

# **Submission to the Senate Inquiry into Matters Relating to Work and Care in Australia**

Centre for Disability Research and Policy

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Centre for Disability Research and Policy

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Thank you for the opportunity to respond to the Senate Inquiry into matters relating to work and care in Australia.

We have made specific responses as supported by empirical evidence under the areas identified in your terms of reference. Please note that as we have addressed only those areas where we have a contribution to make, not all items have been responded to. Also, while we have used person first language throughout our submission, we respect the rights of individuals to identify as they choose.

**d. the adequacy of current work and care supports, systems, legislation and other relevant policies across Australian workplaces and society;**

Shortfalls exist in the National Disability Insurance Scheme (NDIS) which can negatively impact upon the lives of people who are involved in care work and the people with disability that they are in a caring relationship with. These shortfalls are evidenced across diverse areas including those of access, accountability, priorities, and language. In terms of accessibility issues, thousands of primary carers of people with disability continue to miss out on funded support from the NDIS<sup>1</sup>. The NDIS has also struggled to redress the inequalities that can accompany living in rural locations and which subsequently increase pressure on carers and supporters of people with disability<sup>2</sup>.

Regarding the issue of accountability, a cycle of abuse and neglect of Australians with disability can continue through cover-ups, managerial insensitivity, as well as the demotivation of workers, people involved in care-giving and people with disability themselves to intervene or to report issues<sup>3</sup>. These risks of abuse are said to be heightened in decentralised, provider-driven regulation contexts, such as those established under the NDIS<sup>4</sup>, where providers may be either registered or unregistered. Continuing to have unregistered providers in an area like disability, where regulation is clear and necessary is significantly problematic for people with disability and the ability of the government to create standards of practice for the care workforce.

NDIS funding cuts can also dramatically impact upon the lives of carers and people with disability. An Australian workforce development study has noted that carers are calling for

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<sup>1</sup> Broady, T., & Weber, N. (2021). Carers missing out: a scoping study following the introduction of the National Disability Insurance Scheme.

<sup>2</sup> Prowse, A., Wolfgang, R., Little, A., Wakely, K., & Wakely, L. (2022). Lived experience of parents and carers of people receiving services in rural areas under the National Disability Insurance Scheme. *Australian Journal of Rural Health*, 30(2), 208-217.

<sup>3</sup> Ottmann, G., McVilly, K., Anderson, J., Chapman, J., Karlyawasam, I., Roy, A., ... & Stefano, A. (2017). Barriers and enablers to safeguarding children and adults within a disability services context: Insights from an Australian Delphi study. *Social Policy & Administration*, 51(3), 488-510.

<sup>4</sup> Cortis, N., & Van Toorn, G. (2022). Safeguarding in Australia's new disability markets: Frontline workers' perspectives. *Critical Social Policy*, 42(2), 197-219.

the NDIS and disability organisations to improve their performance in terms of prioritising carers and participants over profit<sup>5</sup>.

Australian policymakers need to recognise the importance of consistently using inclusive language that does not contribute to negative stereotypes about people with disability or the people that are in caring or supportive relationships with them, whether paid or unpaid. In this light, the literature has reported that some people with disability do not like the use of terms such as 'carer' or 'disability' as these words can hold negative connotations by focusing on what they cannot do and the more complex and supportive relationships that people with disability have with those who support them<sup>6</sup>. We therefore argue that the language of care should be considered more broadly in light of community concerns.

**e. consideration of the impact on work and care of different hours and conditions of work, job security, work flexibility and related workplace arrangements;**

Having flexible work arrangements in place is described as a significant first step in supporting the needs of working carers<sup>7</sup>. Relating to lessons arising from COVID-19 that can help to improve support for carers and supporters of people with disability (lessons that are to be detailed in our following response), the pandemic has shown that employers can introduce arrangements which benefit carers and others that had earlier been deemed as impossible<sup>8</sup>.

As carer roles can be conducted over many years, a call has been made for investment in the longitudinal research that is needed to critically examine the ways in which people who provide care to people with disability modify their work arrangements over time to reflect the changing needs of the person(s) that they support<sup>9</sup>.

**f. the impact and lessons arising from the COVID-19 crisis for Australia's system of work and care;**

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<sup>5</sup> Hurley, J., & Hutchinson, M. (2022). Carers' experiences of the National Disability Insurance Scheme workforce: A qualitative study informing workforce development. *Australian Journal of Social Issues*, 57(2), 458-471.

<sup>6</sup> Lloyd, J., Moni, K., Cuskelly, M., & Jobling, A. (2022). The National Disability Insurance Scheme: voices of adults with intellectual disabilities. *Research and Practice in Intellectual and Developmental Disabilities*, 1-9.

