

INQUIRY INTO PREVALENCE, CAUSES AND IMPACTS OF LONELINESS IN NEW SOUTH WALES

Organisation: Carers NSW
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NSW Parliament Standing Committee on Social Issues
NSW Parliament House
6 Macquarie Street, Sydney

Inquiry into the prevalence, causes and impacts of loneliness in New South Wales

Carers NSW welcomes the opportunity to provide a submission to the NSW Parliament Standing Committee on Social Issues inquiry into the prevalence, causes and impacts of loneliness in New South Wales (NSW). Drawing on data collected through the Carers NSW biennial National Carer Survey, this submission will highlight the importance of identifying carers as a priority population at particular risk of loneliness and social isolation.

Carers NSW is the peak non-government organisation for carers in New South Wales (NSW). A carer is any individual who provides care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Carers NSW is part of the National Carer Network and a member of Carers Australia. Our vision is an Australia that values and supports all carers, and our goals are to:

- Be a leading carer organisation in which carers have confidence
- Actively promote carer recognition and support
- Actively support carers to navigate a changing service landscape that will be characterised by ongoing policy reform
- Promote connected community experiences and opportunities for carers that are inclusive of diverse carer groups
- Lead and advocate for carer-specific and carer-inclusive policy making, research and service delivery
- Continue to be a quality-driven, responsive and carer-focused organisation.

Thank you for accepting our submission. For further information, please contact Grace Cherrington, Policy and Development Officer at _____ or on _____.

Yours sincerely,

Elena Katrakis
CEO
Carers NSW

Introduction

Carers NSW welcomes the opportunity to contribute to the NSW Parliamentary Inquiry into the prevalence, causes and impacts of loneliness in NSW. While loneliness and social isolation have become well-recognised public health issues, particularly at a federal level, Carers NSW commends the NSW Government on its commitment to understanding and addressing concerns about loneliness at a state level.

Drawing on data captured in consecutive Carers NSW National Carer Surveys, this submission will highlight the unique experiences of family and friend carers in the discussion of loneliness. Noting the limitations of explicit research on carer loneliness, metrics of perceived recognition of the caring role, personal wellbeing, social isolation, satisfaction with personal relationships and psychological distress will be used to reflect the overall health and wellbeing of carers across multiple domains. This submission will highlight the importance of including carers as a priority population in policy responses to reducing loneliness and improving social connection.

Current evidence on carer loneliness, social isolation, health and wellbeing

While there is limited data that explicitly captures carers' experience of loneliness in NSW, there are other datasets available that provide valuable insights into the experiences of carers and can be used to inform understanding about carer health and wellbeing and their social connectedness. Carers NSW has drawn on each of these datasets throughout this submission and in similar consultation opportunities that explore broader themes of health and wellbeing and social isolation.

The best approximations of what caring looks like are represented by the Australian Bureau of Statistics Survey of Disability, Ageing and Carers (SDAC) (latest release 2022) and the Census (latest release 2021). Together these two data sources provide significant, reliable detail regarding the nature of caring, the characteristics of carers and some of the key challenges carers experience. Variables relevant to prevalence, causes and impacts of loneliness captured in the SDAC include levels of social and community participation, impacts of caring on health and wellbeing and economic participation and access to and satisfaction formal and informal supports.

Despite the clear value of the ABS data on carers, due to a reduction in state government funding, the latest release of the SDAC cannot provide reliable insights on the needs of carers on state level or below. This especially affects information on hidden carer groups, such as culturally and linguistically diverse carers, young carers and carers in regional areas.

Carers NSW therefore urges the NSW Government to ensure that future ABS Surveys of Disability, Ageing and Carers are adequately funded to capture and produce generalisable data at NSW and sub-regional level. We also recommend that the NSW Government explore with the ABS whether additional investment may assist with improved reporting on NSW data to support measurement of carer outcomes in NSW.

An additional valuable source of detailed data about carers' experiences nationwide is the biennial National Carer Survey, led by Carers NSW with funding from the NSW Government and supported by the State and Territory Carer Organisations. While the National Carer Survey does not provide a representative sample and is skewed towards primary carers (as characterised by SDAC data), it is a leading source of detailed data about carers' experiences and perspectives, with many variables and demographics not adequately represented elsewhere. Variables relevant to the prevalence, causes and impacts of loneliness available from the National Carer Survey include social connectedness (Hawthorne Friendship Scale), relationship satisfaction, carer recognition, time to oneself, unmet need for carer support services and financial stress.

