

**Supplementary  
Submission  
No 134a**

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

Carers NSW welcomes the opportunity to provide additional commentary to the NSW Parliament Standing Committee on Social Issues inquiry into the prevalence, causes and impacts of loneliness in New South Wales (NSW). This submission provides additional insights in relation to questions and issues raised at the Public Hearing of the inquiry held Thursday, 12 December 2024. It builds on the detail provided in our original submission, submitted 11 November 2024.

As the peak non-government organisation for carers in New South Wales (NSW), Carers NSW believes that this input is vital in ensuring that the findings and recommendations of the Committee accurately reflect the experiences and needs of carers in NSW as they relate to loneliness and social connectedness.

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 additional response. For further or if you have any questions, please contact Melissa Docker, Manager Policy and Development

Yours sincerely,

Julie Toma  
Interim CEO  
Carers NSW

## Introduction

Carers NSW welcomes the opportunity to contribute additional input to the NSW Parliamentary Inquiry into the prevalence, causes and impacts of loneliness in NSW following the Public Hearing held Thursday, 12 December 2024.

Carers NSW supports the evidence presented by Mental Health Carers NSW and the NSW Carers Advisory Council in relation to the high prevalence of social isolation experienced by carers and the significant impacts of this on their health and wellbeing outcomes. However, we would like to provide additional insights on these matters.

### The need for a centralised approach to addressing carer social connectedness

Carers' social connectedness can be affected by multiple, interconnecting factors. These can include, but are not limited to:

- a lack of time and energy, due to the demands of caring, to build or maintain relationships
- diminishing relationships due to stigma or a lack of understanding about the caring experience
- a lack of exposure to peers who understand the caring experience and/or have similar interests
- challenges accessing adequate replacement care from formal services (e.g. 'respite') or other family members or friends to free up time for social participation
- challenges meeting the costs associated with participating in social, recreational or wellbeing-focused activities (e.g. catching up with a friend at a café, or seeing a movie)
- challenges secure suitable accommodation that is nearby to community services and supports
- a lack of suitable transport options to maintain close relationships and attend appropriate activities.

As highlighted in the evidence provided at the 14 December 2024 Public Hearing on behalf of the NSW Carers Advisory Council, carers are also often accessing multiple service systems with or on behalf of the person they care for, or on their own behalf. However, there is currently no centralised or standardised point of reference within existing service systems in NSW for people to have their role as a carer recognised or 'registered'. This can make it challenging to ensure that carers are identified early in their interactions with services and supports and that their needs, including in relation to social participation, are identified and met.

As noted by Mental Health Carers NSW (MHCN) at the Public Hearing, Carers NSW has advocated for many years for the introduction of a NSW Carer Card. While it was raised by MHCN in the context of providing access to discounts and subsidies – important for addressing cost barriers to participation for carers – Carers NSW also believes that a NSW Carers Card would have utility in supporting identification of carers across services and supports in NSW. Sharing of carer status across administrative systems is also key to streamlining carer identification and support. Carers NSW has previously explored this approach with the NSW Department of Customer Service, however, this work does not appear to have progressed.

While Carers NSW acknowledges the work of the Department of Communities and Justice to improve awareness of, and outcomes for, carers, Carers NSW supports the assertion that a whole-of-government approach is needed to better address carers' social connectedness, given the multifaceted causes of social isolation for carers in NSW. An integrated approach at a service level is likely to be the most effective in identifying and supporting carers across all of the systems they are accessing in NSW. Furthermore, a whole of government approach aligns with the NSW Governments commitments under the *NSW Carers Strategy: Caring in NSW 2020-2030*.

### Measuring carer loneliness and effectiveness of responses

Evidence provided during the 14 December 2024 Public Hearing suggested that there was no data available on carers' experience of loneliness and social isolation, especially data that would provide insights on which carers may need or benefit most from particular social participation initiatives. While Carers NSW recognises that research explicitly capturing the prevalence, causes and impact of loneliness among family and friend carers in NSW is limited, we disagree that there is no data available on this topic, and provided extensive insights from the NSW Government funded Carers NSW National Carer Survey in our original submission.

As highlighted in the original Carers NSW submission, there are also several other datasets that can be used to inform and enable evidence-based responses to address carer loneliness, including the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC), Carers Australia annual Carer Wellbeing Survey, Carer Gateway service use data and a range of other datasets.<sup>1</sup> The extensive data available provides valuable insights into the experiences of carers and could be better utilised to inform understanding about, and targeted responses to carer social and relational experiences. Some key relevant findings are highlighted below.

