Australian Government
Department of Social Services

Consultation and Analytical Support for the Development of the National Carer Strategy

Executive Summary

September 2024

The National Carer Strategy and the Experience of Caring

BACKGROUND TO THE NATIONAL CARER STRATEGY

At least three million Australians provide unpaid care for someone with a disability, medical condition, mental illness, addiction, or who is frail due to age. Of this figure, 1.2 million are primary carers, meaning they provide the most informal assistance to individuals with core activity requirements. [1]

In 2020, Deloitte Access Economics estimated that replacing unpaid care in Australia would cost $77.9 billion. This figure would likely be higher today due to the increase in the number of unpaid carers, the hours of unpaid care provided, and the rising costs of formal care. [2]

Unpaid carers make a significant social and economic contribution to Australia. Ensuring carers are appropriately recognised and supported is critical to the safety and wellbeing of carers and care recipients, as well as the sustainability of social care systems, communities, and the economy.

In 2023, the Honourable Amanda Rishworth MP, Minister for Social Services, announced the development of a National Carer Strategy (the Strategy) as a unified framework to champion the needs of Australia's unpaid carers. The voice of carers is a critical input into the development of the Strategy.

Deloitte was commissioned by the Department of Social Services to facilitate a series of face-to-face and virtual consultations to document the experiences of unpaid carers nationwide. These consultations explored the experiences, challenges, and solutions (both new and existing) that carers need to support them in safely providing care.

Between July and September 2024, Deloitte conducted 35 consultations, engaging with 541 unpaid carers across the country. These consultations spanned all major cities and multiple remote and very remote locations. Dedicated First Nations consultations were also held for carers who were First Nations or carers of First Nations people.

This report provides a thematic analysis of the findings from these consultations. It is essential for the reader to appreciate the unique perspectives within each reported theme and acknowledge the significance of voices that are not reflected or are underrepresented in this report.

THE EXPERIENCE OF CARING

The experience of caring is deeply personal and unique. Many factors influence the experience of being a carer, including the nature of the relationship with the person being cared for, the carer's own circumstances, the specific needs of the care recipient, the service systems they access, and their geographic location.

The challenges carers face can also intersect with their experiences, heightening existing issues and introducing new ones. These challenges may include lack of access to services, language barriers, fear of judgement or stigma, cultural barriers, and added financial pressures.

It's important to note that this report focuses on the challenges and solutions required to improve carer experiences, as this is the role of the Strategy. Unpaid care is a complex journey, and many carers reported strong, positive personal returns from their experiences, which can coexist alongside the challenges. While highlighting these positive experiences is not the primary focus of the consultation process, there were some noted. The success of the solutions and the Strategy will be measured by their capacity to amplify and extend these positive experiences.

> *"My wife and I have a pretty consistent testimony in this regard. For us, both of our disabled children are our heroes. They simply give, give, and keep on giving. Not in any tangible, transactional way that can be economically measured; rather, out of their suffering. We are proud of them, feeling that those, who make the effort to engage with them, take away more than they give. Appreciating our children through the prism of such a perspective is a genuine joy."*

> *"The greatest reward isn't just seeing my loved one smile, it's knowing we're facing life's imperfections together, supported by those around us. Those moments of relief, of shared perspective, the small wins we celebrate... The kindness from others remind me that even amidst the challenges, there's still so much good in the world... it fuels my hope and strengthens my resolve."*

Source: [1] ABS (Australian Bureau of Statistics) (2022) Disability, Ageing and Carers, ABS website, accessed 2 September 2024, https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/2022