<sup>7</sup> Vinarski-Peretz, H., & Halperin, D. (2021). Informal Caregivers along the Work–Eldercare Axis: A Comparative Analysis of Australia, England, and Israel. *International Journal of Law, Policy and The Family*, 35(1), ebaa015.

<sup>8</sup> Matheson, R., Judd-Lam, S., Bainbridge, H., & Townsend, K. Flexible working is important, but employers need a broader workplace strategy for carers.

<sup>9</sup> Lafferty, A., Phillips, D., Fealy, G., Paul, G., Duffy, C., Dowling-Hetherington, L., ... & Kroll, T. (2022). Making it work: a qualitative study of the work-care reconciliation strategies adopted by family carers in Ireland to sustain their caring role. *Community, Work & Family*, 1-20.

People with disability are particularly vulnerable to the mental, physical and social impact of pandemics and other social and environmental crises<sup>10</sup>. Hence, there are many lessons arising from COVID-19 for Australian policymakers who are interested in achieving better outcomes for carers of people with disability in current and future pandemics. Key evidence-based lessons centre around the following issues and needs:

- 1) A need for flexible and responsive supports to assist care givers to recover from COVID-19 related stresses<sup>11</sup>.
- 2) Following a breakdown in the care system for people with disability during COVID-19 which had a disproportionate impact on care givers (and in particular, female care givers) a need exists to better redress the discriminatory economic and social impacts of such health emergencies in the future<sup>12</sup>.
- 3) As the pandemic has heightened challenges that are experienced by informal care givers, Australian universities and vocational education providers need to construct and implement specific policies to attract and support students with care-giving responsibilities<sup>13</sup>.
- 4) A need to recognise the role played by technologies (e.g., videoconferencing) in helping to maintain connections for care givers, people with disability and their families<sup>14 15</sup>.
- 5) It is vital that contingency plans are in place for people with disability who are living in long-term care and those who provide care for future pandemics or emergency situations<sup>16</sup>. Disability inclusive disaster risk reduction planning should be considered as key to supporting care givers as well as people with disability (see [here](#))<sup>17</sup>. Also, supporting people with intellectual and developmental disability, pandemic behaviour support response plans need to be available in addition to health response plans<sup>18</sup>.

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<sup>10</sup> Gupta, A., Kavanagh, A., & Disney, G. (2021). The impact of and government planning and responses to pandemics for people with disability: A rapid review. *International journal of environmental research and public health*, 18(12), 6505.

<sup>11</sup> Hofstaetter, L., Judd-Lam, S., & Cherrington, G. (2022). Informal care in Australia during the COVID-19 pandemic. *International Journal of Care and Caring*, 6(1-2), 253-259.

<sup>12</sup> Davies, S. E., & di Piramo, D. (2022). Spotlight on the gendered impacts of COVID-19 in Australia: a gender matrix analysis. *Australian Journal of Human Rights*, 1-21.

<sup>13</sup> Andrewartha, L., & Harvey, A. (2021). Supporting carers to succeed in Australian higher education.

<sup>14</sup> Trip, H., Northway, R., Perkins, E., Mirfin-Veitch, B., & Adams, R. (2022). COVID-19: Evolving challenges and opportunities for residential and vocational intellectual disability service providers. *Journal of Policy and Practice in Intellectual Disabilities*, 19(1), 102-115.

<sup>15</sup> Alexander, R., Ravi, A., Barclay, H., Sawhney, I., Chester, V., Malcolm, V., Brolly, K., Mukherji, K., Zia, A., Tharian, R., Howell, H., Lane, T., Cooper, V., & Langdon, P. E. (2020). Guidance for the treatment and management of COVID-19 among people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 17(3), 256–269

<sup>16</sup> Gupta, A., Kavanagh, A., & Disney, G. (2021). The impact of and government planning and responses to pandemics for people with disability: A rapid review. *International journal of environmental research and public health*, 18(12), 6505.

<sup>17</sup> Villeneuve, M. Disability Inclusive Disaster Risk Reduction (DIDRR) Resources:  
<https://collaborating4inclusion.org/>

<sup>18</sup> Nankervis, K., & Chan, J. (2021). Applying the CRPD to people with intellectual and developmental disability with behaviors of concern during COVID-19. *Journal of Policy and Practice in Intellectual Disabilities*, 18(3), 197-2021.

**g. consideration of gendered, regional and socio-economic differences in experience and in potential responses including for First Nations working carers, and potential workers;**

Culturally aware and respectful policy actions are needed to address the issues that are faced by First Nations people and communities involved in the care of people with disability. Indigenous care givers have provided detailed narratives suggesting that Western constructions about who cares for whom weakens:

a) the capacity of Indigenous carers to offer the quality of care that they desire to give to immediate and extended family members; and

b) the capacity of Indigenous women with disabilities as primary carers and with extended kinship responsibilities for self-care<sup>19</sup>.

