caringfairly

RIGHTS. RECOGNITION. REFORM.

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Who are we?

Caring Fairly is a new national campaigning coalition led by unpaid carers, and specialist organisations and peak bodies that support and advocate for their rights. *Caring Fairly* is particularly focused on policies that bridge the gap between unpaid care and workforce participation. We have invested in leading edge new research - and produced evidence-based policies - that promote fairer and more inclusive outcomes for all unpaid carers in Australia- at home, in the workplace, and in society.

From August 2018, we will be leading a political advocacy and public awareness raising campaign focused on improving and realising the economic, social, and cultural rights of unpaid carers in Australia, with a particular evidential focus on Australia's hidden workforce of unpaid 'mental health carers'.

Caring Fairly is a movement that wants to lead a new public conversation about the value we attach to those who care. *Caring Fairly* is coordinated by Mind Australia[1], and is supported by a wide and growing coalition of partners, including carers, mental health carers, and more than twenty specialist carer support and service delivery organisations, NGOs, and peak bodies.

Caring Fairly will officially launch at Parliament House, Canberra, on 21st August 2018. Please visit caringfairly.org.au for information about the campaign's activities, evidence base, policy agenda, and impact.

[1] Mind Australia Limited: ABN22 005 063 589

Carers

A carer is any person, such as a family member, friend or neighbour who provides regular, ongoing assistance to another person due to a disability or long-term health condition, without receiving a salary, wage or fee for the support provided. The terms 'carer', 'informal carer' and 'unpaid carer' are often used interchangeably, and there are ongoing debates about the appropriate use of language in this space. *Caring Fairly* uses the term '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 they care for[2].

Mental Health Carers

A mental health carer is a person who provides regular and sustained unpaid care to a friend or family member whose main health condition requiring support is a mental illness[3].

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 they care for.

A 'hidden workforce'

Primary carers not only provide invaluable care and support to hundreds of thousands of Australians. They also provide a vast - and effectively irreplaceable- structural support to the Australian economy, and what they do should be properly recognised as 'work'.

In 2015, the replacement value of unpaid care in Australia was $60.3 billion - over $1 billion per week[4]. Mental health carers provide at least $14.3 billion[5] 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 billion[6].

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

[2] 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/

[3] 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.

[4] Deloitte Access Economics, *The Economic Value of Informal Care in Australia*, 2015

[5] 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.

[6] 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

Mind Australia together with the University of Queensland's School of Public Health has produced two major, interconnected pieces of ground-breaking research that underpin *Caring Fairly*'s policies.

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 (forthcoming)

Taken together, these reveal that:

There are an estimated 2.7 million unpaid carers in Australia, of whom at least 240,000 are mental health carers. This latter group comprises 54,000 primary carers.

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.

There are no significant differences in employment rates between mental health carers and carers for people with other disabilities.

42.3% of working age mental health carers are either unemployed or not in the labour force. They are significantly less likely to be employed than working age non-carers.

Less than half (43.8%) of primary mental health carers are in employment.

47% of primary mental health carers who are not currently employed were working prior to commencing their caring role. This rate is similar across primary carers for all types of conditions.

Between 45-56% of working primary carers have reduced their hours or left employment due to caring.

More female than male carers are working part-time or not employed at all.

Carers are significantly 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 significantly greater odds of not being employed.

Over half (54.3%)of employed primary mental health carers aged 15-64 years have a possible need for more employment related support to maintain, improve or re-enter employment based on the available indicators

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 be disadvantaged in terms of participation in education and employment compared to other young people of the same age. School attendance for mental health carers aged 5-14 is significantly lower (87.2%) than for other carers.

Policy Platform

What are the problems, and what needs to change?