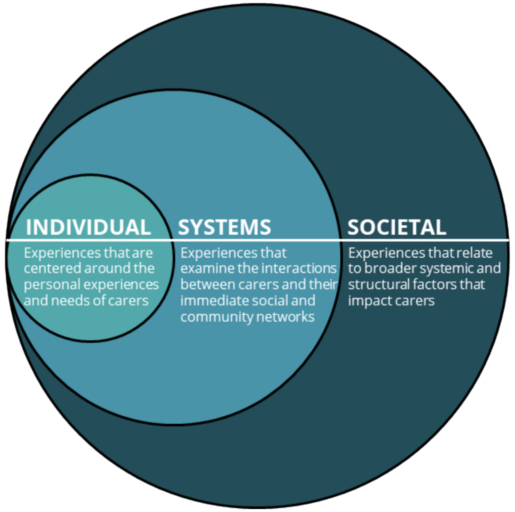
[2] Deloitte Access Economics for Carers Australia (2020) "The Value of Unpaid Care work" accessed 9 September 2024, The value of informal care in 2020 (carersaustralia.com.au)

The Experience of Caring

APPROACH

The experience of caring has been considered in the context of the complex interplay between individual, systems, and societal factors and how these multiple levels individually or simultaneously influence the experience of carers providing care to care recipients and their relevance to carer cohorts.

The First Nations experience has also been highlighted separately to ensure appropriate focus is placed on achieving better outcomes for First Nations communities.



The challenge of intersectionality by carer cohorts who participated in the consultations have also been discussed to provide a comprehensive understanding of the multifaceted nature of caring challenges.

Solutions have been categorised using the same framework as the experience of caring (e.g. related to individuals, systems, and society). Carers shared a broad range of solutions with respect to their needs, and many of these solutions may be within the remit of the Strategy – however others may not be within scope or might require actions of others including other Government Departments, private business or community leaders.

Solutions identified by carers have been included regardless of whether similar solutions or components already exist. Low awareness of existing supports or how to access them was a challenge for most of the carers consulted. Characterising their view of potential solutions provides insights into the effectiveness and awareness of existing supports.

EXPERIENCES

INDIVIDUAL

- Not all carers identify as carers.
- Carers can lose and deprioritise their sense of self.
- Carers feel undervalued.
- Carers carry a mental and emotional burden.
- Carers bear risk.

SYSTEMS

- Carers benefit from organisations that genuinely understand and respect their roles and provide tailored support.
- Formal carer support systems are time limited, hard to access and insufficient.
- Carers Gateway can be slow, time-consuming, and difficult due to limited business hours and accessibility supports.
- Systems are complex and time consuming.
- Carers demonstrate resilience establishing their own support systems or businesses tailored t their individual/community needs.

SOCIETAL

- Systems accessed by care recipients do not appropriately/adequately recognise the role of carers.
- There is a lack of public understanding of the need and value of carers.
- Education systems are not designed to meet the needs of carers.
- The labour-market does not value or support carers sufficiently.

FIRST NATIONS

- Caring and community care is embedded in the tradition and culture of First Nations communities which conflicts with the individualised nature of social support service structures
- Language differences and cultural customs and service awareness impacting access to services.
- Changing cultural expectations and stigma of caring, disability and illness.
- Heterogeneity of First Nations communities.
- Recognising the impact of colonisation and systemic societal inequalities.

Intersectionality | Compounding Challenges

Carers from marginalised and under-represented communities often face compounded and exacerbated challenges associated with their caregiving roles. Below is an outline of some intersectional characteristics and experiences that impacted the carers consulted.

