



Submission to the Australian Government Productivity Commission: Carer Leave

(Examination of the potential economic and social costs and benefits of providing an extended unpaid leave entitlement to informal carers of older Australians under the National Employment Standards)

Arafmi Ltd
PO Box 248
New Farm QLD 4006
Contact: Irene Clelland
Chief Executive Officer



Arafmi Ltd Submission to the Australian Government Productivity Commission: Carer Leave

(Examination of the potential economic and social costs and benefits of providing an extended unpaid leave entitlement to informal carers of older Australians under the National Employment Standards)

25 August 2022

Gerard Dowling, Project Worker, and Irene Clelland, Chief Executive Officer.¹

Arafmi Ltd is pleased to provide this submission for consideration by the Productivity Commission inquiry into carer leave.

As a key carer organisation in Queensland, we have direct contact with carers across the state, actively identify carers' needs, and provide systemic advocacy across all levels of government.

Our submission highlights economic and social benefits of providing an extended unpaid leave entitlement to informal carers of older and other Australians, in particular for carers of people with mental health needs. It provides the Commission with:

- our reflections and suggestions on the *Issues Paper*,
- research not canvassed in the *Issues Paper* including research we have undertaken or commissioned, and
- our recommendations for how a provision for extended unpaid carer leave should be designed and implemented under the National Employment Standards.

Our submission includes:

Executive Summary	2
1. An Introduction To Arafmi Ltd	4
2. The Current Value Of And Future Risk To Informal Caring In Australia	5
3. The Circumstances In Which People Become Informal Carers	7
4. Diversity Of Australian Carers, Exhibit A: Mental Health Carers	9
5. Diversity Of Australian Carers, Exhibit B: Young Carers	14
6. Arafmi Ltd's Perspective As An Employer	18
7. Design Considerations And Recommendations	22
8. Distributional Effects And Communitywide Benefits	29

We thank the Commission for its recent careful consideration of mental health in Australia.¹ We appreciate the groundwork it provides all stakeholders for improving the mental health of people of all ages and cultural backgrounds, working with people who have experience of mental illness, and their families and carers. We look forward to similar outcomes from this carer leave inquiry.

¹ Productivity Commission, 2020. *Mental Health, Report no. 95*. Canberra.
Page 1 of 32



Executive summary

Arafmi Ltd speaks as both a systemic advocate for carers, and an empathetic, flexible, innovative employer of choice for carers. We ask the Commission to consider the following in relation to the potential and benefits of extended unpaid carer leave in Australia, across the eight sections of this submission.

Arafmi Ltd offers experience and credibility as both a systemic advocate for carers, and an empathetic, flexible, innovative employer of choice for carers.

Current value of and future risk to informal caring in Australia. Informal care contributes \$77.9 billion to the Australian economy annually. Australia faces a current and future shortfall in informal care to meet the needs of its older, ageing, and other population. In this context, an entitlement to extended unpaid carer leave offers significant community-wide benefit.

Circumstances in which people become informal carers. Carers become carers when someone they care about needs more extensive support. They become carers regardless of the age of the person needing care. The crossing of an age threshold to being considered an 'older Australian' does not affect the carer relationship or the needs of their carer in any ways that are obvious or significant.

We encourage the Commission to remember the diversity of carers, including mental health carers, and young carers.

Mental health Carers. Carers of older and other Australians who have mental health needs are a key component of the informal carer landscape in Australia, contributing significant economic and social capital. It would cost \$13.2 billion to replace informal mental health care with formal support services.

In a survey of mental health carers, 21% were caring for someone aged over 60.

Many carers self-identify with the term 'mental health carers', regardless of the age of the person/people they are caring for, because it describes something essential about their experience that is different from other carers.

Mental health carers of older and other Australians have care roles and responsibilities that are more likely to be episodic than other carers. They spend relatively less time engaged in caring activities, and more on 'standby'.

Young carers. Young carers are often overlooked. There are 246,000 young carers (aged under 24) in Australia - including 50,000 under 15. They have lower labour force participation and poorer health and wellbeing.

Yet they have many skills transferable to workplaces including maturity, resilience, dedication, good organisational and time management skills, budgeting skills, problem solving skills, and empathy.

Arafmi Ltd.'s perspective as an employer. As an employer, Arafmi Ltd values the lived experience of caring and mental illness that many of our workers bring to their roles and share with us as an organisation. We believe not-for-profits like Arafmi Ltd - 10% of Australia's workforce - will lead the way in championing extended unpaid carer leave and other practices supporting carers. A growing number of Australian businesses are ready to embrace changes supporting employee wellbeing.



Employers like Atlassian see their culture of innovation and corporate social responsibility as a competitive advantage.

Design considerations. Inclusive design provides clear communitywide benefits, and helps to ‘future proof’ any change to carer leave entitlement.

The Carer Recognition Act 2010 (Cth) establishes a broad and encompassing definition of an informal carer. We can see no reason to carve out a particular sub-group from this established definition. The age of the person they are caring for is of very little relevance to anyone’s choice to become a carer, and the impacts of that choice on their employment.

Managing different employee entitlements would add unnecessary complexity to our workforce management. It would also add unnecessary questions of fairness in how we respond to different employees who have the same need. It is not necessary to delineate between ‘primary’ and ‘other’ carers. These delineations do not reflect the lived experience of carers. We note the *Carer Recognition Act* does not make a delineation and suggest that any differentiation would be strongly contested.

Significant changes to carer leave will change the conversation in Australian workplaces and society, in ways similar to the changes we are seeing with parenting leave and accessibility. An understanding that extended unpaid carer leave applies to every employee and can be used flexibly for different durations of time, would build a workplace culture that the entitlement applies commonly to most employees over time rather than being an extraordinary or exceptional occurrence for a few. Carers work in all types of employment in all types of industries and businesses. We can see no correlation between the type of industry or business and the likelihood of a carer being present, or the needs of that carer. Distributional effects and communitywide benefits. A universal entitlement to extended unpaid carer leave would maximise redistributive effects and communitywide benefits.

Recommendations

1. The design of any changes to carer leave entitlement and associated provisions and practices be undertaken within an ‘inclusive design’ framework.
2. Any change to carer leave apply to all carers covered by the *Carer Recognition Act 2010 (Cth)*.
3. Any change: NOT delineate between ‘primary’ and other carers; apply to all employment forms including casual and part-time; and impose as few limitations as possible on the nature of the employee’s relationship to the care recipient
4. Any change of entitlement be designed to bridge the gap between current short-term provisions and any new entitlement.
5. Any change provides for multiple periods of leave.
6. The mechanism for applying be as similar as possible to parental leave, and explicitly state that employees do not have to justify accessing their entitlement or disclose the personal circumstances of themselves or the person they are caring for.
7. Any change to entitlements apply across all types of industries.
8. The Commission should consider the feasibility of implementing the entitlement in very small workforces, but it should apply to all sizes of business.



1. An introduction to Arafmi Ltd

Arafmi Ltd² was founded in Brisbane in 1976 as Association of Relatives and Friends of the Mentally Ill. We are a not-for-profit organisation providing support to people who have a mental illness, their families and informal carers across Queensland.

Arafmi Ltd delivers a range of supports and services:

- Emotional and therapeutic support to people who live with mental illness.
- Emotional and therapeutic support to families, informal carers, and friends of people who experience mental illness via 1-1 support, counselling, group support and respite.
- 24-hour Carer Helpline open to anyone who is caring for or about a relative or friend with a psychosocial disability.
- Systems advocacy to convey the needs of unpaid carers to government, healthcare professionals, and the general community.
- Information and educational support focused on the demands and pressures of caregiving.
- Community awareness and understanding, aiming to decrease the stigma of mental illness.

Arafmi Ltd provides support to over 1000 mental health carers, and families annually. This support is provided by a team of six employees and 40 volunteers.

We are funded by Queensland Health Mental Health, Alcohol and Other Drugs Branch and provide additional services to people living with mental illness via the National Disability Insurance Scheme.