The annual Carer Wellbeing Survey conducted by Carers Australia and the University of Canberra with funding from the Australian Government Department of Social Services includes and reports on a carer loneliness measure, however limited public analysis is available.

Prevalence and impacts of carer loneliness and isolation

In NSW, there are approximately 958,500 family and friend carers, including 349,000 primary carers.¹ This equates to more than 1 in 9 within the NSW population providing care. Caring can have significant impacts on a person's ability to participate in social and community activities, connect with others and maintain existing relationships. As such, carers often report high levels of social isolation and associated poor outcomes in relation to mental health and wellbeing. The relationship between psychological distress and social isolation has also been explored, with analysis of 2020 National Carer Survey data indicating where carers experience greater social isolation their psychological distress is higher.²

The 2024 National Carer Survey found that carers' social connectedness, wellbeing and psychological distress, as reported by NSW respondents, remain at concerning levels, similar to the 2022 and 2020 Surveys. More than half (61.4%) of NSW respondents to the 2024 National Carer Survey (n=1,981) reported being socially isolated or highly socially isolated. Additionally, almost half of NSW respondents (47.5%) experienced high to very high levels of psychological distress. The average wellbeing score for NSW respondents also remained low at 55.3% on the Personal Wellbeing Index (PWI), significantly below the Australian average PWI score of 74.4%. Table 1 demonstrates how social connectedness, psychological distress and personal wellbeing remain at consistently concerning levels across each survey.

Table 1: Social connectedness, distress and wellbeing in the 2024, 2022 and 2020 National Carer Surveys

	2024 National Carer Survey	2022 National Carer Survey	2020 National Carer Survey
Carers reporting being socially isolated or highly socially isolated	61.4%	56.0%	57.4%
Carers reporting high/very high psychological distress (Kessler 5)	53.5%	47.4%	48.5%
Average wellbeing score (PWI, % of scale maximum)	55.2%	58.1%	57.2%
Carers reporting at least one experience of financial stress	59.5%	57.0%	54.3%

While equivalent analysis has not yet been conducted for the 2024 dataset, previous National Carer Surveys have found that social isolation is more prevalent among carers who care for their children (including adult children), CALD carers and LGBTQI+ carers.³ Stigma associated with caring, or the conditions experienced by the person receiving care (especially mental illness, dementia and disability) can also contribute to carers feeling isolated from their friends, family and communities.

Causes of carer loneliness and social isolation

Many carers actively choose to care for a family member or friend and find it to be rewarding. However, research indicates that their health and wellbeing can be adversely affected by the caring role.⁴ Research and policy analysis conducted by Carers NSW indicates there are a variety of factors that can contribute or influence carers social outcomes.

¹ Australian Bureau of Statistics (ABS) (2024), 2022 Survey of Disability Ageing and Carers, Tablebuilder.

² Poon AWC, Hofstaetter L, Judd-Lam S. Social connectedness of carers: An Australian national survey of carers. Health Soc Care Community. 2022 Nov;30(6):e5612-e5623. doi: 10.1111/hsc.13987. Epub 2022 Sep 4. PMID: 36057864; PMCID: PMC10087548.