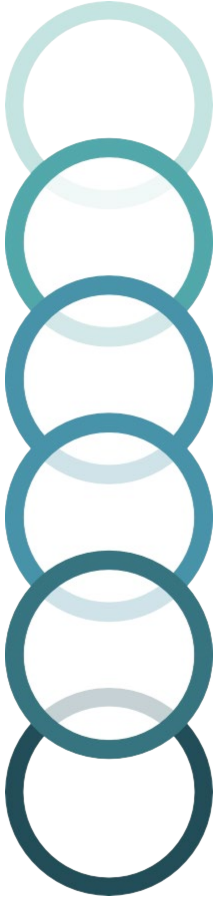
	Rural and Remote	**CALD**	**Young Carers**
Challenges	• Difficulty accessing local respite care (if available) and specialised support services. • Limited options for service providers creates a perception that the lack of competition compromises the quality of services offered. • Limited employment opportunities in rural and remote areas make it difficult for carers to find suitable work. • In small communities, maintaining privacy can be challenging and hinder access to support. • Cost of travel and lack of transportation options to access essential services. • Limited or unreliable digital infrastructure preventing access to necessary information and support.	• Cultural norms and expectations places additional pressure to provide care within families, often without external support. • Cultural stigma and shame surrounding caring roles can prevent CALD carers from seeking support. • Language barriers and limited proficiency in English can hinder CALD carers' ability to understand and access available support services. • Difficulty finding and accessing services that are culturally sensitive and respectful.	• Challenges with identity as they balance being a young person and experiencing a normal childhood and a carer simultaneously. • Strained relationships with siblings and parents due to unequal support and attention. • Personal sacrifices or delayed ability to pursue personal goals due to caring commitments. • Lack of recognition and understanding of their role by teachers, employers, and service providers. • Limited career opportunities and professional growth due to gaps in education or work experience. • Difficulty navigating and accessing appropriate support services due to age-related restrictions.

	Additional Needs	**Gender**	**LGBTQIA+**
Challenges	• Often prioritise the needs of the person they care for over their own, leading to neglect of their health and well-being. • Managing their additional health or personal needs can reduce a carer's capacity to provide effective unpaid care. • Fear about their ability to continue providing care due to their own health challenges. • Carers can feel un-cared for or unsupported, especially if the care recipient is unable to reciprocate emotional or physical support.	• Females are often the 'default' carer as societal norms often associate caring with women. • Female carers often experience a high caregiving burden, career sacrifices, economic disparities, role overload, and tend to neglect their own health. • Male carers face societal stigma and stereotypes that caregiving is a "female" role, resulting in a reluctance to seek support (if available) due to cultural norms around masculinity and self-reliance. • Non-binary carers struggle with finding inclusive services, face discrimination and misunderstanding, lack identity validation, experience social isolation, and encounter higher mental health challenges.	• There are many instances in which services are not designed to cater for the needs of LGBTQIA+ community members. This is because the 'stereotyped' image of a carer does not often consider the experience of members of this community. • Service provision and support networks which are heteronormative in design impact the safety of LGBTQIA+ community members. • Hesitation to seek support due to service providers' lack of cultural competency and appropriate training (misgendering, heteronormative assumptions, lack of recognition and undervaluation).

Principles to Improve the Experience of Caring and Solutions Overview

Throughout our consultations, carers emphasised the need for different solutions based on their individual circumstances and challenges. However, they consistently shared a common set of broader principles for improving their caregiving experience:

PRINCIPLES TO IMPROVE THE EXPEREINCE OF CARING



Respect: Carers want to be treated with respect and valued for their contribution to the lives of the individuals they care for, community, society and the economy.

Recognition: Carers want to be recognised as a critical part of the care team.

Individualised: Carers are individuals with varied needs and require solutions and supports designed to meet their individual needs.

Accessible: Solutions should be designed with consideration of access barriers for carers.

Integrated: Solutions require integration with existing systems as well as the systems that support care recipients, rather than being siloed.

Sufficient: Supports need to be sufficient – recognising the full end-to-end carer experience and the differences in carer needs.

INDIVIDUAL

- Provide comprehensive access to health and wellbeing support.
- Enable carers to build and maintain social networks.

SYSTEMS

- Advocate for and strengthen the legal rights and protections for carers.
- Assist carers in effectively navigating and accessing the necessary supports for their care recipients.
- Ensure carers have easy access to the information they need to fulfil their roles effectively.
- Ensure an appropriate mix of small, large and cohort specific contracted organisations provide support.

SOCIETAL

- Elevate the understanding and recognition of vital role carers play in society.
- Provide pathways and support for carers to pursue education and employment opportunities.
- Implement measures to support carers' financial security, both now and in the future.
- Improve data collection methods to gain a comprehensive understanding of carers’ experiences.

FIRST NATIONS

- Enhance the cultural sensitivity and appropriateness of services provided to First Nations carers.

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