Arafmi Ltd Chief Executive Officer, Irene Clelland, is an appointed member of the Queensland Carers Advisory Council - established under the *Carers (Recognition) Act 2008* to provide advice to the Queensland Minister for Seniors and Disability Services and Minister for Aboriginal and Torres Strait Islander Partnerships. Ms Clelland was a mental health carer for her brother, who developed acute and ensuring psychosis whilst they lived together, as teenagers, in the family home.

Arafmi Ltd speaks as both a systemic advocate for mental health carers, and an empathetic, flexible, innovative employer of choice for carers.

Key findings: introduction to Arafmi Ltd

Arafmi Ltd offers experience and credibility as both a systemic advocate for carers, and an empathetic, flexible, innovative employer of choice for carers.

² There are other organisations in other states who also use or has previously used the name 'Arafmi' in similar models of support to mental health carers.



2. The current value of and future risk to informal caring in Australia

Arafmi Ltd note that Deloitte Access Economics found in 2020:

- Informal carers are critical to the sustainability of the aged and disability care systems. They provide support and services that may otherwise be funded by the taxpayer, the estimated value of which is significant.³
- The annual replacement cost of informal care for Australia is \$77.9 billion.⁴

They estimate 213,900 carers partially or fully withdraw from employment in order to fulfil their caring responsibilities. This is 1.51% of the labour force, and the opportunity cost to the Australian economy is \$15.2 billion annually.⁵

Australia's future - rising demand for informal care, diminishing supply

Deloitte forecast demand for informal carers will rise 23% over this decade - from 1.25 million in 2020 to 1.54 million in 2030, while supply will rise only 16% from 674,000 to 780,000.

This shortfall reflects an ongoing decline in 'propensity to care' - particularly among males.⁶ We agree with their concern that:

"The widening carer gap has significant policy implications for Australia's future with the need to investigate possible solutions to help boost the propensity to supply care and to soften the demand for informal care where possible."⁷

We note that Deloitte takes a similar appreciative approach to the way more flexible employment arrangements are important in addressing Australia's declining supply of informal care:

Greater flexibility for employees in their working hours and arrangements can help to accommodate the provision of informal care in cases where the carer was previously unable or reluctant to due to rigidities in workplace policy...

In fact, a previous study found that access to flexitime and the ability to reduce working hours was associated with a 13% increase in the hours of informal care provided.

While greater flexibility in working arrangements will support more people to provide informal care, it is also likely that this would benefit the existing informal carers who wish to enter or return to the workforce following a prior departure.

In the 2012 SDAC, an estimated 22.9% of primary carers who were not in the labour force expressed a desire to work...

As such, flexible working arrangements will be key to allowing carers to remain in, or return to, employment while responding to the specific needs of their recipients of care.⁸

We note that this Deloitte research specifically addresses the topic of Carer Leave:

³ Deloitte Access Economics, 2020. *The value of informal care in 2020*. Carers Australia, Canberra. pvi

⁴ Deloitte Access Economics, 2020. *The value of informal care in 2020*. Carers Australia, Canberra. piii

⁵ Deloitte Access Economics, 2020. *The value of informal care in 2020*. Carers Australia, Canberra. pvi

⁶ Deloitte Access Economics, 2020. *The value of informal care in 2020*. Carers Australia, Canberra. ppv-vi

⁷ Deloitte Access Economics, 2020. *The value of informal care in 2020*. Carers Australia, Canberra. pvi

⁸ Deloitte Access Economics, 2020. *The value of informal care in 2020*. Carers Australia, Canberra. p36



While the demand for informal care is expected to continue exceeding the supply of informal carers into the future, current rates of informal care provision suggest it may be possible to increase the propensity to care in the future.

One such mechanism that may support such an uplift in informal care provision is greater flexibility in working arrangements, including improvements to carer leave through the Fair Work Act.

Carer leave through Australia's industrial relations system has historically compared unfavourably with many comparable countries.⁹

We believe that in this context, an entitlement to extended unpaid carer leave would confer a significant net community-wide benefit. We support government policy changes Deloitte recommend:

- "Greater flexibility in working arrangements to accommodate workers' caring responsibilities and employment preferences, such as improved carer leave.
- Improvements in access to, and awareness of, carer support services such as respite care to encourage service utilisation and alleviate the impact of caring."¹⁰

An opportunity to build awareness by changing the conversation

One of the reasons we support significant change to the NES is that we believe it will 'change the conversation' - raising awareness about the needs of carers, changing the way the caring role is discussed among employees and employers and in the workplace, and making carers and caring more visible in our social landscapes.

We anticipate a similar impact to the way paid parental leave has changed social and workplace perceptions of parenting, including 'validating' the parenting role and awareness of needs of parents in the workplace and elsewhere.

Key findings: value of and future risk to informal caring in Australia

- Informal care contributes \$77.9 billion to the Australian economy annually.
- Australia faces a current and future shortfall in informal care to meet the needs of its older, ageing and other population.
- Deloitte, Carers Australia and others identify flexible employment arrangements and extended unpaid carer leave as key to addressing this shortfall.
- In this context, an entitlement to extended unpaid carer leave offers significant community-wide benefit.
- Significant change to the NES will 'change the conversation' - raising awareness about the needs of carers, changing the way the caring role is discussed among employees and employers and in the workplace, and making carers and caring more visible in our social landscapes.

⁹ Deloitte Access Economics, 2020. *The value of informal care in 2020*. Carers Australia, Canberra.

¹⁰ Deloitte Access Economics, 2020. *The value of informal care in 2020*. Carers Australia, Canberra. p v

3. The circumstances in which people become informal carers

In our experience, the circumstances in which people become informal carers of older Australians vary from individual to individual in significant ways. Primarily, they become carers because someone they care about needs care.

That person may already be an older Australian, or approaching an older age, or they may be younger but with ongoing or episodic needs for care that will be part of their lives into older age.

Care is often episodic

We encourage the Commission to consider the episodic nature of the role of carer. Carers are carers for the periods of weeks, or months, or years, or sometimes decades of their lives during which they have someone who needs their care.

The decision to become a carer always necessitates changed work arrangements for every carer who is in the workforce. And very few carers are not in the workforce, at the beginning of their caring journey.

The need to leave the workforce rarely coincides with the beginning of a role as a carer. More often their caring responsibilities evolve over time to the point at which they cannot fulfil their competing and ongoing responsibilities as both an employee and a carer.

Becoming a carer is rarely a planned decision and usually not an impromptu decision triggered by an emergency. More often, for a carer who is an employee, it begins with 'flexing off work' to look after someone who is unwell, or to accompany someone to an appointment. It may progress through these kinds of stages:

- Making arrangements to visit or provide care before or after work, or on the weekends.
- Flexing off a shift as a once off, then now and then.
- Responding to an immediate need on a particular day, then retrospectively applying for carer leave if it is available to them.
- If they do not have entitlement to carer leave, they will do their best to respond to an immediate need on a particular day, while concurrently negotiating their absence from the workplace, often including ways of 'making it up to' their employer.

Lack of clarity for carers navigating their first absence from work

We encourage the Commission to consider the current lack of clarity for carers in navigating their first absence from the workplace. In Arafmi's experience, the first episodes are often accompanied by uncertainty.

This starts with the perception of the person - not realising they are stepping into a carer role. They are highly likely to see themselves simply as "helping out", "taking mum to the doctor", or "giving granddad a lift to...".

For many becoming a carer is an incremental process over time. For some the more important moment is when they realise they are a carer.

Diversity of Australian carers

We encourage the Commission to remember the diversity of carers.

There are two groups of carers of which we have particular knowledge, experience and expertise: mental health carers, and young carers. Both groups care for older Australians, as well as for other Australians.

We believe their lived experience as ‘edge users’ is a valuable design resource, in ways discussed later in this submission in relation to inclusive design - see section 6.

Most people who are being cared for in Australia will sooner or later become an older Australian. If they live long enough. By definition it is just a matter of time. The crossing of that threshold does not affect the carer relationship or the needs of their carer in any ways that are obvious or significant to Arafmi Ltd.

Everything we say in this submission applies to carers of older Australians, because it applies to carers of Australians.

