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)

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Submitted to:

Carer Leave
Productivity Commission
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Introduction

Lived Experience Australia is a national representative organisation for Australian mental health consumers and carers, formed in 2002 with a focus on the private sector. Our core business is to advocate for systemic change to improve mental health care across the whole Australian health system. This includes input to important initiatives within state and territory jurisdictions, from time to time, as they relate to mental health communities. This includes advocating for empowerment of consumers in their own care, promoting engagement and inclusion of consumers and carers within system design, planning and evaluation and most importantly, advocating for consumer choice and family and carer inclusion and wellbeing.

Our Submission comes from the perspectives and experiences of people with lived experience of mental health issues, their families, and carers. We welcome the opportunity to provide our comments to the Productivity Commission.

Feedback on Carer Leave Issues Paper

We wish to stress that family members and close friends who provide informal (unpaid) care and support are a critical part of Australia's aged care system, but also the Australian care system, more broadly. They substitute formal care, fill significant gaps in failing systems of formal care, and can delay the need for formal care and placement in institutional care. Informal caregiving is associated with lower labour force participation, with informal carers being more likely to be in part-time employment than non-carers, and primary carers who provide more than 60 hours of care per week being much less likely to be in the labour force than other primary carers. We understand that informal caregiving is associated with poorer mental health and wellbeing; being 2.5 times more likely to report low wellbeing than the average Australian adult and twice as likely to report having poor health.

Current arrangements fail to adequately support informal carers. We therefore appreciate the Royal Commission recognising informal carers' integral role and its emphasis on them as a key priority.
We also appreciate the opportunity to provide our comments to the Productivity Commission on the economic and social costs and benefits of providing an extended unpaid leave entitlement to informal carers of older Australians under the National Employment Standards (NES). We understand that this entitlement could increase the amount of care provided, the quality of care, and support to carers by granting a right to return to work after extended leave caring. Whilst we applaud these goals, we also wish to make comments concerning the potential distributional effects on the welfare of informal carers.
We acknowledge that the Terms of Reference are focused on carers of older people and appreciated the opportunity to also make comment on leave arrangement for other types of care, such as caring for people with disability or mental health challenge.

The Productivity Commission Issues Paper notes that the ABS Survey of Disability, Ageing and Carers estimates that were 2.6 million informal carers in Australia in 2018, including 862,000 primary carers, with nearly half of these (428,000) being primary carers of older people. Given that we know almost half of all people in Australia will development a mental health condition during their lifetime, we also wish to stress that informal care for mental health is likely a significant feature of this population, alongside the informal care of physical health needs.

We also acknowledge the Issues Paper highlighting that most primary carers of older people are women (70%), with 47% of primary carers of older people being their children, and 43% their spouses. Of significant concern, more than half (55%) are aged under 65 i.e., predominantly impacting women who are in the prime of their working life.

We are equally concerned that the Issues Paper states that 35% of carers report that 'no other friends or family were available' to provide care and 16% report they 'had no other choice' but to become a carer. We

have heard from mental health carers across Australia over many years that issues of stigma, isolation, marginalisation, and systems of care that continue to exclude informal carers, contribute significantly to this situation.

The existing leave entitlements for carers are primarily intended for brief periods of care to deal with an illness or unexpected event or emergency. However, we know that informal carers struggle to balance their work and caring responsibilities. We provide insights in these challenges below, from a carer lived experience perspective.

Effects of an entitlement to extended unpaid carer leave

Whilst the entitlement to extended unpaid carer leave might relieve some of the impacts that informal carers experience, we also urge the Productivity Commission to consider the potential for unintended consequences.

The nature of providing informal care to a person with severe mental health challenges means that the current leave arrangements are quite inadequate and the proposed extended leave arrangements may not match their needs either. This is because they do not reflect the ongoing daily role played by informal carers which capture them within a liminal world (and 'in-between' conundrum) in which going to work renders them less able to respond to regular situational fluctuations in the person's needs, with the outcome often being increased burden as they struggle to maintain that employment whilst attempting to juggle their carer responsibilities during their working day, and once they leave work. The other component of this liminality is that leaving work completely and staying home with the person may not match their need or be in proportion to what is needed either. We note the Royal Commission into Aged Care Quality and Safety's acknowledgement that more informal care (alongside more home-based formal care) would support more people to live at home. That is, both forms of care are needed.

