

National Carer Strategy

The needs of women with disabilities who provide care

Submission to the National Carer Strategy Consultation

13 September 2024

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# Language Note

Our organisational submission reflects the needs and concerns of women with disabilities who provide care to someone who has a disability, chronic health issue, medical condition, mental illness, or is frail due to age. Our submission may reflect the overlapping experiences of discrimination and marginalisation felt by cisgendered and transgendered women as well as non-binary, and gender diverse people. However, the caring experiences of transgendered women, and non-binary, and gender diverse people warrant specific and direct exploration. We recognise limitations in aggregating our submission to the broader level of gender-marginalised people (people who do not identify as cisgender men). Instead, Women with Disabilities Victoria (WDV) aims to work in coalition with, rather than replicate the core work of, organisations who represent and advocate for LGBTIQA+ people with disabilities who care for others.

While, for simplicity, we use the Committee’s chosen terminology of “carer” and “caring role”, we wish to highlight that this is often not the terminology used by women with disabilities who provide care. Care recipients are often perceived as family by women with disabilities and many will instead use relational terms such as “parent”, “spouse”, “child”, “friend”, “loved one”. These terms better reflect the mutuality of caring with, for, and from others. We reject the false binary of “care giver” and “care receiver” that can arise from the term “carer”. When we use the terms “caring” and “caring role”, we acknowledge the interdependencies and reciprocal nature of these relationships.

This submission also uses “person first” language (women with disabilities). We acknowledge people describe their experience of disability in different ways, and for many people, “identity first” language (disabled women) is a source of pride and resistance.

# Acknowledgment of Country

WDV respectfully acknowledges Aboriginal people as the Traditional Custodians of the lands and waters on which we work, rest, and continue to benefit from. We pay our respects to the Elders, past and present, of Aboriginal and Torres Strait Islander Communities across Victoria and acknowledge that their continued strength and resilience is built upon more than 60,000 years of history. The WDV community is committed to honouring the unique cultural and spiritual relationship Aboriginal and Torres Strait Islander peoples have with the land and waters, and their rich contribution to society.

# Submission Contact

Belinda Burns

Acting Chief Executive Officer

Women With Disabilities Victoria

E: belinda.burns@wdv.org.au

# About the Authors

**WDV** is a not-for-profit Disabled People’s Organisation (DPO) representing women with disabilities in Victoria. The organisation is operated *by* and *for* women and non-binary people with varied disability experiences. WDV has a diverse membership of people from different backgrounds. Women with disabilities face intersecting forms of structural gender and disability discrimination. WDV actively advocates for our rights to safety and respect, with particular emphasis on disability policy, health services, violence prevention, workforce development, and leadership. WDV envisions a world where all women are respected and can fully experience life.

### Lead Author

**Brigid Evans**, *B.A. (Hons), Grad Dip Ed (TFA), M.A., Ph.D.*, Senior Policy and Research Officer

# Executive Summary

WDV welcomes the development of the National Carer Strategy. WDV recognises and values the often invisible and unremunerated care work performed by women with disabilities. While Australian policy frameworks are beginning to recognise and support the care work performed by women, the same cannot be said for the thousands of women with disabilities who care for others. Our submission draws attention to the experiences and needs of women with disabilities who provide care, either as primary, secondary, or other supportive carers.

Women with disabilities who provide care face specific challenges that must be addressed in the development of the National Carer Strategy. WDV advocates for a holistic approach to supporting carers that acknowledges the specific challenges faced by women with disabilities in care roles. WDV advocates for a Strategy that adopts a research-informed intersectional and human rights approach. WDV also calls for a Strategy that empowers rather than idealises carers, recognises the reciprocal nature of care, and promotes gender equality. Such an approach can improve the lives of both carers and the people for whom they care.

**Recommendation 1:** Ensure that human rights principles are foundational to the National Carer Strategy.

**Recommendation 2:** Adopt a robust and nuanced definition of intersectionality that is embedded across the Strategy.

**Recommendation 3:** Ensure that care recipients are the ultimate beneficiaries of the National Carer Strategy.

**Recommendation 4:** Work with DPOs to develop and promote respite services that are co-designed and led by women with disabilities who are carers.

**Recommendation 5:** Develop and provide training for respite care providers that is co-designed with and led by women with disabilities.