1. *Carers experience multiple barriers to workforce participation*
   Government: improve carers' participation in the workforce

2. *Australian workplaces could do more to ensure carer inclusion*
   Businesses and employers: enhance and ensure carer inclusion in Australian workplaces

3. *The financial impacts of limited participation in the workforce are immediate and cumulative*
   Government: invest in the long-term economic security of unpaid carers

4. *Young carers experience acute challenges, and many face life long disadvantage*
   Government: ensure that all young carers can be identified and assisted

5. *Many carers want to work, but existing policies restrict opportunities*
   Government: remove existing policies that restrict opportunities for unpaid carers to work

6. *Female carers are especially disadvantaged, entrenching wider social patterns of gender inequality*
   Government: recognise, mitigate, and take proactive steps to overcome gender inequality among carers

7. *Some types of care (including mental health care and episodic care) require a specialised response, but government services are being realigned away from targeted support services*
   Government: respond to the distinct features of mental health and episodic caring, and invest in tailored support

8. *Changes to federal and state support systems for carers are creating growing support gaps for mental health carers*
   Government: develop and implement a whole of government response to address growing support service gaps for mental health carers

How will *Caring Fairly* achieve change?

Caring Fairly gives voice to the demands of all unpaid carers (and the many organisations across Australia who strive to support them in their work) for rights, recognition, and reform.

Caring Fairly will:

- Invest in research and evidence based policy development, and use these tools to influence and improve legislation and public policy arrangements for unpaid carers;
- Influence and sustainably improve employer practice and workplace culture 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 and enhance recognition of the value of unpaid carers.

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[7]. For many of us, this will limit our ability to engage fairly with the world of paid work.

This dynamic is already shaping the contours of our 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 we need to fundamentally reassess the economic value we place on unpaid carers.

The public policy implications of Australia's changing demographics around our need for care are enormous. Between 2011 and 2016, more new jobs were created in the care sector than in any other industry[8]. 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[9]. Since the scale of care provided is vast and effectively irreplaceable, we must find solutions to better support them.

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

Our evidence on mental health carers provides detailed insight into this phenomenon. Mental health carers provide $14.3 billion of complex and critical services each year to the Australian economy[11]. It would cost us an additional $13.2 billion on top of existing expenditure to replace their services; an unaffordable sum. In spite of their central importance to our society, mental health carers are systemically undervalued and unfairly and inadequately supported by existing public policy arrangements and workplace culture in Australia. *Caring Fairly*'s evidence base shows that there are more similarities than differences between mental health carers, and carers for people with other disabilities.

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[7] 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

[8] Australian Jobs 2017, Australian Government, Department of Employment

[9] 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

[10] Australian Bureau of Statistics, Survey of Disability, Ageing and Caring, 2015

[11] 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.

The current systems and services that we have in place to support this hidden workforce of unpaid carers are insufficient, inefficient, and precarious. Most crucially they are 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 ensure equitable and effective public policies that promote fairness and opportunity. Through its policies the Australian Government at all levels must promote a paradigm shift in our understanding of, and attitudes to unpaid care; one in which the communal benefits and burdens of our social need are dispersed more fairly.

It is time for a cultural change in Australia about the value we attach to those 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.

The 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 that places the reconciliation of 'work' and 'care' at its core. Businesses, unions, civil society, and carers themselves all have critical roles to play in this proposed solution.

Caring Fairly has developed 8 pragmatic policy solutions that 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 equitable and sustainable social outcomes for Australia's hidden workforce of carers, whilst safeguarding critical care for those that need it. These policies can also spur increased productivity, and generate higher tax revenues from higher workforce participation.

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

Solution 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[12]. 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) recognises 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).

Whilst 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
- Our wider federal and state carer support systems, which are not aimed (at least not widely or consistently) at assisting people retain, enter, or re-enter the workforce[13]

There are no significant differences in the available data for mental health carers and carers for people with other disabilities[14], and we know that the scale of this problem is significant. In 2015, 42.3% of working age mental health carers were not employed (compared to 24% for working age non-carers)[15]. For more than half of mental health carers, caring has 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[16]. 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[17].

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[12] 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.
[13] 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
[14] Diminic S, Hielscher E, Harris M. Understanding factors associated with Australian mental health carers' employment: technical report. Brisbane: The University of Queensland; 2018 (forthcoming)
[15] 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.
[16] 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
[17] 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.

