

Summary report

Summary Report: Caring from the Margins

4 September 2024

Introduction

Our report outlines the experiences of Australian carers from marginalised groups to inform the development of a new National Carer Strategy. Led by the Disability Advocacy Network Australia (DANA) and in partnership with First Peoples Disability Network (FPDN), National Ethnic Disabilities Alliance (NEDA) and Inclusion Australia (IA), this report reveals the lived experiences of carers from First Nations, culturally and racially marginalised (CaRM) backgrounds, caregivers of people with intellectual disabilities and challenging behaviours, and carers with disabilities. The consultation process involved surveys, focus groups, and roundtables to capture the voices of these often-overlooked carers, revealing key themes such as financial strain, emotional and physical burnout, systemic challenges, and the lack of culturally safe services.

Summary of consultations

Overall 72 people participated in the consultation through the project, 65% were women, 31% male and 4% identified as non-binary.

Co-horts	Round tables	Focus groups	Other
First nations (FPDN)	ten people	Community yarn online: Seven people	two in person interviews/Yarns
CaRM/CALD	ten people	Focus group one: six people Focus group two: fourteen people	one translated interview mother of refugee background. one elderly mother from a CALD background.
Intellectual disabilities (IA)	seven people	Focus group one: five people Focus group two: nine people	NA

Carers at the Margins: the complexity of intersectional identities

One of the core insights is the overwhelming strain placed on carers with marginalised identities. Carers often juggle multiple roles—managing their disabilities while providing care for loved ones, all within systems that do not account for their unique needs. Our consultations revealed that while 1 in 3 carers are themselves disabled, their dual experiences as carers and individuals with disabilities are seldom acknowledged in policy. This oversight is particularly pronounced for carers from First Nations and CaLD backgrounds, who face additional barriers due to the lack of culturally safe, trauma-informed, and neurodivergent-affirming services.

Caring is not a one-size-fits-all experience. We found that services are primarily designed for predominantly able-bodied and culturally dominant populations, leaving CaRM and First Nations carers feeling invisible. Carers from these groups expressed feelings of social isolation, systemic racism, and the cultural stigma around disability, which exacerbates their challenges in accessing services. The concept of "care" itself was seen as limiting, with many First Nations carers describing their role as a natural extension of their cultural and familial duties rather than an imposed responsibility.

Systemic Barriers and Financial Strain

The report highlights carers' significant financial strain, often compounded by the costs associated with caring for loved ones with complex needs. Carers reported difficulty navigating bureaucratic systems such as the National Disability Insurance Scheme (NDIS), with many describing the

administrative burden as a "second full-time job." Access to services is even more limited for those living in rural and remote areas, with carers often travelling long distances for primary care, further adding to their emotional and financial burden.

Mental health emerged as a critical issue, with 86% of carers reporting challenges in maintaining their mental well-being. The continuous strain of caregiving, compounded by social isolation and inadequate respite options, leaves carers physically and emotionally exhausted.

The Role of Co-Design and Lived Experience

A strength of this report is its emphasis on co-design and lived experience. Led by a project team composed largely of disabled individuals and carers, the consultation process was designed to reflect the voices of those most affected by the policy. This approach allowed for a nuanced understanding of carers' experiences, uncovering gaps often missed by traditional research methods. The report advocates for carers to be directly involved in policy design, ensuring that future strategies are genuinely inclusive and representative of all carers, especially those at the margins.

Key Recommendations for the National Carer Strategy

The report outlines several critical recommendations. These include:

1. **Culturally Safe and Inclusive Services:** Carers need access to services that understand and respect their cultural and linguistic backgrounds. This includes providing language support, neurodivergent-affirming care, and trauma-informed approaches.
2. **Increased Mental Health Support:** The report calls for more accessible mental health services, with at least 10 Medicare-funded sessions and pathways for crisis support before a breakdown occurs.
3. **Financial and Logistical Support:** Carers should receive additional financial assistance, including paid carer leave, superannuation contributions for carers, and simplified access to services such as the NDIS and aged care.
4. **Respite Care:** The report stresses the importance of accessible, culturally meaningful respite care, particularly for First Nations carers. Respite is more than just a break—an opportunity to reconnect with community and culture.
5. **Public Awareness Campaigns:** There is a need for increased public awareness and recognition of carers' contributions, particularly for those from marginalised groups, to reduce stigma and promote a better understanding of the diversity of caring experiences.
6. **Co-Design and Lived Experience in Policy:** The report underscores the importance of involving carers in the design of policies that affect them, ensuring that future strategies are led by lived experience rather than imposed from above.

Conclusion

Our report reveals the complex, intersectional challenges Australia's most marginalised carers face. It calls for urgent reforms to ensure that carers are recognised for their contributions and supported in ways that reflect their diverse experiences. Our emphasis on co-design and lived experience offers a convincing outline for shaping inclusive, empathetic, and culturally sensitive policies, which have the potential to improve the lives of carers and those they care for.