Key findings: circumstances in which people become informal carers

- Carers become carers when someone they care about needs more extensive support.
- They become carers regardless of the age of the person needing care.
- Often the role is episodic.
- Many do not identify as carers. Others warm to the term to describe their experience over time.
- We encourage the Commission to remember the diversity of carers, including mental health carers, and young carers.
- The crossing of any age threshold to being considered an ‘older Australian’ does not effect the carer relationship or the needs of their carer in any ways that are obvious or significant.
- Everything we say in this submission applies to carers of older Australians, because it applies to carers of Australians.



4. Diversity of Australian carers, Exhibit A: mental health carers

Carers of older and other Australians who have mental health needs are a key component of the informal carer landscape in Australia, contributing significant economic and social capital.

We urge the Commission to keep them in mind when considering how an unpaid leave entitlement might maximise communitywide benefits.

Alan Fels, as Chair of the National Mental Health Commission, wrote in 2016:

“The 2.4 million people who care for those with a mental illness, and those who work with these carers, have been, to a large extent, the unsung heroes in mental health in this country. They will remain the bedrock of the system.”¹¹

Mr Fels was drawing on 2010 research by the schools of Population Health at the University of Melbourne and University of Queensland:

“The current study underscores the vital importance of carers in supporting people with mental disorders. Many people act as carers: 15% of the Australian adult population equates to nearly 2.4 million individuals.

These carers provide a range of emotional and practical supports to close relatives with a range of mental disorders, most notably high prevalence disorders.

People with mental disorders may be unable to access these sorts of supports from elsewhere, and they may make a crucial difference to their well-being, ability to cope and likelihood of recovery.”¹²

The economic value of informal mental health caring in Australia

Research by the University of Queensland School of Public Health, published as *The economic value of informal mental health caring in Australia* in 2017, found that:

- In June 2015, there were an estimated 2.8 million informal carers in Australia,
- of whom 240,000 or 8.6% were caring for an adult with a mental illness.
- These 240,000 provided 208 million hours of care annually - which would cost \$14.3 billion to replace with paid carers.
- \$1.2b was spent on support for mental health carers, including:
 - \$1.1 billion income support payments (Carer Payment, Carer Allowance, Carer Supplement and Rent Assistance)
 - \$69 million other Commonwealth funded services
 - Between \$10 and \$46 million state and territory funded services.

¹¹ Mind Australia, 2016. *A practical guide for working with carers of people with a mental illness*. Mind Australia, Helping Minds, Private Mental Health Consumer Carer Network (Australia), Mental Health Carers Arafmi Australia and Mental Health Australia. p4

¹² Pirkis, J, Burgess, P, Hardy, J, Harris, M, Slade, T and Johnston, A, 2010. 'Who cares? A profile of people who care for relatives with a mental disorder', *Australian and New Zealand Journal of Psychiatry* 2010: 44, p934



- It would cost \$13.2 billion to replace informal mental health care with formal support service¹³

Who are mental health carers?

The economic value of informal mental health caring in Australia provides this profile of mental health carers:

- The majority, 54%, are female,
- 73% are aged 25–64 years,
- more than half, 54%, are married,
- 61% live in a capital city,
- 54% are employed.
- the most frequently reported mental illnesses are depression and anxiety, and
- the majority, 85%, of care recipients have one or more other health conditions - substance use disorders and physical health conditions are common.¹⁴

In a survey of mental health carers Arafmi Ltd conducted in 2019, 21% were caring for someone aged over 60:

- 11% were caring for someone aged 60-69
- 10% for someone aged 70-79
- 0.3% for someone aged 80 or older.¹⁵

Many carers self-identify with the term ‘mental health carers’, regardless of the age of the person/people they are caring for, because it describes something essential about their experience that is different from other carers.

In the same Arafmi Ltd survey, 29% of carers had one or more other dependents:

- 15% had one other dependent
- 10% two, and
- 4% three or more.¹⁶

What do mental health carers do?

The economic value of informal mental health caring in Australia found:

- Mental health carers of older and other Australians have care roles and responsibilities that are more likely to be episodic than other carers.
- They spend relatively less time engaged in caring activities, and more on ‘standby’.

¹³ Dominic, S, Heilscher, E, Lee, Y Y, Harris, M, Schess, J, Kealto, J and Whiteford, H. 2017. *The economic value of informal mental health caring in Australia: summary report*. The University of Queensland, Brisbane. pp4,12.

¹⁴ Diminic S, Hielscher E, Lee YY, Harris M, Schess J, Kealton J and Whiteford H. 2016. *The economic value of informal mental health caring in Australia: technical report*. The University of Queensland, Brisbane. ppxii-xiii

¹⁵ Spinifex, 2019. *Arafmi #becoming visible online survey results 2019*. Unpublished report. Arafmi, Brisbane.

¹⁶ Spinifex, 2019. *Arafmi #becoming visible online survey results 2019*. Unpublished report. Arafmi, Brisbane.



- The care they provide is more focused on emotional support and less focused on practical assistance and assisting with activities of daily living.¹⁷

More specifically, the breakdown of time they spend on different caring activities provides the Commission with detailed information about what mental health carers do and illustrates how they differ from other carers.

68% emotional support and psychosocial care, including:

- 19.2% emotional support and encouragement (emotional support and companionship, encouraging and motivating)
- 24.3% supervising and monitoring (encouraging or prompting, keeping care recipient occupied, supervising to prevent wandering/damage)
- 10.2% responding to behaviour (managing crises, managing inappropriate behaviour)
- 14.2% other emotional support.

29% assistance with practical tasks, including:

- 16.8% household tasks (grocery shopping, preparing meals, housework, property maintenance)
- 5.4% health care coordination (supervision/prompting taking of medication, arranging outside services, liaising with health professionals, assisting with treatment plan)
- 2.9% literacy and communication (managing finances, other paperwork, reading and writing, communication)
- 2.7% transport, e.g., assistance with getting to appointments/workplace.
- 1.3% other practical tasks.

3% Assistance with activities of daily living, including personal hygiene, grooming, bathing, dressing, eating and mobility.¹⁸

How does caring affect mental health carers, in particular?

Arafmi Ltd partnered with other like organisations across Australia in 2016 to research and publish *A practical guide for working with carers of people with a mental illness*.¹⁹ The consensus across our collective wealth of experience and expertise is that:

Mental illness and its treatment is a unique journey.

Illnesses are episodic in nature and the need for care changes.

People will move in and out of different stages at different times.

¹⁷ Diminic S, Hielscher E, Lee YY, Harris M, Schess J, Kealton J and Whiteford H. 2016. *The economic value of informal mental health caring in Australia: technical report*. The University of Queensland, Brisbane. p68

¹⁸ Diminic S, Hielscher E, Lee YY, Harris M, Schess J, Kealton J and Whiteford H. 2016. *The economic value of informal mental health caring in Australia: technical report*. The University of Queensland, Brisbane. p68

¹⁹ Mind Australia, 2016. *A practical guide for working with carers of people with a mental illness*. Mind Australia, Helping Minds, Private Mental Health Consumer Carer Network (Australia), Mental Health Carers Arafmi Australia and Mental Health Australia.



They will also have contact with a range of service providers over time, all of whom have different skill sets.²⁰

Carers supporting a person with a mental illness are generally, especially in the early days, moving through uncharted waters.

Their feelings, experiences and questions may vary considerably as they encounter unexpected situations that they have little experience of and no preparation for. These may cause emotions and feelings that include:

- fear
- confusion
- grief and loss
- wondering how they will cope
- wondering what the cause of their loved one's mental illness is
- wondering why they in particular have been affected by mental illness
- wondering what other people will think
- wondering what the situation means for their family.

These reactions may appear at different stages of the diagnosis, treatment, and journey towards recovery.

Family members and carers have a unique role to play in that journey because they know the person, and probably knew them before they became unwell.