Western values when embedded in government policies and practice can disadvantage Indigenous people in favour of non-Indigenous people<sup>20</sup>. First Nations carers who assist people with chronic health needs are often female, elderly and requiring support themselves<sup>21</sup>. Carers of Indigenous children with disability have also reported being cautious about accessing support on occasions where providers were seen to be disrespectful or judgemental of Indigenous families<sup>22 23</sup>. Calls are therefore made for respect of First Nations values and practices in approaches to assisting family caregivers<sup>24</sup>. The development of guidelines and practices in this area should be led by Aboriginal and Torres Strait Islander people to ensure that it is culturally relevant and appropriate to the local contexts in which it is to be implemented.

**h. consideration of differences in experience of disabled people, workers who support them, and those who undertake informal caring roles;**

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<sup>19</sup> Fitts, M. S., & Soldatic, K. (2022). Who's caring for whom? Disabled Indigenous carers experiences of Australia's infrastructures of social protection. *Journal of Family Studies*, 28(2), 477-492.

<sup>20</sup> Gilroy, J., Dew, A., Lincoln, M., Ryall, L., Jensen, H., Taylor, K., ... & Flood, V. (2018). Indigenous persons with disability in remote Australia: Research methodology and Indigenous community control. *Disability & Society*, 33(7), 1025-1045.

<sup>21</sup> Cooms, S., Muurlink, O., & Leroy-Dyer, S. (2022). Intersectional theory and disadvantage: a tool for decolonisation. *Disability & Society*, 1-16.

<sup>22</sup> Campbell, L., Reath, J., Hu, W., Gunasekera, H., Askew, D., Watego, C., ... & Abbott, P. (2022). The socioemotional challenges and consequences for caregivers of Aboriginal and Torres Strait Islander children with otitis media: A qualitative study. *Health Expectations*.

<sup>23</sup> Green, A., Abbott, P., Davidson, P. M., Delaney, P., Delaney, J., Patradoon-Ho, P., & DiGiacomo, M. (2018). Interacting with providers: An intersectional exploration of the experiences of carers of Aboriginal children with a disability. *Qualitative Health Research*, 28(12), 1923-1932.

<sup>24</sup> Puszka, S., Walsh, C., Markham, F., Barney, J., Yap, M., & Dreise, T. (2022). Towards the decolonisation of disability: A systematic review of disability conceptualisations, practices and experiences of First Nations people of Australia. *Social Science & Medicine*, 115047.

Australian policymakers are challenged to improve the experiences of young carers of people with disability. A systematic review has suggested that young carers can experience poorer mental wellbeing than their peers, and that research is needed to identify suitable supports and resources to help to redress this issue<sup>25</sup>. Furthermore, recognising that providing care can impact in positive and negative ways upon the physical and mental health of young carers, the stigma that is linked to a carer status can impede access to support services among these people<sup>26</sup>.

The literature has also indicated that mental health programs are needed to address the economic challenges and abuse experienced by care givers more broadly so as to be inclusive of those who are caring for more than one person or for persons in complex situations such as those impacted by drug and alcohol abuse<sup>27</sup>.

Attitudes held by paid and unpaid care givers can negatively impact on the quality of life of Australians with disability. Examples include:

- A cross-sectional replication study involving 115 Australian nurses identified a need to improve nurses' attitudes concerning the quality of life of adults with intellectual disability<sup>28</sup>.
- Persons who provide care to people with disabilities including service providers and care givers need to respect the human rights and sexual expression in supporting safe access to dating apps and websites<sup>29</sup>.
- An Australian mixed method study involving 859 trans-gender persons aged between 14 and 25 revealed that those with autism spectrum disorders are more likely to experience barriers in attempts to access gender-affirming care<sup>30</sup>.
- NDIS staff are often placed in the position of advocating for the needs of children when carers, through their personal views, might push against what the child wants<sup>31</sup>.

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<sup>25</sup> Singh, A., Disney, G., Ervin, J., & King, T. (2022). Mental health of young informal carers: a systematic review. *Social Psychiatry and Psychiatric Epidemiology*.

<sup>26</sup> Addo, I. Y., Aguilar, S., Judd-Lam, S., Hofstaetter, L., & Poon, A. W. C. (2021). Young carers in Australia: understanding experiences of caring and support-seeking behaviour. *Australian Social Work*, 1-14.

<sup>27</sup> Obst, P., Murray, K., Walbank, S., Kelly, R., & Brazel, D. (2022). Experiences of abuse in Australian family carers and predictors of mental health and well-being. *Health & Social Care in the Community*, 30(2), 476-487.

<sup>28</sup> Desroches, M. L., Howie, V. A., Wilson, N. J., & Lewis, P. (2022). Nurses' attitudes and emotions toward caring for adults with intellectual disability: An international replication study. *Journal of Nursing Scholarship*, 54(1), 117-124.

