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The National Carer Strategy

Submitted Online to:

Engage.dss.gov.au

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.

All members of our Board and staff have mental health lived experience as either a consumer, family/carer/kin/supporter, or both. 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.

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 supporter 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.

The Carer Advisory Committee want to hear from all carers, including those from diverse backgrounds to ensure the Strategy is responsive to the needs of carers and provide outcomes that will better support all Australia’s unpaid carers. A Discussion Paper accompanying this consultation is intended to outline issues that the Department of Social Services is aware of as being important for carers. It is meant to prompt discussion not necessarily to identify all relevant issues or ways to address them. This Discussion Paper is not government policy; however, it will shape the way the Commonwealth Government understands what the Australian community wants for carers and what the government should prioritise to drive better outcomes for all carers.

Key issues that carers and stakeholders have identified, according to the Discussion paper, are:

- There is a need for more emphasis on addressing the holistic needs of unpaid carers.
- There is a need to better integrate formal and informal caring to improve outcomes for care recipients for example, carers want to be recognised for the expertise they are able to contribute to better understanding the needs and preferences of their care recipient.
- The unique experiences and challenges of First Nations carers and other diverse communities requires culturally safe and tailored services and support. It is essential to include the perspectives and voices of First Nations people and other diverse communities in the development of policies, programs and supports so as to better understand and meet their unique needs.
- There is a need for localised care models and services, designed in collaboration with carer communities, including physical and mental health, financial wellbeing and access to respite care.
- Simplification and streamlining of administrative barriers would assist carers to better navigate the systems they are required to access to fulfil their roles.

Our Response to the Consultation Questions:

We value the opportunity to respond to this consultation. However, upfront, we wish to say that we found the discussion paper limiting in its scope and understanding, and disappointing in merely repeating issues that are largely surface one that have been repeated over and over 'about' carers, whilst leaving the structures that maintain this limited view of carers as 'task providers' to the systems that largely fail to address the unmet needs of the family and kin that informal carers support, and without whose support there would be enormous financial costs to the health and welfare systems, and enormous costs to the community. Please do not merely repeat a process that arrives at the same result, with little real change for carers. For this reason, we have responded to some of the consultation questions, but not others.

1**. What principles do you think should be in a National Carer Strategy?**

We feel strongly that the following should be core principles because they are foundational to addressing and shifting the structures assumptions that keep positioning carers as default workforce to fill gaps in service systems, unpaid labour and with no right to a life of their own.

- **Human Rights** (please see Appendix 1: Joint statement of rights for Australian families, carers and supporters in mental health)
- **Gender equity**
- **The Rights of the Child**

2. **What does your caring role involve or look like for you? a. Are you a Primary Carer? And do you have secondary assistance, such as extended family also providing some care support?**

Mental health carers have been consulted over and over again about what their role involves as carers, for several decades now. It is therefore difficult to understand why you and others continue to ask this question. Carers have repeatedly recounted their experiences in the hope that there will be more support for the person they support, and for themselves. There have been multiple reports, policies and models of care over many years that have continued to describe carer concerns, and the importance of including them in the Triangle of Care, with little real change evident. Most perpetuate structures and a narrative that is only about appeasing carers and 'putting a band-aid' on so that they can be thrown back into filling all the roles and gaps that are left by systems that fail to step up to support people with severe mental ill-health.

3**. What additional supports and/or skills do you need or would like to develop to assist or support you in your caring role?**

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.

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

4. Do you know what services are available to support you in your caring role? a. Do you know how to find and access carer supports? b. Have you used any carer supports or services in the past?

YES. Though, 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.

5**. If you have accessed these services, what has worked for you or where have you experienced challenges?**

As above. Respite as a concept and a practical action.

Amount of psychosocial support is very limited and, for some, non-existent. This unmet need is central to adversely impacting the quality of life of carers.

Services don't communicate with other very well, which leaves the person (where they can) and the carer being the holders of accurate knowledge, and often finding themselves correcting inaccurate information held by services eg. social circumstances, preferences and needs, current medications and treatments, diagnosis, other health conditions, allergies, and so forth.

Casualised paid support workforce is problematic and impersonal. People need consistent and reliable support, when it is available; it builds workers' skills in 'knowing' the person in the way that the family carer knows them too, and it alleviates token or misguided responses and attempts by workers to help.

6**. We are aware that some carers feel they cannot leave their loved one with others due to the complexity of the care required. What has prevented you from accessing respite and what additional support might relieve your hesitancy to access respite in the future?**

As per above. Also, a more pre-planned and staged approach (and commensurate resourcing) upfront that gives the opportunity for respite under these circumstances to even be considered possible, would be useful.

7. **What do appropriate alternative care arrangements look like for you?**

Providers who provide consistent, quality holistic care and support to the person, that treats them with dignity and respect, provides a fulfilling environment where supported decision-making and choice is maximised.

They need to be underpinned by values and implementation that maximises autonomy and minimises institutional impacts.

8. **What carer-inclusive practices could benefit your workplace or education institution?**

More flexible work and leave arrangements.