**Recommendation 6:** Provide assurances that seeking respite will not result in the removal of care recipients.

**Recommendation 7:** Dismantle the practical and attitudinal barriers to accessing respite care faced by women with disabilities.

**Recommendation 8:** Include women with disabilities as one of the core focus groups in the National Carer Strategy.

**Recommendation 9:** Collect disaggregated data to assess the rates of unpaid care provided by women with disabilities.

**Recommendation 10:** Ensure that the Strategy and its related policies and programs are designed with input from women with disabilities who are carers.

**Recommendation 11:** Support DPOs to empower women with disabilities to advocate for their own needs and the needs of those for whom they provide care.

### Questions Addressed:

**Question 1:** What principles do you think should be in a National Carer Strategy?

**Question 6:** We are aware that some carers feel they cannot leave their loved one with others due to the complexity of the care required. What has prevented you from accessing respite and what additional support might relieve your hesitancy to access respite in the future?

**Question 14:** How would you like to see your experiences reflected in the Strategy?

**Question 15:** If you belong to a diverse group, what opportunities do you see for the Strategy to improve access to supports and information in your community? (For example, have you identified a gap or challenge in receiving support and/or information for your particular diverse community and what could Government consider improving the issue)?

**Question 16:** What are some priorities that might assist or improve the experience of carers within your community?

# Background

Caring is gendered work.Today it remains the default assumption that women will assume the majority of Australia’s unpaid and informal care work. According to most recent data, 67.7% of Australia’s 1.2 million primary carers were assigned female at birth (ABS, 2022a). While this unpaid work is fundamental to the sustainability of Australia’s care economy —it is estimated that funding the equivalent paid services would cost $77.9 billion annually (Deloitte, 2022)— informal care remains undervalued and unrecognised. Of course, the value of care cannot and should not be calculated in purely economic terms. Care is at the heart of our society. It is the nurturing, supporting, teaching, protecting, and safeguarding of family and community that holds us together.

While Australian policy frameworks are beginning to recognise and support the care work performed by women, the same cannot be said for the thousands of women with disabilities who care for others. Over two fifths of those assigned female at birth who are primary carers have a disability (41.3%) (ABS, 2022a). Of Australia’s 3.0 million carers more generally, 38.6% have a disability (ABS, 2022a). Note that disaggregated data was not collected on the numbers of non-primary carers who identify as women or are gender diverse. However, we expect that, were data to be collected, we would find that the majority of carers with disabilities are women and gender diverse people.

Our submission draws attention to women with disabilities who provide care, either as primary, secondary, or other supportive carers. This is a group who have garnered insufficient attention within the Strategy’s consultation documents. However, given the size and specific needs of this cohort, it is vital that the National Carer Strategy recognises the diversity and complexity of this group. Again, we note that our submission may reflect the overlapping experiences of marginalisation felt by cisgendered and transgendered women, non-binary, and gender diverse people. However, the caring experiences of transgendered women, non-binary, and gender diverse people warrant specific and direct exploration. We urge the government to collect disaggregated data on carers to better understand the needs and experiences of *all* carers with disabilities.

#  Guiding Principles

#### Question Addressed: 1

The Australian Carer Strategy must adopt a set of principles that fully recognise and respond to the historical and intersecting oppressions felt by women with disabilities who are carers. WDV advocates for a National Carer Strategy that centres the principles of human rights and intersectionality. We further call for the Strategy to embed the principles of gender and disability equality in all its initiatives, to place care recipients at the very centre of the Strategy, and to focus on the support and empowerment of carers rather than their idealisation.

It is concerning that, while the Strategy’s consultation paper briefly acknowledges that almost two-fifths of Australian carers have a disability and that most carers are women, it does not outline a specific focus area for women with disabilities who are carers. Various international human rights conventions and other instruments acknowledge the impact of multiple discriminations caused by the intersection of gender and disability. These conventions and instruments recommend prioritising women with disabilities as a group warranting specific attention. For example, the Convention on the Rights of People with Disabilities (CRPD) (2007, Article 6), the Bangkok Declaration on National Action Planning and Disability-Inclusive Development (United Nations [UN], 2005), the General Recommendation 18 of the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), and the Biwako Millennium Framework (2002), along with recommendations from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2019), all call on governments to implement specific measures to promote the full participation of women with disabilities. To ensure that women with disabilities who are carers can enjoy the same human rights and fundamental freedoms as others, the Government must ensure that human rights principles are foundational to the National Carer Strategy. This would best be achieved by the Government co-designing a Gender and Disability Action Plan with women with disabilities and their representative organisations. These Action Plans must cut across all areas of the National Carer Strategy.

