

WOMEN WITH DISABILITIES AUSTRALIA (WWDA)

Response to the National Health and Climate Strategy – Consultation Paper

National Health, Sustainability and Climate Unit Australian Department of Health and Aged Care

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ABOUT WOMEN WITH DISABILITIES AUSTRALIA (WWDA)

<u>Women With Disabilities Australia (WWDA)</u> Inc is the national Disabled People's Organisation (DPO) and National Women's Alliance (NWA) for women, girls, feminine identifying, and non-binary people with disability in Australia. As a DPO and an NWA, WWDA is governed, run, and staffed by and for women, girls, feminine identifying and non-binary people with disability.

WWDA uses the term 'women and girls with disability', on the understanding that this term is inclusive and supportive of, women and girls with disability along with feminine identifying and non-binary people with disability in Australia.

WWDA represents more than 2 million women and girls with disability in Australia, has affiliate organisations and networks of women with disability in most States and Territories, and is recognised nationally and internationally for our leadership in advancing the rights and freedoms of all women and girls with disability. Our organisation operates as a transnational human rights organisation - meaning that our work, and the impact of our work, extends much further than Australia. WWDA's work is grounded in a human-rights based framework which links gender and disability issues to a full range of civil, political, economic, social, and cultural rights. All WWDA's work is based on co-design with and participation of our members. WWDA projects are all designed, governed, and implemented by women and girls with disability.

Disabled People's Organisations (DPOs), also referred to as Organisations of Persons with Disabilities (OPDs) are recognised around the world, and in international human rights law, as self-determining organisations led by, controlled by, and constituted of, people with disability. DPOs/OPDs are organisations of people with disability, as opposed to organisations which may represent people with disability. The United Nations Committee on the Rights of Persons with Disabilities has clarified that States should give priority to the views of DPOs/OPDs when addressing issues related to people with disability. The Committee has further clarified that States should prioritise resources to organisations of people with disability that focus primarily on advocacy for disability rights and, adopt an enabling policy framework favourable to their establishment and sustained operation.¹

WWDA'S RESPONSE TO NATIONAL HEALTH AND CLIMATE STRATEGY – CONSULTATION PAPER

- 1. Women With Disabilities Australia (WWDA) welcomes the opportunity to respond to the Australian Government's National Health and Climate Strategy Consultation Paper (Consultation Paper).²
- 2. WWDA commends the Government on its efforts to address the critical intersection of health, climate change, and social equity. It is increasingly clear that the impacts of climate change expose existing inequalities, and that those who face the greatest levels of risk are those who face the highest inequality in everyday life. This includes people with disability, women, children, older persons, First Nations peoples, people with chronic health conditions and other contextually marginalised people.³ The risks are further heightened for those who face overlapping marginalisation, including women with disability.
- 3. The United Nations Human Rights Council has recognised that the human rights of people with disability are disproportionately affected by the negative impacts of climate change.⁴ Extremes in weather can prevent access to medication, vital healthcare, and devices that require electricity. A lack of accessible information; accessibility in evacuation, response, and recovery efforts; and exclusion of disability issues in planning and preparedness, means that people with disability are also at higher risk of injury and death. The global mortality rate of people with disabilities in natural disasters is up to four times that of people without disabilities.⁵ Research from the United Nations shows that only 20% of people with a disability could evacuate immediately and without difficulty, in the event of a sudden disaster; the remainder could only do so with a degree of difficulty and 6% would not be able to do so at all.⁶ When able to evacuate, people with disability continue to face additional barriers, violence and discrimination, including a heightened risk of sexual violence in public shelters. They may also lose possession of assistive technology, or be separated from support systems. Articles 9, 11 and 14 of the Convention on the Rights of Persons with Disabilities (CRPD) clearly stipulate that governments have a duty to ensure that people with disabilities have the information and supports they need to stay safe and protected in situations of risk.8 However, people with disability continue to be excluded from, and marginalised within, government and non-government plans and responses to climate-related emergencies in Australia, including bushfires, floods, droughts and virus outbreaks.
- 4. Ultimately, good public policy is good climate adaptation policy, good health equity policy, and good disability policy. This includes addressing everyday inequities, such as ensuring access to adequate healthcare; safe, secure and affordable housing; decent working conditions; social and community participation; income support, and inclusive infrastructure.

Objectives and Principles of the Strategy

5. WWDA supports the Objectives and Principles of the Strategy, and in particular, the focus on addressing health inequities and centring First Nations expertise. Efforts to strengthen the health system must recognise that particular demographics of people in Australia already experience inadequate access to healthcare regardless of a state of emergency. In addition to building a climate-resilient health system, efforts must be directed towards ensuring that the existing health system is accessible, equitable, and affordable. This requires a health system that takes into account the unique healthcare needs and accessibility requirements of people with disability. As identified by the Consultation Paper, this also requires a Health in All Policies approach.