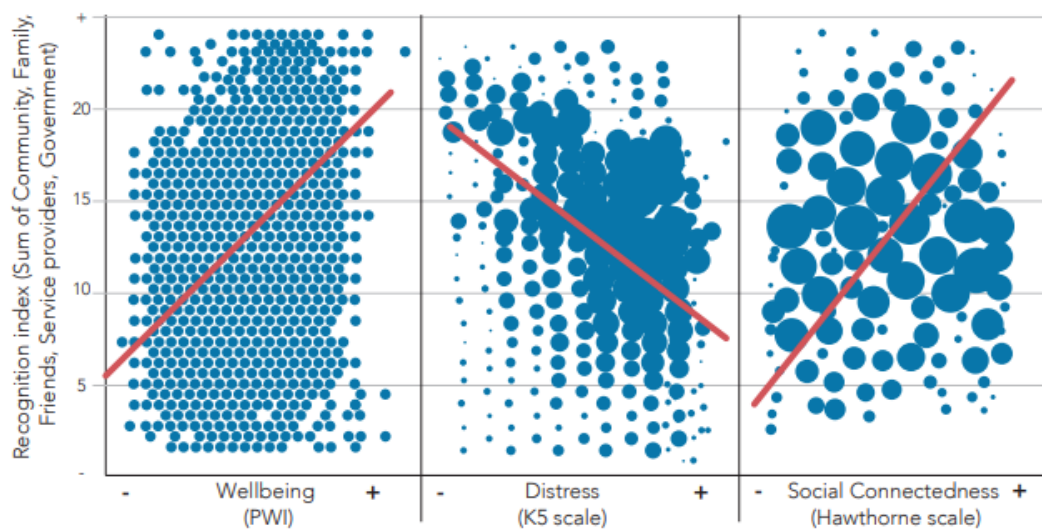
³ Ibid.

⁴ Carers NSW (2022) *Carers NSW Pre-Budget Submission 2023-2024: What carers need*. Carers NSW, North Sydney 2060. Available online at: <https://www.carersnsw.org.au/news/carers-nsw-2023-24-pre-budget-submission>.

Low recognition of carers and the caring role

The appropriate recognition of carers is understood to be foundational to their adequate inclusion and support. Successive National Carer Surveys have shown that there is a significant relationship between feeling recognised in one's caring role and carers' reported wellbeing, psychological distress and social connectedness. Figure 1 demonstrates that respondents in NSW who perceived that their caring role was recognised by others experienced higher wellbeing, lower psychological distress, and greater social connectedness than those who felt less recognised.

Figure 1: Relationships between recognition and wellbeing, psychological distress, and social connectedness (2022 National Carer Survey)



While NSW and Commonwealth carer recognition legislation seek to improve awareness and recognition of carers, they continue to report relatively low levels of recognition by communities, service providers and governments. Perceived recognition from government is especially low according to the 2024 National Carer Survey, with more than half of all respondents disagreeing that their caring role is recognised and valued by government.⁵ Additionally, only approximately 1 in 4 felt their caring role was recognised by the community, while just over half reported recognition of their caring role from family and friends.⁶

Recently published analysis of National Carer Survey data by Carers NSW research partners at the University of Sydney and UNSW positions carer recognition as an important contributor to wellbeing and social connectedness, and as a protective factor against psychological distress.⁷ The analysis found that carers' feelings of recognition are shaped by their experiences with services, at work, and with other family members.

Inability to access to adequate services and supports

Research and policy analysis conducted by Carers NSW also indicates that the intensity of the caring role, lack of formal (or informal) supports, access to regular breaks and geographical location can significantly impact carers' social connectedness. Carers often provide high levels of care, with data

⁵ Carers NSW (2024a). *2024 National Carer Survey, Highlights for NSW*, available online at: https://www.carersnsw.org.au/uploads/main/Files/3.Resources/Policy-Research/Carer-Survey/2024-National-Carer-Survey_NSW.pdf.

⁶ Carers NSW (2024b), 2024 National Carer Survey, Unpublished data.

⁷ Hamilton, M., Bainbridge, H., Baird, M., Zettna, N., Hofstatter, L., Judd-Lam, S., & O'Loughlin, K. (2024). The importance of recognition: predictors and outcomes of carer recognition among working carers of ageing relatives. *Community, Work & Family*, 1–26. <https://doi.org/10.1080/13668803.2024.2413874>.

from the 2024 National Carer Survey indicating that almost 2 in 3 NSW respondents provided 60 hours or more of care per week, on average. Half of all respondents indicated they provide '24/7' care.