The Strategy should embed gender equality in all its initiatives. This includes measuring the amount of unpaid labour done by women and advancing principles of gender equality. We recommend that a broader gender strategy be adopted and integrated into the foundations of the Carer Strategy. Ensuring that gender is a central consideration in the Strategy's implementation is critical in advancing gender equality.

WDV Insight
“*The needs, interests, and safety of care recipients*
*must be at the very heart of the National Carer Strategy.*”

The Strategy must recognise the diverse experiences of carers, particularly those who face multiple forms of discrimination and barriers, such as women with disabilities. WDV support the Strategy’s intention to adopt an intersectional approach and calls on the Government to specifically address the compounded experiences of gender, disability, and care responsibilities. While the Strategy’s intention to collect and report disaggregated data is a positive step forward in improving the visibility of intersectional experiences, the approach to intersectionality cannot replace a close analysis of the needs and interests of specific sub-groups. The limitations of replacing gendered analysis with “intersectional analysis” in the National Disability Insurance Scheme (NDIS) Review, for example, has been reported in *The Conversation* (Piantedosi et al., 2024). The principles of intersectionality ask us to do more than simply collect data on the various identities and experiences of carers. Rather, as a guiding principle, intersectionality requires that the Government carefully analyse how various identities interact with each other, and with broader social, political, and power dynamics/contexts.

Finally, and most critically, in shedding light on the experiences of carers and seeking to improve their quality of life, the Government must be wary of idealising carers. Carers are often portrayed in the media as selfless, overburdened saints. This idealisation must not mask the potential for abuse perpetration —such as, family violence being justified by carer stress. As we learnt from the Disability Royal Commission, serious and significant harm can, has, and continues to be perpetrated by carers. We caution the Government to adopt a Strategy that complements rather than substitutes paid service systems. The idealisation of carer roles is not a sufficient replacement for effective professional services. Unpaid caring should never be used or expected to replace well-delivered services that are appropriately funded by the Government. More inclusive, accessible, and effective service support systems would reduce community reliance on carers, thus increasing the quality of life of both carers and care recipients.

WDV advocates for a Strategy that recognises recipients of care as the ultimate beneficiaries of the Strategy. The needs, interests, and safety of care recipients must be at the very heart of the National Carer Strategy. In this regard, WDV calls for a Strategy that is focused on the support and empowerment of carers as opposed to their idealisation. Carers should be empowered to advocate for their own needs and the needs of those for whom they provide care. Dangerous and harmful narratives of carer idealisation must be challenged by the Strategy.

**Recommendation 1:** Ensure that human rights principles are foundational to the National Carer Strategy. This should involve co-designing a Gender and Disability Action Plan with women with disabilities and their representative organisations, in line with international human rights instruments and conventions.

**Recommendation 2:** Adopt a robust and nuanced definition of intersectionality to ensure it is operationalised correctly. Properly embedding the principle of intersectionality in the Strategy will involve disaggregated data collection and reporting, as well as detailed analysis of how various identities interact with each other and with broader social, political, and power dynamics/contexts.

**Recommendation 3:** Ensure that care recipients are the ultimate beneficiaries of the National Carer Strategy. This will help to challenge the dangerous idealisation of carers and ensure that appropriate support is directed to both carers and care recipients.

#  Recognising the Context of Care

#### Question Addressed: 6

Question Six acknowledged that many carers may feel like they cannot leave their loved ones with others due to the complexity of the care required. While this may be the case for women with disabilities who provide care, their hesitancy to utilise respite services can run much deeper. In understanding what can prevent women with disabilities from accessing respite, the Government must understand the stereotypes and stigma experienced by women with disabilities. The Strategy must also dismantle the additional practical barriers women with disabilities face in accessing service provision.