- 6. WWDA also supports the Strategy's commitment to evidence-informed policymaking. However, in addition to measuring and reporting on health system greenhouse gas emissions, the Strategy should include measuring and reporting on the differential impacts of climate change and health system change on marginalised communities. This includes data that is disaggregated by gender and disability. Article 31 of the CRPD requires Australia to collect and use data to give effect to the rights set out in the Convention.¹⁰
- 7. Further, and contrary to the Consultation Paper's proposition, cost-effectiveness analysis should not take precedence over rights-based approaches to policymaking. 'Maximising population health gains', as described in Principle 5, will exacerbate health inequities unless ethical and rights-based frameworks are used for decision-making. Cost-effectiveness analysis can be problematic for people with disability and other marginalised demographics because it assumes that all people have equal access to healthcare and that cost and benefit apply consistently across different demographics. Further, cost-effectiveness analysis assigns pecuniary value to human life and wellbeing. In an ableist society where the lives of people with disability are chronically under-valued, cost-effectiveness analysis may result in prioritising healthcare for people with less complex health needs, and a belief that health gains are more "valuable" for people without disability. Cost-effectiveness analysis may therefore contribute to the operation of Inverse Care Law in Australia, where the availability of good medical care varies inversely with the need for it in the population served.¹¹
- 8. Article 25 of the CRPD requires Australia to recognise that people with disability have the right to the highest attainable standard of health without discrimination. However, both past and international experience demonstrates that in times of crisis, people with disability are left behind. As WWDA has previously written in a joint Statement of Concern on COVID-19: Human rights, disability and ethical decision-making: decision-making: 13

...as the pandemic progresses in Australia, and there is greater demand on critical health treatment and intensive medical care, we are concerned about the policies, protocols and guidelines that will determine decision-making in the context of lifesaving medical treatment. Our concerns are based on international experience that shows that human rights have not been applied to a number of COVID-19 specific health directives and medical decision-making protocols.¹⁴

This has demonstrated an underlying, pervasive and often unquestioned devaluing of people with disability that is termed 'ableism'. We are concerned, along with people with disability about similar ableist practices and protocols being replicated in Australia.

- 9. Priority setting in healthcare must be informed by ethical principles and a rights-based approach.

 Noting the potential for cost-effectiveness analysis to lead to discrimination against people with disability, we refer to the research conducted by the United States of America's National Council on Disability in relation to alternative models for determining the value of health interventions.¹⁶
- 10. The Strategy must also ensure that the Health in All Policies approach is intersectional. Care must meet the complex and specialised needs of people with disability who face multiple intersecting forms of

- disadvantage, such as First Nations people with disability, gender and sexually diverse people with disability, culturally and linguistically diverse people with disability, and women and girls with disability.
- 11. Finally, ensuring that Principle 6, 'Partnership-based working across all levels of government and beyond', is adequately implemented requires genuine consultation, co-design and co-production with diverse communities. This is discussed in greater detail below.

Actions proposed in the Strategy

Prevention

- 12. As identified by the Consultation Paper, effective preventative health care can reduce the onset and severity of health conditions, mitigate the need for acute care, and reduce the carbon footprint of the healthcare system. However, people with disability are often unable to obtain adequate preventative healthcare.
- 13. Preventable hospitalisation rates are approximately 4.5 times higher for people with intellectual disabilities than for people without intellectual disabilities,¹⁷ and an estimated 400 people with intellectual disability over the age of 20 die in Australia each year from preventable causes.¹⁸ People with disability also attend hospital emergency departments at higher rates than people without disability, even where they feel a general practitioner could have provided the required care.¹⁹ Potentially preventable hospitalisations are a performance indicator of health care accessibility and effectiveness.²⁰ As data from the Australian Institute of Health and Welfare indicates, 1 in 8 people with disability have difficulty accessing medical facilities, and 1 in 8 who need help with health-care activities have no source of assistance (either formal or informal).²¹ As the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Royal Commission) heard during *Public Hearing 4: Health care and services for people with cognitive disability*, the failure to provide adequate preventative healthcare to people with disability results in:

delayed or missed diagnoses; a lack of active management; non-evidence based prescribing practices; poorer health trajectories and over-representation of potentially avoidable morbidities and hospitalisations; poor end of life care; and high rates of premature mortality.²²