Although carers should expect to be supported by formal care services, the growing strain on the care and support economy due to market and workforce shortages mean that carers continue to fill service gaps. Lack of appropriate formal services, including respite services, can significantly impact carers' ability to take a break or prioritise their health and wellbeing, including engaging in activities that support their social participation. Research also indicates that carers who have good access to services for themselves and the person they care for are less socially isolated.⁸

2024 National Carer Survey data also demonstrates the relationship between personal wellbeing and access to necessary services, with many carers citing the impact of limited formalised supports on their physical and mental health.⁹ Formal care services such as respite and other carer-focused wellbeing activities can provide carers with much-needed breaks or opportunities to attend to their own health. However, evidence shows that many carers are unable to access these services at all, or that existing services are insufficient to meet their needs. Carers NSW has written extensively regarding the lack of suitable replacement carer and respite options for carers and the impact this has on carers when regular, scheduled breaks away from the caring role cannot be accessed.

The 2024 National Carer Survey registered a high unmet need for planned and emergency respite services. Around 1 in 7 (13.9%) of those who had used planned respite reported an unmet need. However, this unmet need was much higher for those who had not accessed planned respite, with more than 2 in 5 (42.4%) reporting an unmet need.¹⁰

Responses from the 2024 National Carer Survey reveal that long wait times and limited availability, lack of funding, distance, and unsuitability of respite options to the individual needs of the carer and person being cared for hinder carers' utilisation of respite services.¹¹

In addition to formalised respite services, such as those accessed under Carer Gateway, services provided under the National Disability Insurance Scheme (NDIS), My Aged Care and other service systems that provide care to older people and people living with disability are intended, or believed, to free up time for carers to attend to their own needs and goals, thereby having a 'respite effect.'¹² However, findings from Carers NSW 2022 National Carer Survey (Figure 2) demonstrates that this not always the case, especially those caring for someone accessing NDIS and mental health services.¹³

⁸ Poon, A. W. C et al (2022).

⁹ Carers NSW (2024b).

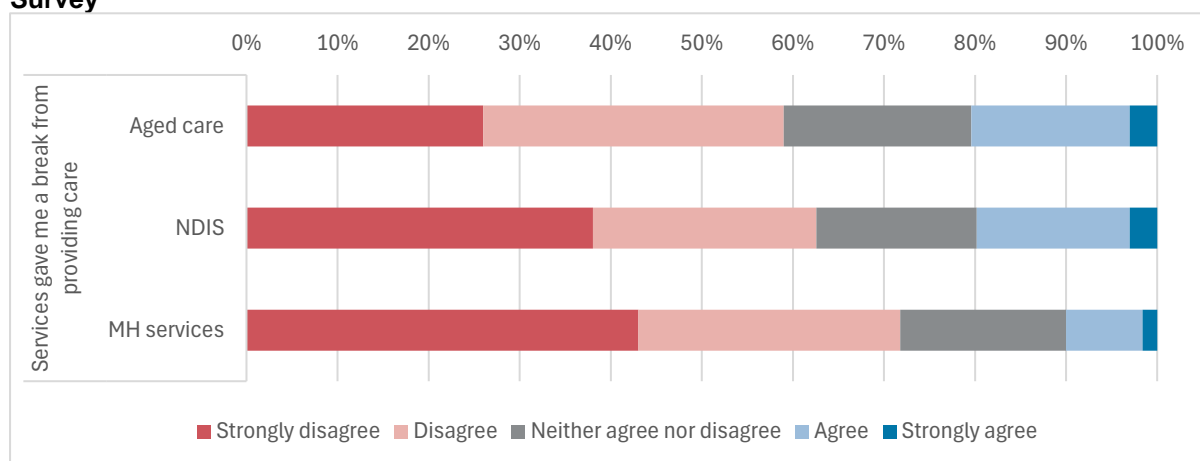
¹⁰ Ibid.

¹¹ Ibid.

¹² Carer Respite Alliance (2021) *Repositioning respite within consumer directed service systems*. Available online at: <https://www.carersnsw.org.au/uploads/main/Files/5.About-us/News/Repositioning-respite-within-consumer-directed-service-systems.pdf>. Carers NSW, North Sydney.

¹³ Carers NSW (2023a), 2022 National Carer Survey, Summary report, available online at: https://www.carersnsw.org.au/uploads/main/Files/3.Resources/Policy-Research/Carers-NSW_2022_National_Carer_Survey-Report.pdf.