They are a source of information about a consumer's life beyond their diagnosis of mental illness, including information about their interests, skills, beliefs, and ambitions.²¹

In Arafmi Ltd's experience, mental health carers:

- May not see themselves as a carer.
- May 'arrive' into the caring role in a sudden crisis, that may be highly emotionally charged.
- May be very confused about what they are experiencing.
- May be very confused about what the person they are caring for is experiencing.
- May be in crisis when they initially contact a service.
- May be shocked or embarrassed - by the ways the person they care for is behaving with them, family, neighbours, extended family and when out and about in the community.
- May be supporting someone who has lifelong, episodic, and reoccurring mental health needs which can be unpredictable and put themselves or others in their home at risk.
- May not understand the episodic nature of mental illness, and the possibilities for and possible limitations on recovery.
- May be surprised by unexpected patterns of relapse.

²⁰ Mind Australia, 2016. *A practical guide for working with carers of people with a mental illness*. Mind Australia, Helping Minds, Private Mental Health Consumer Carer Network (Australia), Mental Health Carers Arafmi Australia and Mental Health Australia. p8

²¹ Mind Australia, 2016. *A practical guide for working with carers of people with a mental illness*. Mind Australia, Helping Minds, Private Mental Health Consumer Carer Network (Australia), Mental Health Carers Arafmi Australia and Mental Health Australia. p10



- May not be consulted or involved in decision making and planning relating to the person they support.
- May have limited or no knowledge of supports and services including acute mental health services, community supports, mental health plans, carer supports and the NDIS.
- May be less visible than other types of carers due to societal and personal stigma surrounding mental illness.
- May be at greater risk of developing significant mental health needs themselves.

Mental health carers current experience of employment

Mental health carers to have lower labour force participation compared to those without caring responsibilities. University of Queensland research has found:

- 72.8% of mental health carers are of working age,
- 38.4% are not in the labour force.²²

Research commissioned by Arafmi Ltd identified mental health carers' experiences linked to lower labour force participation:

- 97% identified with having high levels of stress
- 95% with high levels of tiredness
- 73% with high levels of loneliness
- 75% are worried about their financial future.²³

Mental health and income support

We note the Productivity Commission's Mental Health Inquiry (2020) made findings relevant to its current consideration of carers' leave:

- "About 2.8 million working Australians have mental illness, requiring time off work to maintain their wellbeing; a further 440,000 working Australians are carers of someone with mental illness."²⁴
- "...76 000 Australians receive Carer Payment to support someone who has a psychological or psychiatric disability, while
- a number of other carers of people with mental illness receive the Age Pension, Jobseeker Payment or Youth Allowance."²⁵

We agree with the Commission that:

- "Australia's income support system would ideally enable people with episodic mental illness to flexibly transition on and off income support as their functional capacity to earn income changes with their health.

²² Dominic, S, Heilscher, E, Lee, Y Y, Harris, M, Schess, J, Kealto, J and Whiteford, H. 2017. *The economic value of informal mental health caring in Australia: summary report*. The University of Queensland, Brisbane, p5.

²³ Spinifex, 2019. *Arafmi #becoming visible online survey results 2019*. Unpublished report. Arafmi, Brisbane.

²⁴ Productivity Commission, 2020. *Mental Health, Report no. 95*. Canberra. p49

²⁵ Productivity Commission, 2020. *Mental Health, Report no. 95*. Canberra. p53

Key findings: mental health carers

- Carers of older and other Australians who have mental health needs are a key component of the informal carer landscape in Australia, contributing significant economic and social capital.
- It would cost \$13.2 billion to replace informal mental health care with formal support services.
- In a survey of mental health carers Arafmi Ltd conducted in 2019, 21% were caring for someone aged over 60.
- Many carers self-identify with the term 'mental health carers', regardless of the age of the person/people they are caring for, because it describes something essential about their experience that is different from other carers.
- Mental health carers of older and other Australians have care roles and responsibilities that are more likely to be episodic than other carers. They spend relatively less time engaged in caring activities, and more on 'standby'.
- 68% of the care they provide emotional support and psychosocial care and 29% assistance with practical tasks.
- 72.8% of mental health carers are of working age, and 38.4% are not in the labour force.
- The Productivity Commission's Mental Health Inquiry found "those who care for someone with mental illness should have access to income support that is flexible to their circumstances."

- Similarly, those who care for someone with mental illness should have access to income support that is flexible to their circumstances.
- The episodic nature of many mental illnesses can mean that study or work that is on a part-time rather than full-time basis not only remains possible but is essential to a person's recovery and continued social inclusion."
- "...the nature of care provided for someone with mental illness is not necessarily as 'constant' as that for a physical illness, can vary substantially from day to day, and is less likely to relate to the care recipient's 'bodily functions'." ²⁶

5. Diversity of Australian carers, Exhibit B: young carers

Young carers of older and other Australians are a key but overlooked component of the informal carer landscape in Australia.

We urge the Commission to keep them in mind when considering how an unpaid leave entitlement might maximise communitywide benefits.

²⁶ Productivity Commission, 2020. *Mental Health, Report no. 95*. Canberra. p53
Page 14 of 32



Who are young carers?

In 2021 Arafmi Ltd contracted a team from Griffith University to research the roles of young carers in Australia, their health and wellbeing, educational and work outcomes, and support needs. They found:²⁷

- Young carers can usefully be understood as those aged 24 and younger.
- The youngest participant in their study was aged 9.
- There are 246,000 young carers in Australia - including 50,000 under 15.

The team engaged children and young adults aged 9-24 who provide unpaid care to a family member or friend who has a chronic illness, is frail, aged, or has a disability.

In relation to matters considered by this inquiry, the research found:

- Many young carers do not identify as a carer as they and others assume this is a “normal” role.
- Young carers have diverse care experiences.²⁸

How does caring affect young carers?

Our Griffith University research partnership found:

- There are significant positive benefits arising from caring including increased resilience and maturity; fostering a closer relationship with the caree; and development of life skills.
- Young carers also experience negative aspects of caring which may impact their current and future wellbeing. The challenges of competing demands on their time, burden of responsibility and feelings of isolation may result in a reduction in confidence, self-esteem and hope for their future.
- Young carers have many skills transferable to workplaces including maturity, resilience, dedication, good organisational and time management skills, budgeting skills, problem solving skills, and empathy.²⁹

Employment outcomes for young carers in Australia

The research included a focus on employment outcomes, finding:

- Caring responsibilities impact on young carers’ work opportunities in that it is difficult to maintain regular work.
- Some choose not to work or work only part-time so that they can care for others.

²⁷ Hutchings, K., Harris, N., McMillan, S., Radford, K., Slattery, M., Spencer, N., and Wheeler, A. 2021. *Young Carers in Australia industry research report*, Griffith University, Brisbane. p3

²⁸ Hutchings, K., Harris, N., McMillan, S., Radford, K., Slattery, M., Spencer, N., and Wheeler, A. 2021. *Young Carers in Australia industry research report*, Griffith University, Brisbane. p12

²⁹ Hutchings, K., Harris, N., McMillan, S., Radford, K., Slattery, M., Spencer, N., and Wheeler, A. 2021. *Young Carers in Australia industry research report*, Griffith University, Brisbane. p12



- Young carers are less likely to be employed in their teenage years, isolating them further from their age group. Yet for some, their part-time job is also their respite - their time away from their caring responsibilities.
- The consequence of their caring responsibilities often means they miss shifts, leave early, are considered unreliable etc. and may be unlikely to receive a positive work reference for future employment.
- Many young carers were sometimes late for work or had to take days off work because of their caring commitments and some also felt they had been overlooked for promotion opportunities.
- Young carers need skills in communicating about their caring role and negotiating support with most uncomfortable talking about their caring role with their co-workers and employers.³⁰

Challenges noted included:

- Workplaces not being sufficiently flexible to allow for young carers to take time off/start later for work because of caring responsibilities.
- Young carers not wanting to advise employers of their caring role for fear of stigma or being seen as unreliable, and thus having less opportunities offered.³¹

One interviewee reflected:

“Their challenges come with, how do I ring up and say, look, I really can’t come to work today because Mum’s fallen out of her wheelchair, or Dad’s had another acute episode.