The caregiving efforts of women with disabilities often go unrecognised, partially due to stereotypes about people with disabilities being the *recipients* rather than *providers* of care (Prilleltensky, 2003, see also McKeever et al, 2003, Radcliffe, 2008, Williams & Robinson, 2001). At the same time, as women, they are subject to assumptions that they should be the *providers* of care and are socialised to deemphasise their own needs. Research has found that the internalisation of these seemingly conflicting expectations around gender and disability has meant that women with disabilities are less likely to advocate for their own unmet support needs and are “less effective self-advocates than men” (Yates et al., 2021 p.2).

Women with disabilities who are carers often prioritise the needs of those they care for over their own (Yates et al., 2021). This can lead to their own support needs being overlooked or unmet. They face stereotypes that they are unfit to be caregivers, particularly mothers, resulting in fears that the individuals they care for might be removed from their care if they utilise support services. Women with disabilities can therefore feel that they must work harder than parents and carers without disabilities to be accepted as competent (Smeltzer, 2007). In fact, Women with Disabilities Australia (WWDA) found that many “women with disabilities experience such fear of being judged ‘inadequate’ as a parent (and of the consequences this might bring), that they go to extraordinary lengths to present themselves and their children as managing and competent –often at significant personal cost in terms of comfort, emotional, and physical well-being" (Frohmader, 2009 p. 12, see also, McKeever et al, 2003, Prilleltensky, 2003, Social Care Institute for Excellence [SCIE] 2005, Thomas, 1997, Grue & Laerum, 2002, Malacredia, 2009). While there is no Australian research capturing the specific experience of women with disabilities who are carers, we expect that similar findings would apply.

WDV Insight
“*The historical legacy of policing, controlling, and surveilling women with disabilities’ reproduction, mothering, and caregiving has inevitably eroded trust*”

Supporting women with disabilities who provide care in accessing respite must grapple with the history of women with disabilities having their children removed from their care (Frohmader, 2009). This history informs women’s confidence in seeking assistance and is an under-researched and under-documented area of Australia’s history. The historical legacy of policing, controlling, and surveilling of women with disabilities’ reproduction, mothering, and caregiving has inevitably eroded the trust they have in Government supports. Trust must be rebuilt between the Government and women with disabilities who provide care if appropriate supports and respite services are to be developed, provided, and utilised. Understanding this history and sharing these stories will be crucial to ensuring that women with disabilities who are carers are understood and supported by the Strategy.

In addition to these attitudinal and emotional barriers to accessing respite services, women with disabilities can find system navigation to be complex, inaccessible, and burdensome. There is a lack of access to appropriate content and formats of information (such as Braille, audio, Easy English, and the use of telephone access relay services and sign interpreters) relating to respite services. Women with disabilities who are carers may also face barriers in transporting the person for whom they care to and from respite services. These practical barriers can limit the opportunities of women with disabilities in utilising respite services.

To ensure that women with disabilities who are carers are understood and adequately supported, the National Carer Strategy must adopt an intersectional approach that addresses the specific challenges they face. This includes recognising their care contributions, addressing stereotypes and discrimination, providing adequate financial and systemic support, and ensuring accessibility in all services and information.

**Recommendation 4:** Work with DPOs to develop and promote respite services that are co-designed and led by women with disabilities who are carers. This can help build trust and ensure services are responsive to individual needs.

**Recommendation 5:** Develop and provide training for respite care providers that is co-designed with and led by women with disabilities. This will better ensure that respite carer providers have the necessary skills and understanding to support women with disabilities who provide care.

**Recommendation 6:** Provide assurances that seeking respite care will not result in the removal of care recipients. This includes clear communication and policies that prioritise maintaining family and care structures.

**Recommendation 7:** Dismantle the practical and attitudinal barriers to accessing respite care faced by women with disabilities. This includes challenging stereotypes. It also includes the provision of appropriate content and formats of information, and the inclusion of accessible transport to and from respite services within respite packages.

# 3. Gender, Disability, and Care

#### Questions Addressed: Question 14, 15, & 16

We applaud the Government’s intended focus on the experiences of carers who are First Nations people, from migrant and refugee communities, living in regional, rural, and remote areas, LGBTQIA+, and young and older carers. However, we urge the government to include women with disabilities amongst its key focus groups. Women with disabilities who act as carers face specific challenges that must be addressed in the development of the National Carer Strategy. These challenges are shaped by the intersection of their roles as carers and their own experiences of disability, which often compound existing barriers to support. Many women with disabilities provide substantial amounts of unpaid and informal care. The lack of data, research, and information about women with disabilities who are carers, contributes to their invisibility and marginalisation in society.

