



Inquiry into the Recognition of Unpaid Carers

11th August 2023

Submitted to:

The House of Representatives Standing Committee on Social Policy and Legal Affairs

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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 with a focus on the private sector. All members of our Board and staff have mental health lived experience as either a consumer, family carer or both. This 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 systemic change to improve mental health care (including psychosocial disability) across the whole Australian health system, including within State and Territory jurisdictions. This includes advocating for empowerment of people with mental health lived experience (people with mental health conditions and their family, carers and kin) in the broad range of issues that impact their mental and physical health, and their lives more broadly. It includes empowering them in their own care and contact with health and social services, promoting their engagement and inclusion within system design, planning and evaluation and most importantly, advocating for systems that promote choice, inclusion, justice and fairness, and address abuse, violence, exploitation, neglect, stigma, discrimination and prejudice.

Our recent submission to the Parliamentary Joint Committee on Human Rights regarding a National Human Rights Act noted the resounding feedback from unpaid carers that existing mechanisms to protect human rights at both the federal and state and territory levels through the various Acts and Charters are inconsistent, poorly understood and operationalised into real-world practice, and therefore not adequate to protect human rights of individuals or the families that provide informal unpaid care and support to them. Without a federal Act, there is no consistent guide to build truly accountable systems that promote positive rights or provide sufficient mechanisms to protect people when human rights breaches occur. We have heard repeatedly from our consumer and carer friends about experiences of trauma as a consequence of these failures within policy and practice.

Our recent submission to and appearance before the Productivity Commission inquiry into the need for an Extended Unpaid Carer Leave Entitlement likewise stressed the complexities and nuanced needs inherent in the roles that unpaid mental health carers perform, and therefore how any policy changes in this area require consideration of the diversity of unpaid carer experiences and needs.

We welcome the opportunity to provide our feedback this current House of Representatives Standing Committee on Social Policy and Legal Affairs inquiry into the recognition of unpaid carers. We wish the committee well in its deliberations. We welcome the opportunity to work with the Committee, the federal government, and the sector to ensure unpaid carers across Australia are recognised for their significant roles and contributions.

Purpose of this Inquiry

Lived Experience Australia understands that the Parliamentary House of Representatives Standing Committee on Social Policy and Legal Affairs is tasked by the Minister for Social Services, the Hon Amanda Rishworth MP. to inquire into and report on the provisions and operation of the *Carer Recognition Act 2010* (the Act) in relation to unpaid carers, with a view to reform through legislative amendment. Limited to the Objects of the current Act, the inquiry will have regard to:

- the effectiveness of the Act and the associated Statement of Australia's Carers in raising recognition and awareness of the unpaid caring role, including its obligations on public service agencies

- developments in the policy landscape at a Commonwealth level since the Act's passage in 2010
- the effectiveness of existing state, territory and international recognition of unpaid care (statutory or other practice)
- how to better identify the role of unpaid carers in Australian society and the role of a reformed Act, with regard to:
 - understanding the value of unpaid care,
 - the needs of specific cohorts such as young carers, First Nations carers, LGBTIQ+ carers, or culturally and linguistically diverse carers,
 - the meaningful role that flexible workplaces play in unpaid care, and
 - the Government's broad agenda in relation to the care and support economy, the importance of employment participation, and a strong focus on gender equity, and
- any other related matters, noting that the adequacy of payments for carers is out of scope for this inquiry.

In the conduct of the inquiry, the Committee should consider:

- the views of individual unpaid carers, carers representatives and advocacy organisations, broader representation that relate to unpaid care, not limited to people with disability, women's organisations, family, organisations, and community service providers,
- where possible, the submissions and evidence presented to the Senate Select Committee on Work and Care, in addition to the interim and final reports, including all relevant recommendations to the terms of reference of this inquiry, to reduce duplication.

Our Response

As part of providing this submission, we reached out and heard from 78 mental health family carers who are friends of LEA: two-thirds identified as carers and one third identified as both carers and consumers with lived experience of mental ill-health; 70 identified as women and 9 as men; carers who identifies as either Aboriginal and Torres Strait Islander, CALD, LGBTQI+ or Young Carers were well represented (comprising one-third of those who we heard from).