There’s the embarrassment factor of having to explain the caring responsibility and somebody else’s disability or disorder. I think they have every intent to be good employees like anybody else”.³²

What employment practices would help young carers?

Arafmi Ltd is grateful to have learned from the experiences of these young carers, and those who support them. They offered these insights in relation to matters considered by this inquiry:

“I would guess 99% of employers would have no idea that someone was a carer no matter what age. So, even right at the beginning of when someone is being recruited, just that whole recruitment process and understanding the needs of the individuals that you're employing, so then that you can mutually agree how it’s going to work well for both of you.”

³⁰ Hutchings, K., Harris, N., McMillan, S., Radford, K., Slattery, M., Spencer, N., and Wheeler, A. 2021. *Young Carers Research Final Report*. Griffith University, Brisbane. p103

³¹ Hutchings, K., Harris, N., McMillan, S., Radford, K., Slattery, M., Spencer, N., and Wheeler, A. 2021. *Young Carers Research Final Report*. Griffith University, Brisbane. p103

³² Hutchings, K., Harris, N., McMillan, S., Radford, K., Slattery, M., Spencer, N., and Wheeler, A. 2021. *Young Carers Research Final Report*. Griffith University, Brisbane. pp47-48



“Making it okay to be able to have that conversation and not see it as a limiting experience or something that will negatively impact on their opportunities within that organisation... the workforce culture around really supporting individuals from very diverse backgrounds.”³³

“...I feel like it should be more normalised, I guess, that some people have these roles, and they can be flexible. And I think things like working from home, I think that’s really good. Everyone is a lot more flexible about working from home now. And not necessarily doing nine to five at home either...”³⁴

Another interviewee suggested there should be some personal leave in which someone can say they are taking a leave day without having to explain the circumstances.³⁵

Young carers have strengths they bring to the workplace

In this study, young carers and their supporters were overwhelmingly positive about the benefits to employers who offer flexibility, patience and persistence in maintaining their employment.

They identify positive attributes they have developed in their caring roles that are translatable into the workplace:

- maturity
- resilience
- dedication/standing by their commitments
- being positive role models for other (young) carers
- well organised
- good skill set (time management, problem solving, financial budgeting and communication)
- good emotional intelligence
- being respectful and understanding of people in different situations
- appreciating diversity
- empathy for, and thinking about, others.³⁶

One interviewee referred to employer support and understanding as a win-win situation:

“...The employer gets a committed, hard-working young person and the young person hopefully feels that they’re supported and have a reasonably stable employment.”³⁷

³³ Hutchings, K., Harris, N., McMillan, S., Radford, K., Slattery, M., Spencer, N., and Wheeler, A. 2021. *Young Carers Research Final Report*. Griffith University, Brisbane. p49

³⁴ Hutchings, K., Harris, N., McMillan, S., Radford, K., Slattery, M., Spencer, N., and Wheeler, A. 2021. *Young Carers Research Final Report*. Griffith University, Brisbane. p81

³⁵ Hutchings, K., Harris, N., McMillan, S., Radford, K., Slattery, M., Spencer, N., and Wheeler, A. 2021. *Young Carers Research Final Report*. Griffith University, Brisbane. p49

³⁶ Hutchings, K., Harris, N., McMillan, S., Radford, K., Slattery, M., Spencer, N., and Wheeler, A. 2021. *Young Carers Research Final Report*. Griffith University, Brisbane. p47

³⁷ Hutchings, K., Harris, N., McMillan, S., Radford, K., Slattery, M., Spencer, N., and Wheeler, A. 2021. *Young Carers Research Final Report*. Griffith University, Brisbane. p49

Key findings: young carers

- Young carers are often overlooked.
- There are 246,000 young carers in Australia - including 50,000 under 15.
- Young carers to have lower labour force participation and poorer health and wellbeing compared to young people without caring responsibilities.
- Young carers have many skills transferable to workplaces including maturity, resilience, dedication, good organisational and time management skills, budgeting skills, problem solving skills, and empathy.
- Young carers need skills in communicating about their caring role and negotiating support.
- Most are uncomfortable talking about their caring role with co-workers and employers.

6. Arafmi Ltd's perspective as an employer

Arafmi Ltd is an experienced employer of carers.

We want to be known as an empathetic, flexible, innovative employer of choice for carers, and a 'role model' of good practice for other employers.

We appreciate the positive way the Commission approached workplace issues in its *Mental Health Report*:

"There is a growing focus on the role businesses can play in maintaining the mental health and wellbeing of their workforce - particularly the potential high returns to employers in terms of lower absenteeism, increased productivity and reduced compensation claims from investing in strategies and programs to create mentally healthy workplaces."³⁸

We have seen these benefits in our own workforce.

Caring for carers is in Arafmi DNA

Arafmi Ltd began as a volunteer, mutual aid organisation - an association of relatives and friends of people with mental illness. Caring for carers is in our DNA. That has been extended to our employees as the organisation has taken on employees and developed workplace policies, practices and culture.

We value the lived experience that many of our workers bring to their roles and share with us as a workplace.

Arafmi Ltd currently has a workforce of 150 (combined mental health carer and NDIS workforce), including approximately 30% who identify as carers. In our mental health carer program, 5 out of 6 employees are mental health carers.

³⁸ Productivity Commission, 2020. *Mental Health, Report no. 95*. Canberra. p49
Page 18 of 32



Arafmi Ltd's approach to carer leave entitlements

The *Carer Leave Issues Paper* identifies that existing leave entitlements for carers under the NES are primarily intended for brief periods of care to deal with an illness or unexpected event or emergency. The issues paper notes the disparity that:

“To be eligible for paid or unpaid leave, an employee must be providing care or support to a member of their immediate family or household because of a personal illness, injury or emergency...

In contrast, eligibility to request flexible working arrangements follows definitions under the *Carer Recognition Act 2010 (Cth)* and includes anyone providing care to a family member or friend, who may or may not reside in the same household.”

Arafmi Ltd practice is to use this broader definition for carer leave, as much as we can.

We approve unpaid leave for everyone who applies for it, on every occasion. At the CEO's discretion, we have also occasionally provided paid leave over and above award entitlements in response to particular employees' circumstances of need.

Arafmi Ltd's other policies to support employees who are carers

As an empathetic employer, Arafmi Ltd has responded to our employees who are carers by developing recruitment, workload management and leave practices that meet their needs in innovative, common-sense ways.

This is particularly so in our teams in which the nature of the workload is more flexible - our management team, administration team, and carer support team.

Recruitment. We value lived experience and consider capacity to work full time as a secondary consideration. Our carer team currently has six workers, with only the team leader full-time. All part time roles have been at the request of the employee to manage work/life balance.

Workload management. In our carer support team, everyone is across everyone's role, so the team can cover at short notice if someone needs to take leave.

Training. We train our line managers in:

- understanding mental health wellbeing
- how, when, and why carers and staff with mental health concerns need to be identified and supported
- signs of strain and distress
- what supports are available
- workplace practices that are carer inclusive and support mental wellbeing.

We would welcome the opportunity to provide this training for other workplaces.



Our feedback on employer costs, behaviour and hiring practices

Arafmi Ltd's feedback on how the proposed entitlement might affect employer costs, behaviour is based on our experience of collegiality and partnership with other not-for-profits, and our understanding of changing expectations of Australian employees.

Arafmi is not alone. We are one of 49,165 organisations registered with the Australian Charities and Not-for-profits Commission.³⁹

- Half of Australian not-for-profits, 51%, have no paid staff.
- The other half, 49%, have 1.38 million paid employees – 10.5% of all employees in Australia.⁴⁰
- Social Ventures Australia says that's around the same number of people as retail trade (10%), and more people than other major industries like construction (9.2%), professional, scientific, and technical services (8.6%) and manufacturing (7.2%).⁴¹

PwC Australia's most recent annual survey of not-for-profit CEOs, *Upskilling for the digital world and preparing for the future of work*,⁴² found that Arafmi Ltd is not alone in innovating for inclusive employment practices:

"Not-for-profits are recognising the way in which diversity and inclusion enables business growth and the achievement of business priorities.