The diverse challenges, experiences, and stories of women with disabilities who are carers must be collected, shared, and reflected upon in the Strategy. The Strategy must acknowledge and address the fact that care is a gendered issue. As already stated, women provide most of the informal care work in Australia (67.7%). A significant portion of these women have disabilities themselves (41.3%). Further, many of their care recipients who are women will *only or primarily receive care in informal ways* —despite disability rates being on par between men and women, women and girls only make up 37% of NDIS participants, meaning women with disabilities are more likely to receive care in informal ways (Piantedosi et al., 2024). On average, women wait two to five years longer than men to obtain a diagnosis (Merone et al., 2022), are more likely than men to have at least one chronic health condition (ABS, 2022b), and on average live four years longer than men (Australian Institute of Health and Welfare [AIHW], 2024). These factors mean that women will be more reliant on informal supports than men, and that they may be reliant on these supports for longer. Ensuring that all women have fair and sufficient access to formal supports will ease the pressure on their informal carers.

The Strategy must ensure better access to supports and information for women with disabilities. As already stated, women with disabilities face attitudinal and practical barriers to accessing supports. Women with disabilities who are carers face higher costs related to childcare, transport, cleaning, heating, laundry, food, security, safety, going out with care recipients, holidays, assistive technology, and communication (SCIE, 2005, Preston, 2005). Navigating formal care systems is complex, and access to appropriate content and formats of information (such as Braille, audio, Easy English, and the use of telephone access relay services and sign interpreters) is often limited (WWDA, 2007). Women with disabilities who are carers of children may also face barriers to obtaining adaptive parenting equipment.

WDV Insight
“*Ensuring that all women have fair and sufficient access to formal supports will ease the pressure on their informal carers.*”

These barriers are compounded by the barriers and inequalities felt by women with disabilities more broadly. Compared to women without disabilities, women with disabilities are less likely to be in paid work, are more likely to be in the lowest income earning bracket, they spend a greater proportion of their income on medical care and health-related expenses, and they are less likely to receive appropriate health services (Frohmader, 2009). They are also substantially overrepresented in public housing and are often forced to live in situations in which they experience, or are at risk of experiencing, violence, abuse, and neglect (Barrett et al., 2009). These factors all impact on the capacity of women with disabilities to support themselves and the people for whom they care.

Critically, the Strategy must prioritise and support women with disabilities who provide care while experiencing or fleeing violence. Women with disabilities are significantly more likely to have experienced intimate partner violence compared to those without disabilities (33.2% and 21.2%, respectively [Barrett et al., 2009]). They may be less able to leave abusive situations due to fears that the person for whom they care may lose essential supports or that support systems are tethered to the home/perpetrator (Barrett et al, 2009). Additionally, women with disabilities are more likely to be unlawfully sterilised, face medical interventions to control their fertility, be assaulted, raped, and abused. They are more likely to experience marriage breakdown and divorce, less likely to have children, and more likely to be single parents (Barranti & Yuen, 2008) This can leave women with disabilities who care with reduced access to informal and formal support systems. Many women who have disabilities and are carers must also provide care while living with their own significant trauma.

**Recommendation 8:** Include women with disabilities as one of the core focus groups in the National Carer Strategy.

**Recommendation 9:** Collect disaggregated data to assess the rates of unpaid care provided by women with disabilities. This data should inform policy and program design and provide greater clarity over their specific support needs.

**Recommendation 10:** Ensure that the Strategy and its related policies and programs are designed with input from women with disabilities who are carers. This includes co-designing initiatives that address their specific barriers and support needs.

**Recommendation 11:** Support DPOs to empower women with disabilities to advocate for their own needs and the needs of those for whom they provide care. Commission DPOs to develop training and resources that are co-designed and led by women with disabilities who are carers.

### Conclusion

Women with disabilities who are carers face specific challenges that must be addressed in the development of the National Carer Strategy. By adopting an intersectional approach, recognising the value of informal care, promoting gender equality, and providing targeted support and advocacy, the strategy can improve the experiences of these carers and ensure their needs are met.

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