We asked our LEA carer friends whether they had experienced workplaces that are/were supportive of their carer responsibilities. Of the 76 who shared their experiences, 20 said emphatically that their workplaces were not supportive, 11 had mixed experiences (such as their workplace being supportive, but they were made to feel uncomfortable), and the remainder said their workplace had been supportive.

We also asked our LEA carer friends if they believed that making the Carer Recognition Act legally enforceable would give greater formal recognition of unpaid carers. Of the 76 who shared their views, 62 said emphatically that it would, 11 were unsure, and 3 said it would not lead to greater formal recognition of unpaid carers.

In responding to the consultation questions, we have included direct quotes from some of these family carers.

The effectiveness of the Act and the associated Statement of Australia’s Carers in raising recognition and awareness of the unpaid caring role, including its obligations on public service agencies.

We note that the intention of the Act is to “establish that public service care agencies should take action to reflect the principles in the Statement for Australia’s Carers in developing, implementing, providing or evaluating care supports; consult with carers and involve them in the development or evaluation of care supports, and report on compliance with the obligations established” as well as to “establish that associated providers should have an awareness and understanding of the Statement for Australia’s Carers.”¹

We point to the current slate of NDIA inquiries still underway and repeated reports from mental health carers of how cumbersome NDIA processes greatly impact not only on their caring and work obligations but also their mental health:²

“Our daughter has mild-moderate Autism, is non-verbal and at the time of receiving her NDIS package was school leaving age. When we asked why we hadn’t been allocated a support coordinator we were told that she had two parents at home and that this funding was considered irrelevant for her circumstances. The burden of having to coordinate her supports meant that my husband had to reduce his work hours, so that he could come home and give me some time to leave the house and care for my on mental health. I also had to leave my part-time job, to be full time at home with our adult daughter and manage her plan.” – LEA Friend.

We additionally highlight an example of the inherent stigma and discrimination that carers commonly encounter in dealing with government agencies such as Human Services Australia, where it is understood the Act and its Statement was intended to have the most positive impact in raising recognition and awareness of the unpaid caring role:

“I feel very grateful for the support I receive from the Australian Government and am very aware support like I receive is unavailable in most countries around the world. I have been made to feel by government staff however that I am a burden and should be grateful. The truth is that, if I were unable to care for my son, he would cost this government over a million dollars a year to house and care for him.” – LEA Friend.

Where an Act “does not create legally enforceable obligations... in judicial or other proceedings”³ the obligation of public service care agencies, as well as public service agencies who are not bound to report on compliance at all,⁴ will continue to lack the necessary volition to be bound by this Act and its subsequent clauses. It also does not seek to strengthen any proposed amendments to protect carer rights if an internal culture of fostering carer involvement is not intentionally valued or implemented. This in effect means that with particular reference to Principles 5, 6, 7, 8 and 10, the Statement for Australia’s Carers will continue to simply operate as “a toothless piece of aspirational legislation with little or no impact on achieving the intent of raising recognition and awareness of the unpaid caring role”.

¹ “Carer Recognition Bill 2010 Explanatory Memorandum.”

² “A Case for an Extended Unpaid Carer Leave Entitlement? Response to Follow-up Position Paper Recommendations.”

³ Carer Recognition Act 2010.

⁴ “Carer Recognition Act 2010 Guidelines - A Guide for Australian Public Service Agencies for the Implementation of the Carer Recognition Act 2010.”

Developments in the policy landscape at a Commonwealth level since the Act's passage in 2010.

In relation to the Terms of Reference, we point to developments in policy landscape and their translation, in particular, the recently launched National Safety and Quality Mental Health Standards for Community Managed Organisations.⁵ These Standards explicitly describe how consumers and carers are to be involved in the development implementation, provision and evaluation of care supports. These Standards (and their related iterations in other health settings) have come to pass due to the lackadaisical expectation of compliance maintained by unenforceable legislation such as the Carer Recognition Act currently under review.

“Carers throughout history within the mental health space, have been seen as the problem and not given the recognition and respect that they so desperately deserve. What we have is a vicious cycle of harm where the carer is victimised, and their mental and physical health deteriorates and becomes a burden on the system. But it also causes issues where they struggle to function in their caring role, and this hinders the recovery of the person in crisis.” – LEA Friend.