We have seen a significant uplift in the number of NFPs implementing a diversity and inclusion strategy to attract a wide range of talent and ensure inclusiveness in how they work.

Over half (57%) of NFPs surveyed are starting to make, or are making, moderate progress in this area, up 11% on last year."⁴³

We believe not-for-profits like us represent a whole sector of the economy, and a significant part of the Australia workforce, that is ready to embrace and champion employment provisions like extended unpaid carer leave.

But its not just businesses like ours. Other innovators in Australian business are also leading the way. Research by Atlassian and PwC argues recent experiences have created a seismic shift in the expectations of Australian employees:

"2020 was a unique year, centred around once-in-a-lifetime societal impacts; most notably the global pandemic, as well as political upheaval, environmental disasters, economic volatility and a recession that accelerated trends impacting the way we live and work.

³⁹ Australian Charities and Not-for-profits Commission, 2022. *Australian Charities Report: 8th Edition*. Australian Charities and Not-for-profits Commission, Canberra. p4

⁴⁰ Australian Charities and Not-for-profits Commission, 2022. *Australian Charities Report: 8th Edition*. Australian Charities and Not-for-profits Commission, Canberra. P11

⁴¹ Social Ventures Australia and the Centre for Social Impact, 2020. *Taken for granted? Charities role in our economic recovery*. Social Ventures Australia, Sydney. p3

⁴² PwC Australia, 2021. *2nd Annual Not-for-profit CEO Survey: Upskilling for the digital world and preparing for the future of work*. PwC, Sydney.

⁴³ PwC Australia, 2021. *2nd Annual Not-for-profit CEO Survey: Upskilling for the digital world and preparing for the future of work*. PwC, Sydney. <https://www.pwc.com.au/about-us/social-impact/not-for-profit-ceo-survey/supporting-employees-winning-the-war-for-talent-employee-value-propositions.html> accessed 14.8.2022.



This report provides us with a unique opportunity to explore the cumulative impact of these factors on the workforce's expectations of their employer and business in general."⁴⁴

They conclude:

"We identified a new landscape of expectations on business, where accountability and leadership around social issues is an imperative...

It's now clear that health and the economy matter most to Australian employees. Mental health and wellness is the biggest societal issue, with access to healthcare and cost of living also front of mind.

An increasingly activist workforce is demanding that businesses act on the major issues of the day. Employment is more than just a job, and there are benefits on offer for organisations able to meet these increased expectations. But those that fail to hit the mark will struggle to attract and retain their best people."⁴⁵

In particular they found that employees put wellness before work:

"The experiences of the past 12 months have shaken up priorities and put what matters into perspective for Australians. The majority of workers agree mental health is the biggest concern this year, with career goals now taking a back seat as priorities are reassessed.

This has created a new blueprint for employers which demands businesses take a more comprehensive view of their employee's wellbeing, including greater flexibility, mental health services, and alternative career paths and opportunities for growth.

The 'work-first' culture is being replaced by a workforce that is increasingly prioritising life outside the office and expect their employers to do the same."⁴⁶

We believe a growing number of Australian businesses are ready to embrace changes supporting employee wellbeing – including extended unpaid carer leave and other provisions and practices supporting carer wellbeing. Those who resist this change will be left behind in their attempts to attract and retain valued employees.

Key findings: Arafmi Ltd perspective as an employer

- Understanding the needs of carers, relatives and friends, and people with mental illness is our core business.
- As an employer, we value the lived experience of caring and mental illness that many of our workers bring to their roles and share with us as an organisation.
- We believe not-for-profits like Arafmi Ltd – 10% of Australia's workforce – will lead the way in championing extended unpaid carer leave and other practices supporting carers.
- A growing number of Australian businesses are ready to embrace changes supporting employee wellbeing.
- Employers like Atlassian see their culture of innovation and corporate social responsibility in these areas as a competitive advantage.

⁴⁴ PwC, 2021. *Return On Action Report 2021: The rising responsibility of business*. Atlassian, Sydney. p6

⁴⁵ PwC, 2021. *Return On Action Report 2021: The rising responsibility of business*. Atlassian, Sydney. p1

⁴⁶ PwC, 2021. *Return On Action Report 2021: The rising responsibility of business*. Atlassian, Sydney. p2

7. Design considerations and recommendations

Arafmi Ltd welcomes the Commission's invitation to provide our views on how an unpaid leave entitlement could be designed to maximise communitywide benefits.⁴⁷

Inclusive design

Arafmi Ltd asks the Commission to consider the potential for the innovative paradigm of 'inclusive design' to inform future provisions for unpaid carer leave. When PwC reviewed the potential of inclusive design for Australia in 2019, they found a clear alignment with communitywide benefits.

"Our communities are diverse – we live in different places, with different circumstances. We are old, young, live with disability and difficulties, and speak multiple languages; we are diverse individuals and communities.

However, often goods and services are designed as if we are all the same.

Design that embraces diversity maximises widespread access and usability, meaning more people are included. Both individuals and organisations benefit from making inclusive design a standard practice ...

Designers, companies, and government all have a role to play, by designing, investing, and legislating with difference in mind, so that a design process that is inclusive becomes standard practice ...

There is clear evidence of the financial, economic, and social benefits associated with including those that are left out in design. Designing with our differences in mind does not limit the commercial potential of a product or service, in fact, it increases it – to consumers, designers and organisations alike ...

Inclusive design is a powerful source of innovation and creativity that leads to multiple demonstrated benefits – when designing inclusively, organisations can create exceptional products and services, which are available and desirable."⁴⁸

Inclusive design encourages input from edge users and would encourage the Commission to consider the diversity of Australian carers and care situations – including mental health carers and young carers.

The inclusive design methodology is about the design of mainstream products and services that are accessible to, and usable by, as many people as reasonably possible ... Recognising diversity and uniqueness ... and

Aiming for the broadest beneficial impact ... aware of the context and broader impact of any design and strive to effect a beneficial impact beyond the intended beneficiary of the design.⁴⁹

PwC acknowledge that universal design is gaining credibility in building design in Australia. They see inclusive design gaining similar ground in other fields:

⁴⁷ Productivity Commission, 2022. *Carer leave: Issues paper*. Canberra. p16

⁴⁸ PwC, 2019. *The Benefit of Designing for Everyone*. The Centre for Inclusive Design, Sydney. pi

⁴⁹ PwC, 2019. *The Benefit of Designing for Everyone*. The Centre for Inclusive Design, Sydney. p9

Inclusive design, used to better craft products and services, will open opportunities to vulnerable communities and edge users in areas education, employment, financial security, and overall personal independence.⁵⁰

We believe inclusive design will eventually become part of the framework for legislative reform in Australia. We would argue that this Carer Leave Inquiry is an opportunity for the Commission to become an early adopter.

Inclusive design will also help to ‘future proof’ the entitlement. As PwC say – “The world is rapidly transforming. Design can too.”⁵¹

Our reflections and recommendations below apply an inclusive design approach to maximising communitywide benefits across the design parameters the Commission is considering.

Key findings

- Inclusive design provides clear communitywide benefits.
- Inclusive design is gaining credibility in education, employment, financial security, and overall personal independence.
- We believe inclusive design will eventually become part of the framework for legislative reform in Australia. We would argue that this Carer Leave Inquiry is an opportunity for the Commission to become an early adopter.
- Inclusive design will also help to ‘future proof’ the carer leave entitlement.

Recommendation

1. The design of a new carer leave entitlement and associated provisions and practices be undertaken within an ‘inclusive design’ framework.

Extension to carers other than carers of older people

Arafmi Ltd is pleased that the Terms of Reference direct the Commission to consider the application of paid leave or extended unpaid carer leave in other areas, such as care for people with a disability or people with temporary or terminal illness.⁵²

We note from the *Carer Leave Issues Paper* that the *Carer Recognition Act 2010 (Cth)*

“establishes a broad and encompassing definition of an informal carer. It defines informal carers to be:

⁵⁰ PwC, 2019. *The Benefit of Designing for Everyone*. The Centre for Inclusive Design, Sydney. p16

⁵¹ PwC, 2019. *The Benefit of Designing for Everyone*. The Centre for Inclusive Design, Sydney. pi

⁵² Productivity Commission, 2022. *Carer leave: Issues paper*. Canberra. p19



...individuals who provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, alcohol or other drug issue, or who are frail aged.”⁵³

We believe that any new entitlement to carer leave should adopt this broad definition of who the entitlement is for. We can see no reason to carve out a particular sub-group from this established understanding.