Figure 2: Services provided a break from caring, by service system, 2022 National Carer Survey



Lack of finances to participate in social and community activities

The Survey also found that there was a significant relationship between carer financial stress and social connectedness, due to the costs of participating in social activities. Reduced participation in the workforce and the additional associated costs of caring can lead carers to experience higher rates of financial distress and insecurity, limiting their ability to access healthcare services. Financial stress experienced by carers can significantly impact their ability to engage in recreational or social activities. Data from the 2022 SDAC indicates that cost was a common barrier to engaging in social and community activities for just over 1 in 3 (34.4%) carers. While this data only reflects a three-month period in 2022, Carers NSW believes these trends are consistent with what carers have identified anecdotally, with many carers reporting that they are unable to afford to meet with a friend for a coffee in the community.

The relationship between financial stress and social participation has been highlighted by Carers NSW in various consultation opportunities. Carers NSW has highlighted the importance of including carers in targeted rebates and schemes that support community participation of older people and people living with disability, especially as people in these cohorts may rely on an income support payment or pension and have higher or additional costs of living. In each of these contexts, community participation is considered not only a right and entitlement of older people and people with disability, but also as a way to maintain health and wellbeing. Many family and friend carers share similar experiences of financial hardship or insecurity,¹⁴ however are often excluded from schemes and initiatives that may encourage broader community participation or support the prioritisation of their own health and wellbeing.

Solutions to carer loneliness and social isolation

Recognition and identification of carers

Service providers and governments can improve carer recognition by improving the adequacy and quality of formal care services, reducing the administrative load on carers to access services and supports, and by working with carers as partners in care. While carer recognition is higher in community settings, there remain opportunities to improve broader community understanding and awareness of carers and the impacts of caring responsibilities.

Access to carer support services

Data from the 2022 National Carer Survey is helpful in demonstrating how measures for wellbeing, distress and social connectedness interact with reported use and need for carer services. This

¹⁴ Carers NSW (2023) 2022 National Carer Survey Briefing 1: Carers and the Cost of Living. Carers NSW, North Sydney 2060. Accessed online at: https://www.carersnsw.org.au/uploads/main/Files/3.Resources/Policy-Research/Carer-Survey/2022_National_Carer_Survey_Briefing_1_Carers_and_the_cost_of_living.pdf

relationship signals the important role carer support services have in supporting carers' health and wellbeing, especially in situations of increased carer stress, as carers were more likely to access services once the caring situation had deteriorated. Furthermore, many carers who do not access services also report no unmet need, while also reporting the highest levels of wellbeing and social connectedness of all respondents, and the least psychological distress.

Peer support

Research indicates that connecting with peers and sharing experiences can significantly reduce feelings of isolation. However, not all carers are able to engage with traditional models of peer support or have the confidence (or capacity) to navigate online equivalents. Many carers – especially those in regional or remote communities – may not have access to the digital infrastructure required to connect to their communities online. Peer support is an important element of support for carers, with carers reporting high regard for opportunities to be able to share their experiences with, and receive understanding and guidance from, other carers in similar circumstances. The Carers NSW 2024 National Carer Survey found that while many carers who were accessing online or in-person peer support were having their needs for this type support met, more than 1 in 3 (36%) were not accessing peer support but reported an unmet need for online and in-person peer support.¹⁵ This suggests that where carers are able to access appropriate peer support options that align with their availability and needs, they are satisfied with this support, however there is a significant cohort of carers who would like to access peer support and are unable to find any suitable peer support options to do so.

Carers NSW recognises the existing peer support options available to carers through Carer Gateway, however, Carers NSW has also heard through on-the-ground service delivery and consultation with carers and stakeholders, that some carer cohorts, such as young carers and male carers, often face additional barriers to engaging in peer support or connecting with peers under the current model and offerings. Therefore additional, complimentary and targeted approaches for these groups may be needed to support them to develop and maintain meaningful peer connections.

Respite

Although the scope of Carer Gateway intends to capture and support the diverse needs of carers, there remain service needs that go beyond the purview of Carer Gateway services, especially in the context of respite. Where respite needs cannot be adequately addressed by Carer Gateway or other existing formal service systems, Carers NSW believes the NSW Government must invest in complementary services and programs that provide carers with regular breaks from their caring role and support optimal wellbeing.