The National Mental Health Commission similarly identified that 79% of carer respondents who contributed to the National Stigma and Discrimination Reduction Strategy consultation process said they “had experienced being treated unfairly because of their caring role”.⁶ We can confirm that we hear these experiences reflected back to us frequently from our lived experience membership and question the validity of a piece of legislation that has no ability to hold those accountable for the distress this creates for countless Australians. If the Government truly wishes to raise recognition and awareness of the unpaid caring role, legislative reform is essential to moving beyond a purely educative approach which continues to leave mental health consumers and their carers vulnerable to ongoing stigma and discrimination.

The effectiveness of existing state, territory and international recognition of unpaid care (statutory or other practice)

While acknowledging that the intention of the Act was not to “establish carers’ rights”⁷, in light of the inherent duty of care that public service care agencies have, we find this omission deeply concerning. It also stands in direct conflict with the Statement for Australia’s Carers which points twice to inherent human rights which at present are also not legally enforceable despite Australia’s obligations to UN Human Rights treaties⁸.

In the same way that we highlighted in a recent submission in relation to human rights that “state and territory Human Rights Acts/Charters currently offer no explicit guidance on how to operationalise and implement the very protections that they espouse”, we believe this to be equally true of existing state and territory carer recognition legislation.”⁹

“There is a difficulty with the national Carers Recognition Act given the various state and territory Carer Recognition Acts. There are many circumstances where... there is nothing

⁵ “National Safety and Quality Mental Health Standards for Community Managed Organisations.”

⁶ “What We Heard: Insights from the Public Consultation on the Draft National Stigma and Discrimination Reduction Strategy.”

⁷ “Carer Recognition Bill 2010 Explanatory Memorandum.”

⁸ “Inquiry into Australia’s Human Rights Framework.”

⁹ “Inquiry into Australia’s Human Rights Framework.”

done to audit compliance. Often it can be just lip service, tick-box, tokenistic compliance.”
– LEA Friend.

Without a legally enforceable legislative approach, the nature of these Acts remains largely as rhetorical documents. Where stigma, discrimination and human rights abuses remain rife in Australian society, it is not enough to simply state “this is the way the Government would like you all to consider your fellow humans.”

How to better identify the role of unpaid carers in Australian society and the role of a reformed Act, with regard to understanding the value of unpaid care.

We believe that the Act remains dismissive of the value of any carer who is excluded by the language of this Act by virtue of being a “spouse, de facto partner, parent, child or other relative of an individual” or “the guardian of an individual”¹⁰ as at part 1, section 5. The statement of negation here undervalues the legacy of “hidden carers”.¹¹ We reiterate the statement we made in 2009 which informed the drafting of this Act where we stressed that:

“Becoming a carer is usually not based on a conscious decision of the carer but on an event in the life of someone else. Sometimes the onset of caring is very sudden, for instance when one’s partner, child or parent is involved in an accident and is seriously injured. In other cases, especially with the development of mental illness, it may be a slower process, particularly in situations complicated by substance abuse where diagnosis can take some time.”¹²

“It always feels like a burden to ask for 'carer's leave to take my loved one (who has a progressive neurological disease) to his specialist appointments or any other appointments and also having to always get supporting evidence. To take Carer's leave as well, comes out of my sick leave. I don't think this is right.” – LEA Friend.

“I do know that if I was paid for the full-time support that my daughter needs, at the rate stated in the NDIS pricing schedule, I would be highly paid! However, most NDIS providers have one thing in mind- money! They charge more for the same service they would provide someone who is not on NDIS, and unfortunately the level of care required is not always there. I have not chosen this job, but I would not leave the care of my daughter up to anyone else, as I have her best interests at heart. The government needs to realise that unpaid carers put themselves last, provide quality care to their loved ones, and take strain of the care system, but there is a huge cost to their own health & financial wellbeing.” – LEA Friend.

Where the Act currently refuses to acknowledge the impact of familial responsibilities commonly interlinked with caring responsibilities, the Statement for Australia’s Carers will continue to inadequately define Australia’s carers and actualising all principles of the Statement for Australia’s Carers.

“I care for my friend/housemate who is Autistic and approved for receiving NDIS supports. My employer will not allow me to use Carers Leave when taking time off to care for my friend/housemate. Under my employer’s Leave Policy and Award eligibility criteria, I am

¹⁰ Carer Recognition Act 2010.

¹¹ “Who Cares...? Report on the Inquiry into Better Support for Carers.”