### **The Survey of Disability, Ageing and Carers**

The Survey of Disability, Ageing and Carers (SDAC), conducted at the population level by the ABS every 5 years, collects a number of objective measures that explore social or community participation by carers, such as the number of times a carer has participated in social or recreational activity. While Carers NSW acknowledges that this may not reflect a carer's experiences of connection during participation in these activities, it provides key insights into community engagement.

The SDAC also collects information about barriers to social participation, such as cost, the caring role, and other factors. This information, used in conjunction with other relevant data can support the development of targeted responses that address barriers to carer's community participation. However, it is important to note that while the SDAC is a national survey, recent reductions in contributions to the delivery and analysis of the survey by the NSW Government have limited the availability of reliable state-level data that was previously available.

This has made it more difficult to understand carers' current experiences in NSW, especially for diverse carer cohorts who are already often underrepresented in population level surveys. Carers NSW has therefore been continuing to advocate that the NSW Government prioritise a restored financial commitment to the state-level insights generated by this important data source, which also includes social participation data for people living with disability and older people.

### **Carers NSW National Carer Survey**

#### *Experiences of social connectedness*

Social connectedness is a subjective measure that explores an individual's feelings of connection or disconnection to others. As a construct it is closely related to loneliness, however is in its formulation strengths-based. Social connectedness measures, such as the Hawthorn Friendship Scale used by Carers NSW in the 2024 National Carer Survey,<sup>2</sup> provide valuable insights that enable comparisons between carers and other cohorts. The Carers NSW 2024 National Carer Survey received responses from 1,981 carers across NSW, of whom 15.1% identified as culturally and linguistically diverse, 4.9% identified as LGBTQ+, 5.9% identified as Aboriginal and/or Torres Strait Islander.<sup>3</sup>

As highlighted in Carers NSW original submission to the inquiry, the 2024 National Carer Survey found that more than half (61.4%) of NSW respondents were socially isolated or highly socially isolated.<sup>4</sup> Further analysis of the data indicated that a number of carer cohorts report social isolation at higher rates than others, including female carers, carers aged 15-65 years, culturally and linguistically diverse carers and carers in outer regional areas (Figure 1).<sup>5</sup> However, it is important to note that social isolation remains high across all groups. Carers NSW is also able to share even more

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<sup>1</sup> Carers NSW (2024a) *Australian carer data sources: A comparative guide*, available online at: [https://www.carerknowledgeexchange.com.au/assets/Publications/8/Australian-carer-data-sources-A-comparative-guide\\_V3-v3.pdf](https://www.carerknowledgeexchange.com.au/assets/Publications/8/Australian-carer-data-sources-A-comparative-guide_V3-v3.pdf).

<sup>2</sup> Carers NSW (2024b), *2024 National Carer Survey, Unpublished data*.