<sup>29</sup> Martino, A. S., & Kinitz, D. (2022). "It's just more complicated!": Experiences of adults with intellectual disabilities when navigating digital sexual fields. *Cyberpsychology: Journal of Psychosocial Research on Cyberspace*, 16(2).

<sup>30</sup> Strauss, P., Cook, A., Watson, V., Winter, S., Whitehouse, A., Albrecht, N., ... & Lin, A. (2021). Mental health difficulties among trans and gender diverse young people with an autism spectrum disorder (ASD): Findings from Trans Pathways. *Journal of Psychiatric Research*, 137, 360-367.

<sup>31</sup> Robinson, S., Graham, A., Canosa, A., Moore, T., Taylor, N., & Boyle, T. (2022). Ethical Practice in Disability Services: Views of Young People and Staff. *Ethics and Social Welfare*, 1-20.

The mental health of carers of people with disability can be promoted through screening processes. Research supports the important role of general practitioners in the screening of psychological distress among primary carers of people with disability<sup>32</sup>.

Australian research has highlighted the need to: 1) ensure that policies which endeavour to assist caregivers also take into account the experiences of older gay and lesbian people; 2) encourage aging caregivers to attain financial and other kinds of support where needed; and 3) promote access to support services that hold attributes of being inclusive and culturally safe<sup>33</sup>.

**i. consideration of the policies, practices and support services that have been most effective in supporting the combination of work and care in Australia, and overseas;**

Flexibility in terms of work hours and the capacity to take leave when needed is reported to be essential for working carers<sup>34</sup>. Acknowledging the importance of this flexibility for working carers of people with disability, uncertainties nevertheless remain around the ongoing availability of flexible work practices such as remote working in a post pandemic phase<sup>35</sup>. Organisational policies therefore need to ensure that advances in inclusive workplace practices resulting from COVID-19 are not diminished or lost.

It is also important that the practices which support working carers of people with disability are sustainable. Longitudinal data has supported the role of replacement care involving respite care, home care and providing personal assistants as helping carers to stay in the workplace<sup>36</sup>.

## About the Centre for Disability Research and Policy

The Centre for Disability Research and Policy (CDRP) at the Faculty of Health Sciences of the University of Sydney aims to change the disadvantage that occurs for people with disabilities. We do this through addressing their social and economic participation in society, and their health and wellbeing. By focusing on data that demonstrates disadvantage, we can

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<sup>32</sup> Wang, J., & Du, W. (2019). Factors associated with high psychological distress in primary carers of people with disability. *Australian Journal of General Practice*, 48(4), 234-238.

<sup>33</sup> Waling, A., Lyons, A., Alba, B., Minichiello, V., Barrett, C., Hughes, M., ... & Bath, N. (2022). Experiences of informal caregiving among older lesbian and gay adults in Australia. *Australasian Journal on Ageing*.

<sup>34</sup> Vinarski-Peretz, H., & Halperin, D. (2021). Informal Caregivers along the Work–Eldercare Axis: A Comparative Analysis of Australia, England, and Israel. *International Journal of Law, Policy and The Family*, 35(1), ebaa015.

<sup>35</sup> Lafferty, A., Phillips, D., Fealy, G., Paul, G., Duffy, C., Dowling-Hetherington, L., ... & Kroll, T. (2022). Making it work: a qualitative study of the work-care reconciliation strategies adopted by family carers in Ireland to sustain their caring role. *Community, Work & Family*, 1-20.

<sup>36</sup> Pickard, L., Brimblecombe, N., King, D., & Knapp, M. (2018). ‘Replacement Care’ for working carers? A longitudinal study in England, 2013–15. *Social Policy & Administration*, 52(3), 690-709.

develop models of policy and practice to better enable support and opportunity for people with disabilities.

## About the authors

Dr Damian Mellifont is a Lived Experience Researcher Fellow with the Centre for Disability Research and Policy at The University of Sydney and lead of the lived experience-led research work stream. Damian's work informs evidence-based ways to redress ableism and endeavours to improve the social and economic inclusion of people with disability. Damian is also an editor of the Disability Studies Collection at Lived Places Publishing.

Professor Jennifer Smith-Merry is Director of the Centre for Disability Research and Policy (CDRP) in the Faculty of Medicine and Health at The University of Sydney. Her academic research has focused on policy and service development, primarily in mental health and the study of adverse events. Jen is lead Chief Investigator on multiple grants which aim to evaluate or develop policy and services in disability and mental health. She works closely with people with a lived experience of disability and has a strong interest in the value of lived experience in informing policy and service design. Jen led the development of the *Mind the Gap* report into the National Disability Insurance Scheme (NDIS) and psychosocial disability.