be interpreted so as to place undue burdens on carers.
 2. Ensure that the way in which carers can access supports which assist them as well as the person with disability should be transparent to applicants, participants, and planners and reviewers.
-