We believe reforms to supports for carers of older people should apply to other carers as well.

In our experience, we can identify very few significant ways in which informal care of older people differs from the care that other people might require. The age of the person they are caring for is of very little relevance to anyone’s choice to become a carer, and the impacts of that choice on their employment.

There are no convincing reasons to have different policies for informal carers of older people than for informal carers of other people.

As an employer we do not differentiate now. If the NES were to introduce a change only for carers of older Australians, we (and other employers like us) would have to introduce discrimination into our workplace that is not there now.

Managing different employee entitlements would add unnecessary complexity to our workplace practices and our workforce and payroll management. It would also add unnecessary questions of fairness in how we are able to respond to different employees who have the same need, potentially undermining the harmonious workplace culture we are working to achieve.

We support the recommendation by Carers NSW (to the Royal Commission into Aged Care Quality and Safety, noted in the *Carer Leave Issues Paper*) that the entitlement should apply irrespective of the age of the care recipient.⁵⁴

⁵³ Productivity Commission, 2022. *Carer leave: Issues paper*. Canberra. p3

⁵⁴ Productivity Commission, 2022. *Carer leave: Issues paper*. Canberra. p15

Key findings

- The *Carer Recognition Act 2010 (Cth)* establishes a broad and encompassing definition of an informal carer: ...individuals who provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, alcohol or other drug issue, or who are frail aged.
- We can see no reason to carve out a particular sub-group from this established definition.
- The age of the person they are caring for is of very little relevance to anyone's choice to become a carer, and the impacts of that choice on their employment.
- Managing different employee entitlements would add unnecessary complexity to our workforce management. It would also add unnecessary questions of fairness in how we respond to different employees who have the same need, potentially undermining the harmonious workplace culture we are working to achieve.

Recommendation

2. Any new entitlement to carer leave apply to all carers covered by the Carer Recognition Act 2010 (Cth).

Eligibility for all carers

We believe it is not necessary to delineate between 'primary' and 'other' carers, and particularly for the purpose of considering access to unpaid carer leave. 'Primary' and 'core' delineations do not reflect the lived experience of carers.

We note that the *Carer Recognition Act* does not make a delineation.

It is not necessarily the carer who provides the 'most' or the 'core' support who takes time off work. It is often better for all concerned if the person who is available to provide support is the person in the 'care eco-system' who is best suited to respond to the particular need at the time. For example, it may be that mum does the bulk of the caring over several months, but during an 'acute' time of heightened symptoms, the person who is best to de-escalate and calm the situation is a sibling, cousin, or friend.

Any differentiation between abstract descriptions like 'primary carers' or 'core' activities or 'activities of daily living' is problematic because these definitions would:

- be so subjective and arbitrary that they will be strongly contested, particularly in credible academic and professional literature,
- impose an unhealthy and unnecessary burden of proof on recipients, creating hoops for carers to jump through depending on how their situation is framed, and
- be unfair because two carers doing almost exactly the same thing will fall either side of any definitional line, regardless of where it is drawn.

We note that the Commission cites an ABS classification:



“Primary carers are those who provide those who provide primary assistance with one or more of the ‘core activities’ of mobility, self-care and communication.

Other carers are those who provide secondary assistance with one or more of the core activities, or assist only with non-core activities (for example, household chores).”⁵⁵

We urge the Commission to consider a recent University of Queensland study which found that only 3% of the time mental health carers spend caring is focused on assistance with activities of daily living (ADL), including personal hygiene/grooming, bathing, dressing, eating and mobility. 68% of mental health carers time is focused on emotional support and psychosocial care, and 29% is focused on assistance with practical tasks.⁵⁶ We have provided a more detailed breakdown of these activities in section 4.

For the same reasons we support a broad approach to other criteria including:

- All employment forms including casual and part-time.
- As few limitations as possible on the nature of the employee’s relationship to the care recipient.
- Minimal limitations on intensity and/or type of care required by the recipient.

Key findings

- We believe it is not necessary to delineate between ‘primary’ and ‘other’ carers, and particularly for the purpose of considering access to unpaid carer leave. These delineations do not reflect the lived experience of carers.
- We note that the *Carer Recognition Act* does not make a delineation.
- Any differentiation would be strongly contested, particularly in credible academic and professional literature, would impose an unhealthy and unnecessary burden of proof on recipients, creating hoops for carers to jump through depending on how their situation is framed, and be unfair because two carers doing almost exactly the same thing will fall either side of any definitional line, regardless of where it is drawn.
- For the same reasons we support a broad approach to other criteria. Any change to carer leave should apply to all employment forms including casual and part-time, with as few limitations as possible on the nature of the employee’s relationship to the care recipient.

Recommendation

3. Any change of entitlement apply to all carers, and in particular:
 - NOT delineate between ‘primary’ and other carers,
 - apply to all employment forms including casual and part-time, impose as few limitations as possible on the nature of the employee’s relationship to the care

⁵⁵ Productivity Commission, 2022. *Carer leave: Issues paper*. Canberra. p3

⁵⁶ Dominic, S, Heilscher, E, Lee, Y Y, Harris, M, Schess, J, Kealto, J and Whiteford, H. 2017. *The economic value of informal mental health caring in Australia: summary report*. The University of Queensland, Brisbane, p5

Duration of 'extended' leave

In terms of duration, we note the Commission recognises that “existing leave entitlements for carers are primarily intended for brief periods of care to deal with an illness or unexpected event or emergency.”⁵⁷

Yet the discussion of duration in the issues paper then goes to a suggestion that the NES “provide up to 12 months of leave in the first instance, with a right to request up to a further year.”⁵⁸

We request the Commission to consider the vast gulf between these.

Because current provision and practice is that existing leave entitlements for carers are primarily intended for brief periods – then anything more than three days should be considered ‘extended’.

We would support providing, for example, something like: ‘short-term’ extended unpaid leave of three to ten working days; ‘medium term’ of two to twelve weeks; and ‘longer term’ of three months or longer. This may not necessarily be included in the NES, but we would encourage it as a workplace practice, because:

- Using these kinds of time horizons would give both employee and employer a timeframe of expectation to manage to.
- Common usage of this kind of language would be very beneficial for changing workplace culture and practice, raising awareness of carer roles and needs, and making extended unpaid carer leave a normal part of the everyday workplace.
- It would build a workplace culture that carer leave applies to most employees over time (as parental leave is becoming) rather than an extraordinary or exceptional occurrence for a few (as parental leave was perceived not so long ago).
- This is similar to the understanding that accessibility is not just for people in wheelchairs – it benefits a much wider range of people including older Australians, parents with prams, and all of us at one time or another if we twist an ankle or break a leg.
- We believe there is a strong case that such an approach maximises communitywide benefits.

We would also ask the Commission to consider the possibility of perverse consequences of the 1+1-year model described in the *Issues Paper*. How does it accommodate a carer/employee who needs three weeks to meet the needs of caree in a particular circumstance, then another five weeks a few months later? Have they exhausted their entitlement?

Repeatable and flexible

We cannot see how extended unpaid carer leave can be a once-off entitlement, because many of the circumstances requiring additional levels of care are episodic by nature. We support multiple periods of leave.

We support a flexible length of leave. We concede that there may be workplace circumstances in which employee may need to specify the duration of the leave in advance, in order to facilitate the hiring of a replacement. However, we support the maximum possible flexibility - for example to

⁵⁷ Productivity Commission, 2022. *Carer leave: Issues paper*. Canberra. P8

⁵⁸ Productivity Commission 2022. *Carer leave: Issues paper*. Canberra. p15



return sooner might be advantageous to some carers, as some caring needs may drastically reduce without much advance notice.

