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The Draft National Carer Strategy

Submitted via Email to:

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For:

The National Carer Strategy Advisory Committee
Department of Social Services, Australian Government

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Introduction

Lived Experience Australia Ltd (LEA) is a national representative organisation for Australian mental health consumers and carers, families and kin, formed in 2002. Our 'friends' include approximately 9000 people with lived experience of mental health concerns across Australia. This includes lived experiences with all parts of the mental health care system, NDIS, psychosocial disability support outside the NDIS, public and private service options, and service provision across urban, regional, rural and remote Australia. All members of our Board and staff have mental health lived experience as either a consumer, family/carer/kin/supporter, or both.

Lived Experience is core to our advocacy, recognising that the impacts of policy and practice are felt not only by individuals, but also by families and whole communities. Our core business is to advocate for effective policies and systemic change to improve mental health care and psychosocial disability support services and support across the lifespan, across the whole Australian health and social care system, including within State and Territory jurisdictions.

We welcome the opportunity to provide our feedback to this crucially important issue for families, kin and other unpaid caregivers and supporters of people with mental health challenges and psychosocial disability in the Australian community.

Purpose of this Consultation

In April 2024, Minister Rishworth appointed a lived experience Carer Advisory Committee to guide and work alongside the Australian Government to oversee the development of the National Carer Strategy. This was to ensure the views, perspectives, collective experiences and aspirations of all carers were reflected in the final Strategy. Public consultation on a draft National Carer Strategy commenced in August 2024, with submissions closed on 13th September. Then on 16 October (only one month later), the Draft National Carer Strategy was released for consultation, providing only two and a half weeks for feedback.

Our Response to the Consultation

In Summary

We acknowledge and appreciate the work undertaken to develop this Draft Carer Strategy and the many positive proposed actions that are proposed within it.

Whilst we value the opportunity to respond to this consultation, we wish to highlight 4 key concerns that we have about the Draft Strategy:

1. **The Consultation Process:** We are deeply concerned about the process that the Department of Social Services has followed, particularly as they relate to the timeframes in which the consultations have occurred.
2. **Mental Health Carers Invisible:** There appears to be no identification of mental health carers as a significant group.
3. **Systems not Addressed/Carer Sacrifice Assumed:** There is very little here about the systems that largely fail to deliver on their responsibilities. This significant unmet need is largely borne by family, carers and kin.
4. **Carer Literacy Assumptions:** Worse still, there seems to be a focus on 'training' carers to do this carer task better, based on some assumption that they just need more information and skills to do this 'job' better.

Our Detailed Comments on these 4 key Concerns

1. The Consultation Process

As stated earlier, public consultation on a draft National Carer Strategy commenced in August 2024, with submissions closed on 13th September. Then on 16 October (only one month later), the Draft National Carer Strategy was released for consultation, providing only two and a half weeks for feedback. With only 1 month between the 2 processes, and our understanding that you received over 750 submissions to the initial inquiry, it is hard to see how these submissions were considered properly AND a Draft Strategy then formulated based on the key issues raised by the submissions. We are concerned that the inquiry was a token process, with already prepared Draft Strategy. The short timeframe for feedback on the Draft Strategy also suggests that you wish to limit feedback to those who are able to meet this very short deadline. You are essentially asking this of carers who are already stretched and tired and who have limited time to spare.

2. Mental Health Carers Invisible

Whilst the Draft Strategy lists a priority outcome area as 'Carers have access to supports that safeguard their psychological, physical and social wellbeing' (p.27), a significant disappointment is that there is nowhere in the draft that identifies mental health carers, despite them being a sizable proportion of overall carers. The SNAPSHOT section at the back of the Draft Strategy, would seem an obvious place to say something more meaningful about mental health carers. Other focus carer cohorts are mentioned there. For example, defence families and veterans' carers, noting the very nature of service meaning this group of care recipients are more likely to develop physical and mental health conditions. We argue that mental health carers already experience the impacts of caring for family with significant physical and mental health conditions. The evidence on earlier deaths and earlier morbidity and disability is well-established for people with mental health conditions.¹ There are multiple social, physical, psychological/emotional and financial impacts for mental health carers.

The comments about safety, behaviours, symptoms, suicide attempts, and family violence (not mentioning mental health carers but perhaps implying their experiences) are dominant themes listed. Whilst, these issues are certainly relevant, they reinforce a focus on risk which is problematic for mental health carers, and which can reinforce the very psychological distress that this part of the Draft aims to mitigate.

The Draft's suggested mitigating strategies (What we will do) include improving responsiveness of carer services and improve services for carer's social participation; measures that are band-aids which do not alter the causes of their potential psychological distress. Again, the Draft suggests 'training' carers to improve their wellbeing.

3. Systems not Addressed/Carer Sacrifice Assumed

Similar to the initial discussion paper, our feedback then and now remains that the process and resultant Draft Strategy is limiting in its scope and understanding. It speaks generally to the issues and impacts of caring for carers, using largely placating language, whilst leaving untouched the structures that maintain this limited view of carers as 'task providers' who will simply just keep doing what they do.