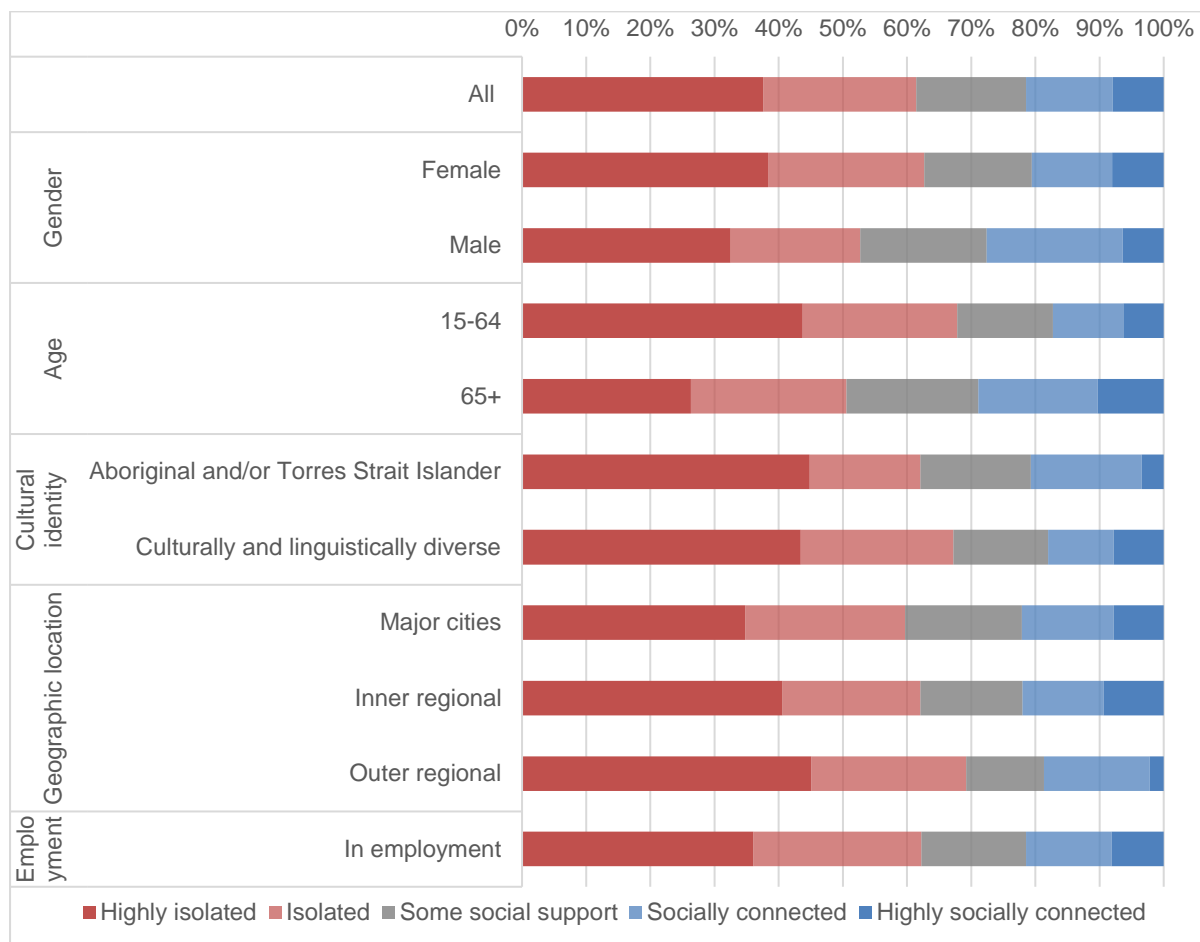
<sup>3</sup> Carers NSW (2024c). *2024 National Carer Survey, Highlights for NSW*, available online at: [https://www.carersnsw.org.au/uploads/main/Files/3.Resources/Policy-Research/Carer-Survey/2024-National-Carer-Survey\\_NSW.pdf](https://www.carersnsw.org.au/uploads/main/Files/3.Resources/Policy-Research/Carer-Survey/2024-National-Carer-Survey_NSW.pdf).

<sup>4</sup> Ibid.

<sup>5</sup> Carers NSW (2024b).

granular data from the NSW Carer Survey in relation to social connectedness with the NSW Government, including on regional or Local Health District level and would welcome further inquiries from the Committee about the data and analysis available.

**Figure 1. Carer experiences of social connectedness<sup>6</sup>**



*Factors and characteristics that influence carers’ social connectedness*

Recently completed analysis of Carers NSW 2024 National Carer Survey data not available at the time of our original submission also provides further insights into the factors influencing carer social connectedness. Following the regression methodology in Poon et al. (2022)<sup>7</sup>, Carers NSW tested a regression model estimating social connectedness (measured through the Hawthorne friendship scale) from NSW respondents to the 2024 National Carer Survey, confirming the 2022 results.

The fitted regression model found that psychological distress, unmet need for carer support services, and living in a regional area were all found to negatively influence social connectedness, whereas recognition of the caring role, practical support from family and friends, more time for themselves, age, and not receiving a Centrelink payment (i.e. economic independence) were found to be conducive for increasing carers’ social connectedness.<sup>8</sup>

<sup>6</sup> Carers NSW (2024b).

<sup>7</sup> 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.

<sup>8</sup> Carers NSW (2024b).

### Carer service use and unmet needs

Carers NSW biennial National Carer Survey also collects data on the use of and demand for carer support service, as reported by respondents. This data can be explored in relation to carer demographics, caring situations and location, providing key insights into the different service needs of different carer cohorts across NSW.

While meaningful participation in social and community activities is often reliant on a range of factors, such as access to adequate replacement care and appropriate activities, Carers NSW analysis of carers' use of, and unmet need for, peer support highlights key gaps in existing service systems and supports and potential opportunities for the NSW Government to invest in peer connection activities.

The Carers NSW 2024 National Carer Survey<sup>9</sup> found that of respondents in NSW, while around 1 in 5 were accessing online or in-person peer support, approximately 2 in 5 reported an unmet need for peer support. Notably, Aboriginal and Torres Strait Islander carers, carers aged 15-64 years, carers in paid employment and carers living in inner regional areas were likely to report higher levels than other carers of unmet need for in-person and online peer support (Table 1).

