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## **Submission to the Inquiry into Unpaid Work**

## Women with Disabilities ACT

Thank you for the opportunity to submit to the Inquiry into Unpaid Work. Women with Disabilities ACT (WWDACT) is a Disabled People's Organisation advocating on behalf of women, non-binary and gender diverse people (women\*) in the ACT. Our submission is guided by the lived experience of our broader membership, and specifically by conversations with our Policy Advisory Committee (PAC) made up of 6 women\* with lived experience of disabilities. Through this submission we wish to draw attention to the uneven burden of unpaid work done by people with disabilities, and specifically by women\* with disabilities.

Our members are involved in a diverse range of unpaid activities including parenting, caring for someone with a disability or illness, unwaged academic research, and volunteering for sporting clubs, camps, political parties, or community service organisations – as just a few examples. It is important to note that people with disabilities are more likely to have caring responsibilities - according to the survey of Disability, Aging and Carers, 22.5% of women with disabilities in Australia are also carers themselves for someone with a disability; this is over twice the rate for women without disabilities<sup>1</sup>.

Our members are active in the ACT community and many enjoy regularly volunteering – however systemic barriers can prevent people with disabilities from participating in these volunteer activities. One of our members was recently forced to stop volunteering for 6 weeks whilst waiting for a replacement wheel for her wheelchair. Her funding through the NDIS did not cover enough for a yearly battery replacement let alone a replacement wheel, or hire of a replacement chair whilst waiting for

<sup>&</sup>lt;sup>1</sup> Australian Bureau of Statistics. (2018). Disability, Ageing and Carers, Australia: Summary of Findings. ABS. <a href="https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release">https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release</a>. This survey had a binary indicator of gender and does not reflect the experiences of non-binary people with disabilities in Australia.



repairs. This is just one example of how women\* with disabilities experience additional barriers to participation in volunteer work.

What is often left out in analyses of unpaid work is that people with disabilities must undertake significant unpaid labour to manage their own wellbeing and overcome systemic barriers to participation in society. Navigating complex systems like healthcare, education, welfare and the NDIS requires an immense amount of work – managing appointments, keeping track of paperwork, and self-advocacy to prove the impact of disability and qualify for needed supports all require substantial amounts of unpaid work. Women\* with disabilities must undertake more of this work as they are less likely to be believed by healthcare professionals or by the NDIA when they reach out for support<sup>2</sup>. They must prepare and produce more evidence, more documentation and often seek multiple appointments or prepare multiple applications to access the same support. Moreover, simply making it to work or going to the shops to purchase groceries can require a significant amount of effort, from navigating Canberra's inaccessible transportation system to managing overwhelming sensory environments. We hear from our members that 'managing disability is a full time job' – but whilst primary care work is well recognised in discussions around unpaid labour, the self-care and self-management required of people with disabilities is rarely discussed.

Many people with disabilities rely on NDIS support to meet some of their care needs. However, for many people with disabilities there is significant unpaid work involved if they either choose or are forced to manage their own NDIS plans. Our members have pointed out that managing one's own NDIS plan essentially means becoming an employer of support workers, equivalent to running a small business and being responsible for the management of as many as 12 workers. People with disabilities face the pressure of hiring and firing workers, knowing that both their ability to have their basic needs met *and* the financial livelihoods of support workers depends on their effective management of their NDIS plan. This plan management work can be

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<sup>&</sup>lt;sup>2</sup> Women with Disabilities ACT. (2023). Submission to Third Women's Action Plan. WWDACT. https://wwdact.org.au/wp-content/uploads/2023/02/WWDACT-Submission-to-Third-Action-Plan.pdf



done by a support coordinator, however some of our members have been told they were 'not disabled enough' to qualify for support coordination and were left with the burden of managing their own plans. Plan management can be especially difficult for people who have difficulty with executive functioning, but if they do not qualify for support coordination there are few options available. Even when support coordination is funded, there are often not enough hours to ensure plan participants can get the help they need, and our members have reported that they've relied on support coordinators doing pro bono work and not billing for all their hours.

Support for people with disabilities depends on a whole network of unpaid and largely unrecognised work. It is important to focus on not just economic policy changes, but policy changes that address systemic barriers faced by people with disabilities across all portfolios. Without significant change, people with disabilities will continue to carry out disproportionate amounts of labour managing their own supports and services just to have their basic needs fulfilled. We urge the Committee to consider ways to support people with disabilities, including funding for individual and systemic advocacy, service navigation and support coordination, and increased accessibility across all policy portfolios and domains. We have made clear calls for funding, policy and programs that will support people with disabilities through our recent submission to the ACT Budget along with other Disabled People's Organisations<sup>3</sup>. People with disabilities should not have to perform additional unpaid work in order to fully participate in the ACT community.

If you would like to discuss this submission further, please contact WWDACT CEO Kat Reed <a href="mailto:ceo@wwdact.org.au">ceo@wwdact.org.au</a>.

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<sup>&</sup>lt;sup>3</sup> WWDACT, AFI and ACTDSID. (2023). Joint Submission: ACT Disabled Peoples Organisations set out share priorities for the 2024/25 ACT Government Budget. https://wwdact.org.au/wp-content/uploads/2023/12/07.-Advocacy-for-Inclusion-ACT-Down-Syndrome-Association-Women-with-Disabilities-and-Mental-Health-Community-Coalition.pdf.