To give an example:

> *Mrs X is 60 years old and has cared for her husband who has schizophrenia for the past 25 years. She is tired and has made several sacrifices in her career during that time, foregoing promotion, travel for work, and so forth. It is hard work and tiring juggling her busy career and the 40 plus hours per week of hands-on support that she provides to Mr X. Mrs X has contemplated many times whether to give up work and stay home. The nature of her husband's condition is that he sleeps much of the day and even being present to 'walk alongside him' to prompt him to do more doesn't necessarily work. Otherwise, he sits and smokes or is largely preoccupied with his delusions. He becomes overwhelmed with too much stimulation and so leads a very quiet life with few social contacts. When Mrs X has had extended periods of time with him at home, he has expected her to 'do everything', more so that he already does. At least by Mr X going to work, Mr X is prompted to do some basic tasks for himself. Mrs X loves her work and it is also her 'respite' from the poor quality of life that she experiences as part of her caring role at home. She is determined to remain working because the alternative is watching her husband sleep. His only other support is 4 hours pers week of NDIS support and regular contact with his GP, and an occasional appointment with a psychiatrist. Equally, Mr X's mental health fluctuates, and this is unpredictable; there is no finite start of end point; it's just the way it is. The times when he has been admitted to hospital have again served to give Mrs X a rest and an opportunity to catch up on her work. Extended unpaid carer leave would not offer any tangible benefit to Mrs X or her husband. It would likely add unintended burden for her and disruption to her and her husband when she did eventually return to work. What Mrs X needs is more formal support for Mr X at home and in the community until she is ready to retire from work.*

It has been our experience and that of the many mental health informal carers we represent that, when informal carers fill the gaps in care systems, those very systems and support providers tend to step back or step out of their responsibilities for providing care completely. We have heard this occur for many people

who have gone on to receive NDIS packages, for example, with clinical mental health services then stepping out and discharging the person to a GP or to no formal clinical alternative source of coordination of care support at all. This has left informal carers as the primary navigator and responsible person supporting the individual. It has contributed to a crisis-driven system which has left many informal carers and those they care for few options other than to present to emergency departments in crisis, merely to prove the need for support to get back into 'the system', to have the merry-go-round start all over again. This occurs regardless of the age of informal carers or their employment status.

Distributional effects within families and society

As stated in the Issue Paper, "there is gendered dynamic to the carer-to-care-recipient redistribution. 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. This would be further reinforced by and consistent with economic decisions that impose the care task on the person in a household with the lowest income, often a woman. The decision to care can have large effects on someone's income, superannuation and savings, and ultimately their total wealth.

We are concerned that the entitlement will lead to different distributional impacts for employers and employees and for carers and care recipients. Leaving one's career or occupation for an extended period, with the assumption of being able to return when able, is not necessarily straightforward. Depending on the role, this can create significant disruption to employers, to supervisory arrangements, workflow and so forth. Technological advances within workplaces and other forms of change are a perpetual feature of most workplaces, and this can have adverse impacts on those who leave for extended periods, only to have to be retrained or to catch up with new technologies when they return to work. We have seen this when women leave work to have children then struggle to return to former careers with skillsets that may have become redundant whilst they were away from the workplace. This is a cost to the person but also to employers.

The other significant concern is the disproportionate number of women who make up informal carers and the potential for extended unpaid leave to reduce their superannuation, and their career advancement and therefore their salaries in comparison with their male counterparts. This has the potential to perpetuate an already concerning structural inequity in the workforce and in society. It then also means that the care recipient is more likely to be supported by others on lower incomes which then places them also at a socio-economic disadvantage. However, care recipients may represent some of the most socially and economically disadvantaged people in our community already. Design considerations and their implications

Alternative policies to support informal carers of older people

In addition to leave and flexible work arrangements, the main forms of support for carers are financial assistance through the Carer Payment, Carer Allowance and Carer Supplement. They also value practical supports such as support with housework, transport, and occasional social connection and respite.
We know that many young people provide care to a parent, even though they may still be attending school, that many informal carers in some sub-populations may not identify themselves as informal carers. This may be cultural or contextual; many spouses, for example, do not regard themselves of 'carers'.

There are many challenges faced by older carers, and other informal carers, to access the support they need. These include lack of providers or diversity of providers, especially in rural areas. Quality of support provision is also problematic, including issues with skill levels, adequate supervision and accountability. Sometimes, basic support like receiving 2 hours of house-cleaning support can in reality be a 'quick flying visit' of 1 hour which leaves the informal carer picking up the workload anyway. We know of informal carers who put up with poor support service for a full range of reasons including not wanting to cause trouble, get people into trouble, fear of losing

the support altogether, fear of reprisal if they complain, and so forth.

Alternative supports for informal carers

Other forms of support for carers who remain in the workforce that could be considered are in-home support for the care recipient if the carer needs to travel for their work. Any respite care needs to be flexible, responsive and accessible, not take weeks to set up and require excessive paperwork and processes to establish. Working carers have enough administrative burdens on their time, often juggling work, multiple medical and other appointments for the person, and undertaken all administrative tasks for themselves for the household, other family members if they have children at home, and the person.

Whilst respite care is known to be useful, it is not surprising to find that 87%t of primary carers of older Australians had never used respite care. They are busy pragmatic people juggling many responsibilities, and they will not seek out or use processes that create more work or don't align with tangible benefits to them or the person they care for.

Extensions to carers other than carers of older people

We believe that different types of carers have sufficiently different needs to warrant different types of supports. Our comments above, including the case scenario given of Mrs X, demonstrates the nature of some of this difference as it relates to informal carers of people with enduring or episodic mental illness.

Contact

We thank the Productivity Commission for the work that has gone into the development of this Issues Paper and wish you every success with the next steps in its development. We would be keen to discuss further, any clarification or issues raised with you.

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