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 caring[18]. This group has an identifiable need for focused help in balancing work with their caring responsibilities.

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. For some carers, including mental health carers, they 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 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 tells us 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[19]. Being on a Carer Payment is associated with moving onto another form of income support when caring ends[20]. A coordinated federal government policy framework is needed to guide and incentivise workplace reforms, and address the specific needs of carers in accessing employment opportunities on equal footing to others. Mutual Obligation Requirements are inappropriate given the nature of carers' unpaid responsibilities, and should not apply to carers seeking a return (on any terms) to paid work. Whilst workplaces, as covered later, need to adapt and change in parallel, leadership and coordination must come from government at all levels.

To achieve change:

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. Within this initiative there should be specific focus (and further research) on the workplace needs and experiences of mental health carers, and carers with other types of episodic caring responsibility. This investment should draw specific guidance and direction from the Work and Care Initiative spearheaded by Carers Australia[21],

[18] Diminic S, Hielscher E, Harris M. Understanding factors associated with Australian mental health carers' employment: technical report. Brisbane: The University of Queensland; 2018 (forthcoming)
[19] ibid
[20] Ganley R. Carer payment recipients and workforce participation. Department of Families, Housing, Community Services and Indigenous Affairs. Canberra. 2009
[21] See 'Work & Care: The Necessary Investment', Carers Australia, key information and documents accessible at: http://www.carersaustralia.com.au/work-and-care/

and new and emerging international initiatives from both government and civil society[22].

2. *Reformulate, expand, and invest in the Department of Social Services' 'Carers and Work' Program*

   The Department of Social Services' *Carers and Work* Program has existed to provide "*intensive support to carers of people with mental illness to address non-vocational barriers to carers achieving workforce participation*"[8]. Currently, there are only 4 such services nationally (two in Victoria, and one each in Queensland and New South Wales). The small reach of the program is a significant limitation to its systemic impact. Since the available data around workforce participation indicates an overwhelming pattern of similarities between mental health carers and carers for people with other disabilities, the program should be expanded and reformulated to target all carers.

   Treasury should initially invest $10 million per annum in *Carers and Work*, commencing in FY2019-20 and over two financial years. *Carers and Work* should be radically expanded in scope, and sit within a cross-departmental portfolio taskforce jointly overseen by the Department of Jobs and Small Businesses and DSS.

   During FYs 2019-21, the taskforce should co-design (and develop a costed implementation strategy for) a renewed systemic national program that seeks to improve workforce participation by carers by 5% over 5 years (during FYs 2022-2027). The program should be designed during the initial two years with substantive input from businesses, unions, and carer support organisations.

   This can be achieved- in part- through extending and promoting a tailored version of the government's existing *jobactive* program to carers, without mutual obligation requirements. A pool of *jobactive* providers should be identified and trained to respond to the specific workplace needs of mental health carers, and carers with other types of episodic caring responsibility.

   The renewed *Carers and Work* program should first develop a carer identification strategy, specifically focused on carers who wish to work but are unable to find suitable employment. During implementation phase, carers should be provided with highly nuanced support in matching their skills with employers' needs, and employers should be provided with expertise and ongoing support to design or adapt flexible roles for mental health carers and carers with other types of episodic caring responsibility within their business structures. Specific investment is needed in outreach, mentoring, and peer support, (programmatic activities out of scope of the current program).

[22] 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/

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.

Solution 2: Enhance and ensure carer inclusion in Australian workplaces

What do we know?

Australia need laws, policies, and workplace practices that will keep unpaid carers, including mental health 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[23].

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[24].

We know that mental health carers face particularly acute challenges in the workplace. Of employed mental health carers, 13.8% have required at least 3 months off work to care for their loved one, and 28.9% have needed time off work to care[25].

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[26]. Flexible working arrangements are critical to supporting carers in the workplace, but are not sufficient in isolation. A wider cultural change is needed within Australian workplaces.

Why does this matter?

More than one third of the Australian workforce has some form of caring responsibility. Employers therefore have a large stake in building carer-friendly workplaces[27].