9. **What types of assistance are available to you in your education setting, or in the workplace that you find helpful?**

Flexibility to work from home, without undue scrutiny.

10. **How can we best support carers to stay in or re-enter the workforce or education system?**

We have already provided a written detailed submission and presented to the House of Representatives Standing Committee on Social Policy and Legal Affairs inquiry on 'Recognition of Unpaid Carers' and implications for employment. Please refer to the Hansard on submissions to that Inquiry and to the many submissions made.[1]

11. **What are the top three challenges you face as a carer?**

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[1] https://www.livedexperienceaustralia.com.au/_files/ugd/07109d_71d5e29dd7b346c297fdfd60c85abda3.pdf

1. Fundamental impact of the caring role on quality of life of carers which are inescapable because of the nature of their situation and the limits of the formal care systems to respond. A recent project on Mental Health Carer Human Rights which was led by TANDEM in collaboration with Lived Experience Australia and others, spoke to carers basic rights to financial security and housing, relationships and community connection, health and wellbeing, safety, identity beyond the carer positioning, and so forth (Please see Appendix 1).
2. 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 inter-personal relationships. Organizational responses to families (or lack of) are rarely examined as contributing to that distress."[2]

3. The Carer Payment is not enough to live on for those carers who cannot work or prioritise not working in paid employment in order to care for the person. We note that, during the COVID-19 pandemic, this payment was not considered to need any adjustment or increase (even temporarily). This reflected inequity in how carers were regarded during that time. For many carers, the responsibilities inherent in their roles significantly increased and altered in impacts during that time, and in the aftermath with long-COVID and other felt impacts. Please refer to the national award-winning project led by the National Mental Health Consumer Carer Forum, in which Lived Experience Australia was a collaborating organisation through our membership of the Forum and of the project working group.[3]

12. **What do you consider are the biggest opportunities to improve the lives of carers and the people they are supporting?**

Provide more tangible support, in situ/where people live in their communities.

13. **Have you accessed peer supports? What did you find beneficial, or can you identify areas for improvement?**

There is significant evidence for the effectiveness of peer support. We recently undertook an international scoping review for the Department of Health. It included the past 20 years of evidence for peer support across various mental health contexts and parts of the mental health system. The broad outcomes were that there is clear evidence for the benefits of this role. There

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[2] Lawn, S., Waddell, E., Rikkers, 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

[3] https://nmhccf.org.au/our-work/discussion-papers/report-mental-health-family-carer-experiences-of-covid-19-in-australia

continue to be significant challenges that can undermine these benefits. These included: service cultural issues and peer integration; adequate and quality supervision and training to ensure peers work to their scope and values of peer role; sufficient resourcing of lived experience/senior peer supervisor roles; casualisation of peer workforce and retention issues, and so forth. Evidence available for the value of carer peer roles is extremely limited – ironically, there is 'invisibility' in the evidence, similar to the invisibility that carers consistently report. More understanding of the carer peer role by services and the community is needed. **Please contact us for more information on the review and contacts within the Department of Health, if needed.**

14. **How would you like to see your experiences reflected in the Strategy.**

We would like to see the National Carer Strategy have the courage to not simply repeat the rhetoric of the past.

15**. If you belong to a diverse group, what opportunities do you see for the Strategy to improve access to supports and information in your community? (For example, have you identified a gap or challenge in receiving support and/or information for your particular diverse community and what could Government consider improving the issue).**

16. **What are some priorities that might assist or improve the experience of carers within your community?**

17. **Do you have any views on how the assessment process for carer payments in the social security system is working?**

    a. **Are there any ways we could make it easier for carers to demonstrate they are eligible for a payment?**

    b. **What barriers have you experienced in demonstrating your eligibility for a payment that we should be aware of?**

18. **Have you ever required emergency assistance or emergency support/s in your capacity as a carer?**

    a. **Did you experience any barriers to accessing these emergency support/s due to your role as a carer?**

    b. **Did the emergency support/s meet your and your care recipients' needs adequately (for example, was there wheelchair access to emergency evacuation points; access quiet spaces for neurodiverse people?**

    c. **Would you like to share your experience?**

19. **Is there anything else you would like to tell us?**

Thank you for the opportunity. We really hope that this National Carer Strategy leads to strategies for meaningful improvement in the lives of mental health and other unpaid carers. One thing that carers are very good at is maintaining hope! It's imperative for our own mental health and wellbeing, though challenging.

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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A joint statement of rights for Australian families, carers and supporters in mental health

Why mental health families, carers and supporters need their rights enacted:

Australian families, carers and supporters of people living with mental illness, distress or psychosocial anguish, urgently need their citizen and human rights enshrined in Commonwealth, state and territory legislations and charters.[1] Current carer legislation, while valuable in acknowledging challenges this community face, falls short in providing legally enforceable rights or imposing obligatory duties on public entities and services.[2]

Evidence shows that mental health families, carers and supporters experience serious human rights violations.[3] Their rights are denied through neglect and insufficient social policies that place significant demands on them, compounded by inadequate systemic support. This leads to widespread social disadvantage that amounts to breaches of fundamental human rights, as recognised under international law, including the Universal Declaration of Human Rights (UDHR)[4], Convention on the Rights of the Child[5], the International Covenant on Economic, Social and Cultural Rights[6], and the Convention on the Elimination of All Forms of Discrimination against Women[7], which Australia is a signatory.