**Table 1. Use and unmet need for carer peer support services by NSW carers<sup>10</sup>**

		In-person carer support groups		Carer peer support online	
		Used	Unmet need	Used	Unmet need
	All	26.2%	38.0%	13.2%	36.8%
Gender	Female	26.7%	38.2%	12.6%	36.9%
	Male	22.4%	36.6%	18.0%	34.4%
Age	15-64	21.2%	43.7%	13.3%	41.7%
	65+	35.1%	27.3%	13.4%	27.5%
Cultural identity	Aboriginal and/or Torres Strait Islander	16.3%	49.0%	14.3%	42.9%
	Culturally and linguistically diverse	28.0%	40.2%	18.1%	41.2%
Employment	In paid work	22.0%	40.3%	14.0%	38.9%
Geographic location	Major cities	23.2%	37.5%	14.5%	35.7%
	Inner regional	30.6%	38.8%	10.5%	39.0%
	Outer regional	21.7%	39.2%	12.2%	33.8%

This data also provides insights into service use trends, such as that male carers and culturally and linguistically diverse carers were more commonly accessing online peer support options than other

<sup>9</sup> Carers NSW (2024b).

<sup>10</sup> Ibid.

carers, and that regional carers were least commonly accessing online peer support options.<sup>11</sup> While further investigation is required to understand these trends, this data can still provide vital insights to guide future investment by the NSW Government.

### **Carer Gateway service use data**

In relation to carers' use of services and supports and the effectiveness of these services in relation to social connectedness, Carer Gateway service user data, collected by the Australian Government Department of Social Services is likely to provide the most in-depth insights. While Carers NSW acknowledges that this data is not publicly available and that not all carers in NSW are accessing Carer Gateway services, this data is likely to provide detailed insights into carers' demand for, and use of, activities that support social connectedness, such as peer support, both online and in-person, and online carer forums.

Within NSW, with limited funding of carer-focused services and supports across NSW following the introduction of Carer Gateway, it is pertinent that the NSW Government work closely with DSS to understand the uptake and use of carer services across NSW, this will also provide insights into potential service gaps, areas of high and low usage and effectiveness of services that will enable the NSW Government to develop and implement targeted responses that meet carers' unmet needs. Additionally, Carers NSW recommends streamlining and consistency of data collection across NSW Government funded carer-focused programs and supports.

### **Young carers**

Carers NSW supports the emphasis on the need for improved support for young carers, highlighted by the NSW Carers Advisory Council at the Public Hearing. There are approximately 132,100 young carers in NSW,<sup>12</sup> however, this number is estimated to be much higher as many young carers are hidden, or not well identified through data collection or in community and service settings. Young carers face a number of complex barriers to self-identification and support seeking that can negatively impact on their social connectedness. These include:

- real and perceived stigma in relation to their caring role from peers, educators or service providers
- reduced time to participate in extra-curricular or social activities with peers
- limited family finances to pay for extra-curricular or social activities
- challenges finding appropriate services or supports outside of school or work hours
- concerns about potential child protection involvement should the extent of their caring responsibilities be known.

The Carers NSW 2024 National Carer Survey included a dedicated module for young carers to complete, to support improved understanding of young carers' experiences. The Survey found that 83.3% of young carers who responded felt their caring role affected their relationships with people their own age to some degree. More than 1 in 4 (28.6%) reporting that caring affected their relationships with peers a lot.<sup>13</sup>

Improved identification and recording of young carers in data and service settings, initiatives that aim to improve awareness of young carers in education and community settings, ensuring services align with young carers' availability and preferences, and addressing time and cost barriers to social participation are likely to support young carers to better connect with peers and networks and establish strong social connections. Carers NSW has been working with the NSW Department of Education to improve information and resources for educators, school wellbeing staff and families to improve awareness and identification of young carers in school settings. However, there remain a

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<sup>11</sup> Ibid.

<sup>12</sup> Australian Bureau of Statistics (ABS) (2024), *2022 Survey of Disability Ageing and Carers, Tablebuilder*.

<sup>13</sup> Carers NSW (2024b).

number of opportunities to better equip educators and school staff to identify and support young carers.

Carers NSW Young Carer Awareness Training, funded by the NSW Department of Communities and Justice, aims to improve awareness, understanding of and response to young carers and their needs, however, uptake by educators remains low due to significant competing priorities within NSW education settings. Carers NSW believes that additional, targeted investment by the NSW Government and ongoing collaboration with the NSW Department of Education may be needed to enable and encourage uptake to ensure early identification and support for young carers.

### **Conclusion**

Carers NSW again thanks the Committee for the opportunity to provide additional information and welcomes the opportunity to support the work of the Committee to enable optimal outcomes for carers across NSW.