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

[23] Australian Human Rights Commission. 2013. Investing in care: recognising and valuing those who care, Volume 1. Australian Human Rights Commission. Sydney.
[24] 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,
[25] Diminic S, Hielscher E, Harris M. Understanding factors associated with Australian mental health carers' employment: technical report. Brisbane: The University of Queensland; 2018 (forthcoming)
[26] Fair Work Commission, 4 yearly review of modern awards — Family Friendly Working Arrangements, AM2015/2, Summary of Decision 26 March 2018
[27] 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

or confidence while out of the workforce, and lack of appropriate training or re-training options[28].

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[29].

To achieve change:

1. Businesses, unions and representative business bodies should 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*.

2. 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'.

3. As part of this framework, 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.

4. As part of this framework, employers should directly provide information and commit to offering or providing linkages to pragmatic support services for carers within their workforce.

5. As part of this framework, employers should adopt a policy for rapid job redesign where caring responsibilities emerge suddenly, and offer flexible hours, home working, and leave arrangements reflecting the specific demands of caring on the individual.

6. Undertaking 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.

[28] Diminic S, Hielscher E, Harris M. Understanding factors associated with Australian mental health carers' employment: technical report. Brisbane: The University of Queensland; 2018 (forthcoming)
[29] Carers Australia, Work & Care: The Necessary Investment. 2014. Report No. 2 Work & Care Initiative. Canberra

Solution 3: 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.

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 billion[30]. 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 in the short-term. In the longer term, intensive caring has been shown to yield a negative effect on a carer's health, including mental health[31]. Poor health outcomes for carers increases the burden on public health services in the short, medium, and long-term. 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 provisions[32].

Why does this matter?

Many carers subsist in weak or precarious economic conditions that can extend 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 (including the Age pension and superannuation that is tied either to paid work or income of assets test limits) should be reviewed and reformed to account for the inequity of retirement incomes and savings that leaves many mental health carers in poverty in older age, especially women.

To achieve change:

1. The Treasury should lead a multi-stakeholder project to investigate, cost, trial and monitor a limited superannuation replacement scheme for primary carers whose capacity to earn is impacted by their unpaid care work. This scheme should explore the efficacy (and potential cost savings) for a scheme operating at scale.

[30] 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.
[31] OECD, Help Wanted? Providing and Paying for Long-Term Care, 2011, pp.85-103
[32] Australian Human Rights Commission. 2013. Investing in care: Recognising and valuing those who care. Volume 1 Research Report,.Australian Human Rights Commission. Sydney.

Solution 4: Identify and assist all young carers

What do we know?

All 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[33]. Some evidence suggests that young carers are more likely to receive income support at some stage after exiting Carer Payment[34].

Young mental health carers face specific and acute disadvantage[35]. Mental illnesses have a younger age of onset than many other conditions that lead to unpaid caring such as cardiovascular, musculoskeletal and neurological disorders. As a result, mental health caring is often taken up by people at a broader range of ages and life stages, including children, and the impacts on their lives may be substantial, and long-term.

Our data shows that significantly fewer children with mental health caring responsibility attend school compared to other carers[36]. Most alarmingly, almost 13% of children with mental health caring responsibility aged 5-14 are not attending school. This compares to 100% school attendance for other categories of children with caring responsibilities in this age group, and 95.7% school attendance for all other children.

Why does this matter?

More than 60% of young carers have not studied beyond high school, and on average, current young carers are expected to be on income support in 43 years over their lifetime[37].The emerging data points to the need for urgent government attention, and a robust policy response.

The long-term individual and societal impact of such a high proportion of children with mental health caring responsibility not attending school between the ages of 5 and 14 is hard to overstate.

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

[33] 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.
[34] 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
[35] Diminic S, Hielscher E, Harris M. Understanding factors associated with Australian mental health carers' employment: technical report. Brisbane: The University of Queensland; 2018 (forthcoming)
[36] Ibid.
[37] Australian Government, Department of Social Services, Try, Test and Learn Fund, Data-driven job opportunities for young carers. See: https://www.dss.gov.au/sites/default/files/documents/05_2018/d18_531592_data-driven_job_opportunities_for_young_carers_factsheet.pdf

seek support or assistance[38]. Unpredictable care requirements associated with episodic mental health problems could make regular school attendance and maintaining employment particularly difficult.