Economic participation

Carers balancing work and care responsibilities indicated that paid work provides important social connections outside of their caring role, with 82% of respondents from the 2022 National Carer Survey reporting that it gives them a sense of purpose. Respondents balancing care with paid work also demonstrated significantly lower psychological distress and higher wellbeing than those who did not have a paid job. Importantly, paid work is also a necessity for many carers simply because it provides the income required to meet living costs.¹⁶

Opportunities to reduce social isolation among carers

Research shows that carers' social isolation can be largely influenced by low recognition, a lack of time or oneself, lack of appropriate services, lack of finances and reduced social connectedness. Carers NSW believes that the targeted investment that addresses these factors would significantly improve carers' social isolation and loneliness.

¹⁵ Carers NSW (2024b).

¹⁶ Carers NSW (2023) 2022 National Carer Survey Briefing 2: Supporting carers in the workplace. Carers NSW, North Sydney 2060. Accessed online at: https://www.carersnsw.org.au/uploads/main/Files/3.Resources/Policy-Research/Carer-Survey/2022_National_Carer_Survey_Briefing_2_Supporting_carers_in_the_workplace.pdf

Recent national inquiries and consultation opportunities, including community consultation on the National Carer Strategy, the Parliamentary Inquiry into the recognition of unpaid carers,¹⁷ the Select Committee inquiry into Work and Care,¹⁸ and the Productivity Commission inquiry into Carer Leave¹⁹ have provided a number of insights and recommendations about opportunities to improve experiences and support for carers across Australia.

Carers NSW has also undertaken comprehensive consultation with carers and stakeholders over the past 12 months, including consultations held with carers in coordination with Carers Australia to inform and support the development of the National Carer Strategy, Carers NSW delivery of interactive webinars and events with carers, research and services providers through the Carer Knowledge Exchange,²⁰ analysis of Carers NSW 2022 National Carer Survey²¹ data and early analysis of qualitative data from the 2024 National Carer Survey. Together, report and consultation findings indicate that in order to reduce social isolation and loneliness among carers, the NSW Government should:

- Fulfil their obligations under the NSW *Carers (Recognition) Act 2010*, including that all public service agencies must consult with such carers or bodies representing carers as the agency considers appropriate when developing policies that impact on carers.
- Fulfil their obligations under the NSW Carers Charter, ensuring carers are supported to enjoy optimum health and well-being and to participate in family, social and community life, employment and education.
- Noting the high prevalence of social isolation within carers in NSW, recognise and identify carers as a priority cohort in government-led initiatives that seek to address or improve social and economic participation.
- Increase investment in data sources that capture population level data on carer social connectedness including the Survey of Disability, Ageing and Carers.
- Explore opportunities to establish and fund complimentary formal services outside of established service systems (My Aged Care, NDIS and Carer Gateway) to meet the ongoing unmet needs of carers and the people they care for, including enabling carers to take breaks from caring to participate in social and economic activities.
- Invest in initiatives aimed at strengthening carers' access to ongoing and appropriate peer support, especially for young carers and male carers who report additional barriers to accessing peer support.
- Invest in subsidies, rebates or vouchers to enable carers to participate in social and recreational community activities where cost may be a barrier to participation.
- Invest in dedicated programs and initiatives that promote and support carers engagement in the workforce, including building the capacity of employers to adequately recognise and support carers in their workplaces through the Carers + Employers program.

Conclusion

Carers NSW thanks the NSW Parliament Standing Committee on Social Issues for the opportunity to respond to this inquiry. This inquiry presents a unique opportunity to broaden the understanding and impact of loneliness in NSW, particularly for populations a greater risk of experiencing social isolation. As evidenced throughout this submission, Carers NSW believes family and friend carers should be identified as a priority population who are more likely to be impacted by loneliness.

¹⁷ <https://www.apf.gov.au/UnpaidCarers>.

¹⁸ https://www.apf.gov.au/Parliamentary_Business/Committees/Senate/Work_and_Care/workandcare.

¹⁹ <https://www.pc.gov.au/inquiries/completed/carer-leave/>.

²⁰ <https://www.carerknowledgeexchange.com.au/>.

²¹ <https://www.carersnsw.org.au/about-us/our-research/carer-survey>.