¹² McMahon and Hardy, “Carers Identified? Final Report.”

not eligible for Carers Leave as my friend/housemate is not a relative or partner (however, we reside at the same address). I instead need to take Annual Leave when needing to provide care for my friend/housemate.” – LEA Friend.

Where the Act continues to ignore a broader definition of carers, this realisation of the Act’s intent will not prove effective.

The needs of specific cohorts such as young carers, First Nations carers, LGBTIQ+ carers, or culturally and linguistically diverse carers.

While Principle 1 addresses multiple potential points of discrimination in relation to carer roles, like many other similarly worded discrimination legislation and treaties, it fails to acknowledge the impact of intersectionality upon each of the above stated identities. As per this inquiry’s Terms of Reference, to truly consider the “the needs of specific cohorts such as young carers, First Nations carers, LGBTIQ+ carers, or culturally and linguistically diverse carers” it must be acknowledged that each of these stated ‘identities of marginalisation’ are further compounded not only by the caring role but by the intersectional impact of other stated identities highlighted in The Statement for Australia’s Carers. Where a carer is a young First Nation’s carer who is also gay, or where a carer is from culturally and linguistically diverse community, is a refugee, from a lower socioeconomic circumstance and possessing religious beliefs that are different from dominant Australian religious ideology, there will be further experiences of discrimination and marginalisation in relation to the recognition of the value of unpaid carers.

We note that, while ABS statistics in 2018 reflected that “There were 2.65 million carers, representing 10.8% of all Australians”, this figure was “down from 11.6% in 2015”¹³. We also note that there are ongoing cultural and socioeconomic implications particularly amongst the target groups identified in the Terms of Reference. We also refer to the recent Productivity Commission Inquiry in which the Position Paper stated that “about one third of informal carers of older people are from CALD backgrounds”¹⁴ and reiterate our response to this paper, namely that “the nature of the caring role is diverse; there is no one approach to support that will meet the needs of all carers.”¹⁵

We support the observations of Dr Tania King and Ms Ludmila Fleitas Alfonzo, cited in the recent Final Report issued by the Senate Select Committee on Work and Care, who aptly stated that “Young carers often do not consider themselves to be carers because they don’t see their actions and responsibilities as atypical.”¹⁶ This is further reflected in statements related to CALD and migrant workers and First Nations workers who are similarly underrepresented in general carer-related statistics due to a lack of identification with the politicised term of carer and intersectional barriers to claiming any kind of carer-identified supports, which is currently the most current representative subset of data collection. It should also be noted that, due to expectations of higher degrees of education in relation to employment within the public service where CALD, First Nations and young Carers are statistically and traditionally under-represented, identification with a caring role is also likely to be under-represented for fear of stigmatised responses that might reflect poorly upon their perception of their assessed capacity to work.

¹³ “Disability, Ageing and Carers, Australia.”

¹⁴ “A Case for an Extended Unpaid Carer Leave Entitlement? Position Paper.”

¹⁵ “A Case for an Extended Unpaid Carer Leave Entitlement? Response to Follow-up Position Paper Recommendations.”

¹⁶ “Senate Select Committee on Work and Care- Final Report.”

It is important to note that where this Act “does not create legally enforceable obligations... in judicial or other proceedings”¹⁷ the aspirational nature of Principles, but especially Principles 2, 3, 4 and 9 will remain purely aspirational and will fail to activate any duty of care on behalf of the public service and its agencies, particularly in relation to stated negative outcomes for young carers. These include poorer mental health wellbeing, significant negative implications for their own educational, occupational and economic outcomes, risk of homelessness¹⁸ and “lifelong effects on cognitive and social development.”¹⁹

We raise concern regarding the process of information seeking currently employed to establish “the effectiveness of the Act and the associated Statement of Australia’s Carers” especially in relation to CALD communities, First Nations communities, young carers and LGBTIQ+ carers. These conversations should rightfully be the focus of targeted community consultation and not simply subject to an invitation for public submission to an open parliamentary inquiry. These conversations by necessity are nuanced conversations. To appropriately address the diversity of need and intersectional impacts upon carers who may be positively impacted by any legislative reform, an extended community consultation period is recommended. It is imperative that the very nature of legislative language that continues to create silos, adding to the already complex burden of caring responsibilities be appropriately addressed. This can be achieved through intentional consultation and co-design of any proposed legislation introduced to parliament for considered amendments. The co-design process²⁰ as championed by lived experience advocates has proven successful in many arenas of clinical, non-clinical and social reform and we encourage this inquiry to consider its specialised application in addressing legislative reform that has direct personal implication for the lives of many Australians.