What needs to change?

All young carers need to be identified, and they must receive appropriate support- in the home, in schools, and in workplaces- to ensure that they are not economically and socially disadvantaged.

To achieve change:

1. The federal Department of Education and Training, together with State education departments, the Department of Social Services, The Australian Bureau of Statistics and the Australian Institute of Family Studies should design a national strategy to identify all children with caring responsibilities in Australia, and facilitate universal access to a statutory carer assessment.

2. For children aged 0-16, the above departments should develop and implement a national framework for schools and teachers to better identify those students that provide care to a relative with mental illness, to allow for ongoing monitoring, additional assistance from teaching staff, and provision of support from school counselling services where need be to prevent disengagement or poor outcomes.

3. The above departments should invest in a focused primary/secondary school based anti-stigma campaign, co-designed with schools, including curriculum based learning programs focused on the experiences and rights of young mental health carers, to assist in identifying and reaching young mental health carers.

4. For young people aged 17-24 years, similar policies may be required within the post-compulsory education sector (including Technical and Further Education (TAFE), Vocational Education and Training (VET), and universities) involving coordinated action from academic and administrative staff, as well as across institutional counselling services to help identify and support students caring for a person with mental illness in order to prevent low attendance and dropout.

[38] 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 (forthcoming)

Solution 5: Remove existing policies that restrict opportunities for unpaid carers to work

What do we know?

The Carer Payment is a critical system of income support for Australia's unpaid carers. However, the design of the Carer Payment system currently restricts opportunities for carers to participate in paid work and education, through both the income and assets test, and the '25 hour rule', which restricts a carer's participation in work or education to 25 hours (including travel time).

Why does this matter?

The '25 hour rule' disadvantages 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 who provide care on an unpredictable and episodic basis.

The rule creates particular challenges for young carers, who are participating in primary, secondary or tertiary education and who are often attempting to undertake part-time work in order to support their families. It creates challenges for anyone undertaking education of training for any reason, including so as to return to work. Carers in education or training can be incentivised to disengage with further study or employment, forced to make important life choices based on arbitrary factors such as the number of course contact hours, or geographic location of the institution, and compelled into a problematic relationship with welfare agencies and consider concealing study or employment to circumvent rules[39].

What needs to change?

To achieve change:

1. Abolish the 25 hour rule.

[39] 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/

Solution 6: Take proactive steps to recognise, mitigate, and overcome gender inequality among carers

What do we know?

Caring responsibilities can emerge for anyone, but our data show that the impacts on employment are experienced more acutely by women than men. 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)[40]. In contrast to male mental health carers, whether their care recipient receives formal support services does not impact on employment prospects for female mental health carers; that is to say, potential policy solutions to this problem need to be targeted at the female carer themselves, as opposed to the person they provide care to. Our data indicates that there are no significant differences between the factors associated with employment for female mental health carers versus those found for female carers of other conditions.

Why does this matter?

The impacts of caring are experienced more widely by women than by men, and include lower workforce participation, lower income, lower standards of living, career disruption, reduced social networks, lower savings and retirement provisions, and poorer health outcomes[41].

The impact is most acutely felt during peak earning ages. Our data tells us that there is a 40.7% unemployment rate for female mental health carers aged 35-54 (compared with 24% for male mental health carers)[42]. Again, our data indicates overwhelming similarities between mental health carers and carers of other conditions.

What needs to change?

Recognising and articulating that the burdens of caring fall disproportionately to 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.

To achieve change:

1. Reinstate a formal government commitment to producing annual gendered budget analyses.

2. In all policy initiatives proposed by Caring Fairly, including most pertinently those that relate to workplace reform, ensure involvement and oversight by the Workplace Gender Equality Agency.