Without informal carers support, there would be enormous financial costs to the health and welfare systems, and enormous costs to the community. The Draft Strategy makes no mention of the financial implications for systems and the default use of carers. Instead, there are a range of 'soft' words in the early pages of this Draft which reinforce the status quo assumption that carers will just keep picking up the tab. Adverse impacts on carers are just assumed, with any proposed actions merely offered to try to mitigate

¹ Roberts, R., Wong, A., Lawrence, D., **Lawn, S.**, and Johnson, C. (2024). Summary Report: Mortality of people using Australian Government-funded mental health services and prescription medications: Analysis of 2016 Census, death registry, MBS and PBS data. Charles Sturt University, Bathurst, ISBN 978-1-86-467447-7.

these impacts, rather than eliminate them. Again, the overall tone of the Draft Strategy seems to be to placate carers, but essentially take them for granted:

'With ingenuity and resilience, carers keep Australia going.'

[In reference to young carers, lifelong ageing carers, and carers sandwiched between generations]
'Such shortfalls are not ours as carers, but ours as a nation.'

'Australia's 3 million unpaid carers play a vital role in society, delivering significant social and economic benefits to individuals, their families and the broader community. They play an integral role in the nation's health and social care systems, offering critical, unrecognised contributions.'

As we stated in our earlier submission, service failures and pernicious assumptions about the carer role that can, in some circumstances, cause harm to carers. A recent published research paper on Moral Distress and families/carers for veterans and first responders with mental health issues describes issues of relevance to mental health carers generally. It describes how families are performing the moral behaviour of taking responsibility in lieu of the organizations and systems that are failing to meet their obligations and responsibility to community members with significant mental health issues.

"Poor organizational responses that many families perceive when attempting to navigate help-seeking, [mean] they can be caught in a liminal space in which they can see the problem, and grasp potential support solutions, but have nowhere to go to realize those supports for family members. ...and the role of institutions and systems, which highlighted individuals "being given no alternative," ...and family/carers' experiences of being shut out and excluded from decisions, despite their efforts... organizations hold significant responsibility for creating moral distress for family/carers." ²

The participants in that research provided rich descriptions of how they directly and indirectly bore the consequences of organizational failures through the reluctance of the family member to seek help, and the distress and trauma it created for the family. These consequences were largely portrayed, and arguably masked, in mental health family 'carer burden' concepts and understandings of carer experiences. "The problem is therefore seen and situated only within interpersonal relationships. Organizational responses to families (or lack of) are rarely examined as contributing to that distress."²

4. Carer Literacy Assumptions

As stated earlier, there seems to be a focus on 'training' carers to do this carer 'task' better, based on some assumption that they just need more information and skills to do this 'job' better. One priority outcome area (p.25) even states that they may want 'mental health training'. This sounds like a very 'clinical' response that could have been worded better to reflect the family context and complexity in which they find themselves in a caring role.

As stated in our earlier submission, our lived experience is that "Carers already have many skills; they have to in order to survive in their daily life. Being shut out of services, but ironically still being called on to step in when life goes haywire for the person, is a common theme we hear from carers. Skills in getting services to actually listen and include them, rather than merely pay lip service, may be an option; many carers are pushed to advocacy because of the barriers they experience with services. Skills in how to navigate the complex and tricky space of honouring confidentiality and privacy for the person may be of some use, for carers and for service providers."

Also, as stated in the earlier submission, "Suggestions like self-care for carers are too simplistic and can be viewed as patronising, especially as they often don't match the reality of living with being a mental health carer. E.g. "It's virtually impossible for me to look after my sleep when the person I care for is up and down at all hours, disrupting the whole household with responding to voices or generally moving about and potentially getting into activities like drinking, smoking far too much, falling over, driving without a licence

² Lawn, S., Waddell, E., Rijkers, W., Roberts, L., Beks, T., Lawrence, D., Rioseco, P., Sharp, T., Wadham, B., Daraganova, G., Van Hooff, M. (2024) Families' experiences of moral distress as a consequence of supporting Australian military Veterans and public safety personnel to seek help for a mental health problem: a conceptual model Journal of Military and Veteran Family Health (JMVFH). 30(6): e4522–e4534. doi: [10.1111/hsc.13856](https://doi.org/10.1111/hsc.13856)

to get yet more Pepsi from the petrol station, etc and more things than that I need to fix the next day...and no mental health support to be seen. This is the reality.”

Other Comments

Many strategies listed in the Draft Strategy, designed to address the priority outcome areas in focus, place significant weight on carers gaining knowledge and awareness in how to access services and supports. However, as stated in our earlier submission, the Carer Gateway continues to be a major challenge to access and navigate for many mental health carers. It's either not accessed because some carers are not 'digital natives', don't have easy internet access, the site is complex and not user friendly to get to the information that you need to find there, and things like respite options are impractical, not responsive and don't reflect the reality of the circumstances in which carers and the person they care for live. Respite is not just a service that can be 'plugged in' to perform tasks; to take this approach makes the same false assumptions that are levelled at carers. For a person with severe mental ill-health, trust and nuance are essential, and are very relational, fluid and ongoing.” Many of the services and supports available simply do not meet the support needs of mental health carers.

Contact

We thank the Department of Social Services and the Carer Advisory Committee for their work, and for the opportunity to put our views forward. We wish you well with the next steps and would be pleased to contribute our lived experience perspectives to any future discussions about this important topic.

Your sincerely

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