The meaningful role that flexible workplaces play in unpaid care.

We reiterate our position stated in the recent Senate Select Committee on Work and Care:

“The COVID pandemic has taught us all that many jobs can be performed from home and that doing so does not reduce people’s productivity. In fact, it may increase it. Carers who are also employed in paid roles, in particular, have valued these flexible arrangements.”²¹

As one LEA Friend reflected:

“I have recently experienced great recognition of my carer role when my loved one was in hospital. This has not been the case in the past and I think is the exception rather than common practice.”

While another stated:

“I am a carer for my husband with complex PTSD, depression and anxiety, and also for my daughter who has Anxiety. I have been honest with my workplace as I have needed flexibility when my husband has had hospital admissions for his mental health, I have been able to work from home, been offered EAP counselling services.” – LEA Friend.

¹⁷ Carer Recognition Act 2010.

¹⁸ “Senate Select Committee on Work and Care- Final Report.”

¹⁹ “Mental Health Carers Submission 109 to the Senate Select Committee on Work and Care Final Report.”

²⁰ “Advocacy Brief - Co-Design and Co-Production.”

²¹ “Senate Select Committee on Work and Care: Evidence on the Extent and Nature of Work and Care Arrangements, the Adequacy of Current Support Systems, and Effective Work and Care Policies and Practices in Place in Australia and Overseas.”

We caution against one-size-fits all policy, however, again stressing that “work can serve as an important form of respite and social connection for some family carers, given the rigors of their caring role.”²²

“Employers are hesitant to trust our professional judgement, despite our knowledge or experience because we can be viewed as being less committed to our roles due to absences outside our control. Additionally, some employers are hesitant to give us meaningful or challenging projects because they are worried about causing us further stress. From the employer's perspective, they are reducing workplace risk. However, this reduces our job satisfaction- we just want meaningful and challenging work like anyone else.” – LEA Friend.

Any other related matters, noting that the adequacy of payments for carers is out of scope for this inquiry.

We additionally point to developments in the policy landscape as per the Terms of Reference and highlight the lived experience preference for the use of the terminology of mental health challenges in deference to the Act's current language usage of “mental illness.”²³

Conclusion

We note that the intention of the Carer Recognition Act is to “establish that all public service agencies should have an awareness and understanding of the Statement for Australia's Carers and develop internal human resources policies, in so far as they may significantly affect an employee's caring role, with due regard to the Statement for Australia's Carers”²⁴ We also note that intention of the Carer Recognition Act (2010) when proposed as a Bill to Parliament was to establish “a legislative framework to increase recognition and awareness of informal carers and acknowledge the valuable contribution they make to society”.²⁵ We also note that purpose of this bill is to “establish a broad and encompassing definition of carer.”²⁶

We highlight the myriad instances of governmental, workplace, mental health system and public stigma, discrimination and human rights abuses that continue to play out in a the 21st century Australian sociopolitical landscape. We submit to this inquiry the argument that a strong case for legislative reform exists in relation to matters of familial, economic, social, cultural and personal security. In order to truly value and recognise the role of unpaid carers in our society, we cannot simply hope that “walking the walk and talking the talk” will engender lasting cultural change. We believe it is imperative for legislation that directly impacts the lives of arguably much more than 10% of the Australian population, to be made enforceable. To ensure its longevity, practical implications and pragmatic implementation, this passage of legislative reform must be subjected to community consultation and co-design, rather than purely the passage of parliamentary debate and approval.

²² “Senate Select Committee on Work and Care: Evidence on the Extent and Nature of Work and Care Arrangements, the Adequacy of Current Support Systems, and Effective Work and Care Policies and Practices in Place in Australia and Overseas.”

²³ “The VMIA Declaration.”

²⁴ {Citation}

²⁵ “Carer Recognition Bill 2010 Explanatory Memorandum.”

²⁶ Carer Recognition Act 2010.

Contact

We thank the Representative Standing Committee of Social Policy and Legal Affairs for the opportunity to put our views forward on the recognition of unpaid carers. We wish you well with the next steps and would be keen to contribute our lived experience perspectives to any future discussions about this important topic.

Your sincerely

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