More than ninety mental health families, carers and supporters, and allies came together to discuss experiences of rights violations and to identify urgent actions required to uphold the collective rights of this community.[5]

This rights statement is the product of this discussion.

> "The way mental health families and carers are exploited by the system is a justice issue."
> – Discussion participant

> "I want to feel safe and secure and have the opportunity or the space to develop, play and grow securely, and live free from fear and guilt."
> -Young participant

Call to action:

Collectively, we call for our rights to be enshrined in Australian legislation and reflected in the policies, practices and reform processes of mental health services and public entities across Australia.

With our rights clearly articulated, together, we can create a fairer, more compassionate system that recognises and upholds the rights of mental health families, carers and supporters in the Australian mental health system, in workplaces, and across society. We call on our community of families, carers and supporters, our allies, and policymakers to join us as partners and support immediate action on these rights.

Take action today:

- Pledge your support at change.org at https://chng.it/Y8kLGYnrFX
- Share this statement with your own organisation, networks and connections
- Write to or meet with ministers or local members

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[1] Knight, K. and Davy, L. (2019) Claiming rights: the future for carers and the need for a radical imagining , International Journal of Care and Caring, 3(3): 453 458, DOI: 10.1332/239788219X15597493546643

[2] Arafmi (2024), Submission to the Independent Review of the Human Rights Act 2019, 21 June 2024 , Review of Queensland's Human Rights Act 2019.

[3] Katterl, S., Lambert, C., MacBean, C., Grey, F., Downes, L., Cataldo, M., et al (2023) Not Before Time: Lived Experience-Led Justice and Repair, www.livedexperiencejustice.au/; Productivity Commission (2020). Mental Health Inquiry Report (No. 95). Commonwealth of Australia. p873-875;

[4] Universal Declaration of Human Rights, G.A. Res. 217A (III), U.N. Doc A/810 at 71 (1948), Articles 1, 2, 22, and 25.

[5] Convention on the Rights of the Child, opened for signature 20 November 1989, 1577 UNTS 3 (CRoC).

[6] UN General Assembly, International Covenant on Economic, Social and Cultural Rights, 16 December 1966, United Nations, Treaty Series, vol. 993.

[7] UN General Assembly Convention on the Elimination of All Forms of Discrimination against Women , adopted in 1979 by the UN. General Assembly

[8] Workshop facilitated at the Mental Health Services Conference, 15 August 2023, Adelaide: TheMHS Conference 2023 Program - Carer Forum Session 2: Collective Rights (eventsair.com)

Mental health families, carers and supporters have the right to:

1

Rights recognition in legislation

Effective legislation recognises and upholds our rights as mental health families, caregivers, and supporters, with clear accountability mechanisms to safeguard these rights across all levels of government and service provision.

2

Respect, dignity and freedom from discrimination

A life free from stigma and discrimination within the health system, workplaces, and throughout society.

3

Financial security and housing

Financial security means flexible work opportunities that balance work and caring responsibilities. It is also the provision of accessible and liveable carer payments, superannuation and stable and long-term housing.

4

Safety

A life free from fear with protection from harm, abuse, and violence. This includes the right to privacy, confidentiality, personal safety, a secure home, and comprehensive safety plans. The right to not suffer harm and subsequent trauma.

5

Relationships, social connection and community

Support for our relationships, including diverse family models, and to a sense of belonging within our communities.

6

Opportunity, freedom and choice

To carry out activities based on our own needs and desires, and the freedom to say 'no' without facing consequences like homelessness or loss of life.

7

Health and wellbeing

Physical and psychological health, and the support needed to achieve associated feelings of contentment, happiness and overall wellness.

8

Identity

Being seen as a person that has an identity beyond our caregiving role. Families, carers and supporters have multiple identities encompassing our personal, familial, cultural, and consumer identities.

> "Carers actually have multiple roles, identities and relationships with others. But the 'carer' identity seems to be all that is seen or acknowledged. It serves to keep a person in a limited gaze."
> – Discussion participant

> "Financial insecurity is becoming intergenerational for mental health families and carers"
> – Discussion participant

Mental health families, caregivers, and supporters also identified the importance of the right to enjoyment of life, self-care, and comprehensive support. They emphasised the need for access to information, inclusion in decision-making, recognition of their experience and expertise, and the ability to set boundaries. The group further underscored the right to childhood and education, trauma-informed care, and meaningful participation in advocacy and system design.

This statement was prepared by a group of mental health family carers from the following organisations:

tandem · Lived Experience AUSTRALIA · mental health families & friends TASMANIA · Flinders University · MONASH University · RMIT UNIVERSITY