We suggest that if there is a process for revising a return-to-work date, that process should include an assumption that the leave will continue if the employee requests an extension or renewal of their leave.

Applying for extended carer leave

In relation to type of mechanism for applying for extended carer leave, we support a design as similar as possible to parental leave - because in our experience it is easier to administer employment policies and procedures that have a high level of consistency and congruence for employees, line managers and payroll staff.

This would also make it easier to build a culture of support for these provisions within the organisation. We would not want employees to feel like they have to justify accessing their entitlement or disclose the personal circumstances of themselves or the person they are caring for.

Key findings

- Because current provision and practice is that existing leave entitlements for carers are primarily intended for brief periods - then anything more than three days should be considered 'extended'.
- Extended unpaid carer leave will change the conversation in Australian workplaces and society, in ways similar to the changes we are seeing with parenting leave and accessibility. It will raise awareness of carer roles and needs, and make extended unpaid carer leave a normal part of the everyday workplace.
- An understanding that extended unpaid carer leave applies to every employee and can be used flexibly for different durations of time, would build a workplace culture that the entitlement applies commonly to most employees over time rather than being an extraordinary or exceptional occurrence for a few.
- We support multiple periods of leave, because many of the circumstances requiring additional levels of care are episodic by nature. We support a flexible length of leave.
- We support a mechanism for applying for extended carer leave as similar as possible to parental leave - giving a high level of consistency and congruence for employees, line managers and payroll staff.

Recommendations

4. Any change of entitlement be designed to bridge the gap between current short-term provisions and any new entitlement.
5. Any change provide for multiple periods of leave.
6. The mechanism for applying be as similar as possible to parental leave, and explicitly state that employees do not have to justify accessing their entitlement or disclose the personal circumstances of themselves or the person they are caring for.



Maximum employer coverage

As advocates for carers, we support maximum possible employer coverage.

Carers we are connected with work in all types of employment in all types of industries and businesses across Queensland. We can see no correlation between the type of industry or business and the likelihood of a carer being present, or the needs of that carer.

But we also concede that we do not know enough about other employers who will have different capacities to manage extended staff-absences - possibly depending on the size of their business and the industry they operate in, among other things. We concede that there may be a rationale for allowing some types of employers or industries to be excluded from the entitlement.

The opposite of this is that we and other carer organisations may be able to provide a 'vanguard of innovation' - championing carer-friendly workplace culture, policy, and practice. It would be nice if these efforts were given some recognition and encouragement by bodies interested in promoting good workplace relations.

Key findings

Carers work in all types of employment in all types of industries and businesses. We can see no correlation between the type of industry or business and the likelihood of a carer being present, or the needs of that carer.

Recommendations

7. Any change to entitlement apply across all types of industries.
8. The Commission should consider the feasibility of implementing the entitlement in very small workforces, but it should apply to all sizes of businesses.[Cite your source here.]

8. Distributional effects and communitywide benefits

We note that the *Carer Leave Issues Paper* asks for our views on redistributive effects and communitywide benefits of the proposed entitlement.

Distributional effects

We understand the Commission's concern that "Historically, women have borne the majority of the care load and anything that encourages greater informal care without any other consideration, is likely to compound this historical burden."

We urge the Commission to take into account the other following considerations that we believe will help prevent this compounding effect.

We believe that a universal entitlement to extended unpaid carer leave would confer a significant net community-wide benefit. Making the entitlement available to all carers, for all episodes of care, will also have significant redistributive effects including:



- Redistributing resources by spreading the load of the burden of care among carers and across a particular care eco-system.
- Improving carer and care recipient well-being by enabling a wider care network to engage in a more episodic way - in an immediate family, children may be more able to step into a caring role mainly held by their mother or father; in an extended family, more uncles and cousins would 'step up' and 'take their turn'.

A future scenario: universal entitlement maximising communitywide benefits

In writing our response we've found ourselves imagining a future scenario in which in which many people access an entitlement to unpaid carer leave in order to respond to episodic need:

- we are not imagining a devoted solitary stoic carer 'wedded' to their caring task,
- but rather a diverse ecology of caring and carers able to respond fluidly to changing needs,
- matching capabilities of different people for different types of care needed at different times,
- because everyone has an understanding and supportive workplace.

In this scenario we may have a society in which:

- propensity to care is growing, and meeting our national need;
- Australia's informal carers are continuing to provide for their loved ones, and feeling supported to do so;
- employers have a skilled resilient, flexible workforce in which carers contribute to a compassionate workplace culture;
- and the nation values its carers and our government re-invests some of the \$77.9 billion it is saving into supporting them in their important social, economic and health role and responsibilities.

We are daring to imagine a future in which caring is a much more joyful experience. We wonder if these are the kind of communitywide benefits the Commission is charged with achieving?

Key comments: Distributional effects and communitywide benefits

A universal entitlement to extended unpaid carer leave would maximise redistributive effects and communitywide benefits.

We are daring to imagine a future in which a diverse ecology of caring and carers are willing and able to respond fluidly to changing needs, in the caring eco-systems that they are a part of, because everyone has an understanding and supportive workplace.

And a future where a growing number of employers are willing to innovate to meet changing social needs - and benefiting from a skilled, resilient, flexible workforce in which carers are valued for their attributes and their contribution to compassionate workplace cultures.



Conclusion

Arafmi Ltd appreciates the opportunity to present this submission.

We believe it provides our own unique insights into some of the economic and social costs and benefits of providing extended unpaid leave entitlements to informal carers of older and other Australians.

We have focused on our own particular areas of expertise - carers of people with mental health needs.

We believe we have also taken a wider perspective and made design and other recommendations that we believe would also provide significant communitywide benefits for Australia into the future.



Bibliography

Australian Charities and Not-for-profits Commission, 2022. *Australian Charities Report: 8th Edition*. Australian Charities and Not-for-profits Commission, Canberra.

Centre for Change Governance, University of Canberra 2021. *Caring for yourself and others: The 2021 carer wellbeing survey*. Carers Australia, Canberra.

Deloitte Access Economics, 2020. *The value of informal care in 2020*. Carers Australia, Canberra.

Dominic, S, Heilscher, E, Lee, Y Y, Harris, M, Schess, J, Kealto, J and Whiteford, H. 2017. *The economic value of informal mental health caring in Australia: summary report*. The University of Queensland, Brisbane.

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

Furnival, A. and Cullen, D. 2022. *Caring costs us: The economic impact on lifetime income and retirement savings of informal carers*. Carers Australia, Canberra.

Hutchings, K., Harris, N., McMillan, S., Radford, K., Slattery, M., Spencer, N., and Wheeler, A. 2021. *Young Carers in Australia industry research report*, Griffith University, Brisbane.

Hutchings, K., Harris, N., McMillan, S., Radford, K., Slattery, M., Spencer, N., and Wheeler, A. 2021. *Young Carers Research Final Report*. Griffith University, Brisbane.

Mind Australia, 2016. *A practical guide for working with carers of people with a mental illness*. Mind Australia, Helping Minds, Private Mental Health Consumer Carer Network (Australia), Mental Health Carers Arafmi Australia and Mental Health Australia.

Pirkis, J, Burgess, P, Hardy, J, Harris, M, Slade, T and Johnston, A, 2010. 'Who cares? A profile of people who care for relatives with a mental disorder', *Australian and New Zealand Journal of Psychiatry* 2010: 44, p929–937.

Productivity Commission 2020. *Mental Health, Report no. 95*. Canberra.

Productivity Commission 2022. *Carer leave: Issues paper*. Canberra.

PwC, 2019. *The Benefit of Designing for Everyone*. The Centre for Inclusive Design, Sydney.

PwC Australia, 2021. *2nd Annual Not-for-profit CEO Survey: Upskilling for the digital world and preparing for the future of work*. PwC, Sydney.

PwC, 2021. *Return On Action Report 2021: The rising responsibility of business*. Atlassian, Sydney.

Social Ventures Australia and the Centre for Social Impact, 2020. *Taken for granted? Charities' role in our economic recovery*. Social Ventures Australia, Sydney.