[40] Diminic S, Hielscher E, Harris M. Understanding factors associated with Australian mental health carers' employment: technical report. Brisbane: The University of Queensland; 2018 (forthcoming)
[41] Ibid.
[42] Ibid.

Solution 7: Respond to the distinct features of mental health and episodic caring, and invest in tailored support

What do we know?

All intensive caring is profoundly challenging, and mental health caring shares more similarities than there are difference with other types of care. However, there are a range of complex features associated with mental health caring that can exacerbates the challenges[43]. The same is true for carers of people with other types of episodic conditions.

Unpaid mental health care has an intrinsic focus on emotional support, managing crises, and supervision of behaviour[44]. Mental illness has a younger age of onset than many other conditions that lead to unpaid caring; therefore the economic impact on mental health carers can be experienced for longer. Stigma associated with the caring role can impact a person's help seeking in public, with the effect that people may end up needing more (and more costly) support than they would have, had they accessed help earlier. Unexpected fluctuations in support needs, together with an average of 60 hours per week 'on call', precludes the ability to take up stable and predictable employment patterns[45].

Why does this matter?

The increasing drive towards rationalising, mainstreaming, and simplifying government service delivery models (including the Integrated Carer Support Service) heightens the risk that the unique support needs of mental health carers will be overlooked. Unmet support needs exacerbate the short and long term social and economic impacts of unpaid caring.

What needs to change?

To achieve change:

1. Mental health carer organisations should be engaged from the outset in the regional delivery of the Integrated Carer Support Service (ICSS). This will act to ensure service continuity, the maintenance of existing infrastructure, and the maintenance of a specialist workforce.

2. A mental health carer specific gateway should be embedded within the Regional Development Partner model proposed by the Department of Social Services.

3. The Department of Social Services needs to harmonise the proposed rollout of the ICSS with (among other agencies and bodies) the National Disability Insurance Agency and State governments, and produce a clear strategy for identifying and mitigating gaps in carer support services.

[43] 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.
[44] 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.
[45] Ibid.

Solution 8: 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 mental health across Australia. While the NDIS provides much needed long term support for people with significant psychosocial disability, it does not offer a coherent framework for supporting their carers. Nor does it replace state funded services providing support to a wider range of persons with mental health issues. Moreover, not everyone who needs support because of mental illness is eligible for the NDIS. Others (who may be eligible) do not apply[46]. In these cases, carers are vulnerable to being left without support[47]. Chronic underinvestment, and the withdrawal of funding for critical carer support services, are exacerbating unmet support needs for mental health carers[48].

The primary focus of the NDIS is on the needs of the person with disability, not the needs of the carer. Successful mental health carer support services (including Mental Health Respite: Carer Support and Personal Helpers and Mentors (PHaMs) have been or are in the process of being defunded, with services rolling, in some fashion, into the NDIS. The carer/ NDIS interface is highly problematic, and is exacerbating support gaps for mental health carers.

Why does this matter?

Mental health carers cannot directly access services though NDIS, as a product of its fundamental design and its focus on the individual. Many mental health carers who previously used effective carer support services are not eligible for NDIS in their own right[49]. State and territory services for carers have largely been withdrawn, whilst the process for their reformulation under the NDIS model remains opaque.

The need for discrete, targeted reforms within the NDIA to benefit mental health carers has been well articulated. In August 2017, the Joint Standing Committee recommended that clients currently receiving mental health services, including DSS funded programs like *Mental Health Respite: Carer Support* should not have to apply for the NDIS to have guarantee of continuity of supports and access services[50].

What needs to change?

To achieve change:

1. The NDIS should introduce a dedicated carer package, representing a formal pathway for carers to access support in their own right.

[46] 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.
[47] Ibid.
[48] Carers Australia. 2016. Submission to the draft Service Concept: Designing the new integrated carer support service. Canberra
[49] Tandem Inc. 2018. Victorian mental health carers in the NDIS: issues and recommendations. Briefing paper. Melbourne.
[50] Joint Standing Committee on the National Disability Insurance Scheme, Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition, August 2017