14. Although efforts have been made to increase access to preventative and comprehensive health assessments for people with disability, these assessments have not been adequately implemented. ²³ Improving access to preventative care requires addressing all barriers to access, including physical and financial barriers, as well as barriers related to travel and distance, communication, practitioner training and education, wait times, trauma, and support and assistance. It also requires addressing attitudinal barriers to proper care, including prejudice, ableism, and diagnostic overshadowing. These barriers are discussed in greater detail in the Public Hearing Report. ²⁴ During the Public Hearing, the Royal Commission also heard evidence that there is a dearth of research examining preventable hospitalisations or causes of death among people with intellectual disability and Autistic people in Australia. ²⁵ The lack of a consistent method for tracking and publishing such data is a missed opportunity to detect gaps in care and direct future health care spending, ²⁶ and also undermines Australia's obligations under the CRPD.

- 15. Unnecessarily extended durations of hospital stay are also associated with increased emissions, as well as dire consequences for people with disability. In a recent study of patients with acquired disability, some patients waited up to 600 days between being clinically ready for discharge from hospital, and the actual date of discharge.²⁷ The most common reason for the delay was that patients were waiting on the finalisation of processes to access supports through the National Disability Insurance Scheme.²⁸ Unnecessary bed days are directly linked to the availability of public services, and social and community support and care.
- 16. At the intersections of gender and disability, women with disability face compounding barriers to adequate preventative healthcare, including due to medical gender bias which impacts interactions with health services, access to and provision of healthcare, and medical research into treatment and diagnostic options. For example, the only reliable method of diagnosis for endometriosis is laparoscopic surgery, which is both an invasive procedure and associated with significant carbon footprint through the use of anaesthesia.²⁹
- 17. When addressing the availability and uptake of preventative healthcare initiatives, policy decisions must also consider the specific economic disadvantages that face different cohorts of people with disability across Australia. For example, research indicates that women with disability spend more of their income on medical care and health related expenses than men with disability and are in lower income brackets on average.³⁰ The economic disadvantage of First Nations people with disability is similarly exacerbated.

Optimising models of care

- 18. The Consultation Paper notes that the Strategy may involve reviewing existing health services and models of care, including Telehealth, to understand their potential to contribute to emissions reductions. In other countries, digital and telehealth services have been associated with significantly reduced carbon emissions.³¹ However, such models of care must be assessed for their accessibility and impacts on people with disability. The increased use of Telehealth throughout and following the COVID-19 pandemic has provided some benefits for people with disability, including reduced costs and decreased need for assistance to access medical facilities. However, the increased use of digital health services also leaves many people with disability behind. A shift to digital services will exacerbate existing inequities unless barriers to digital inclusion are addressed.
- 19. Like healthcare, digital inclusion is socially and economically distributed.³² Globally, there remains a gendered gap in access to digital technologies, as well as gaps for First Nations Australians, people with disability, older persons and people living in remote, rural and regional areas. Accessibility, cost, digital literacy and network availability remain barriers to digital inclusion in Australia. People with disability experience barriers to digital inclusion both materially (in access to digital goods and services), and functionally (in use of digital goods and services). When healthcare services employ new technologies, disparities in digital literacy and accessibility can mean that those who rely on these services experience the greatest disadvantage. The right to equal access to technology is enshrined in Article 9 of the CRPD,³³ and is an enabling right, or 'a vital precondition for the effective and equal enjoyment of civil, political, economic, social and cultural rights by persons with disabilities'.³⁴ The United Nations Committee on the Rights of Persons with Disabilities has stated that 'it is unacceptable to use public funds to create or perpetuate the inequality that inevitably results from inaccessible services and facilities'.³⁵ Therefore, unless digital healthcare services are designed to meet the unique needs of

- people with disability and other marginalised demographics, the Australian Government will not fulfil its international human rights obligations.
- 20. The Consultation Paper also proposes a focus on social prescribing, which it defines as 'referring patients to social services, community support or voluntary activities as opposed to prescribing them a medicine or referring them for medical care'. While WWDA agrees that there is great value in the use of social and community supports for addressing the social determinants of health and wellbeing, these supports must be accessible. This includes by ensuring that they are funded, widely available, and genuinely disability inclusive. Currently, there is a scarcity of funded community supports for the vast majority of people with disability in Australia who are not participants of the National Disability Insurance Scheme. The redirection of people with disability to community services, in the absence of improved care and support infrastructure, will result in further exclusion and a decline in health outcomes.
- 21. When reviewing existing and potential models of care, the Strategy must also have regard to growing recognition that emissions can be reduced by ensuring value-based care. Recent estimates indicate that about 30% of health care is wasteful or low value, and a further 10% is actively harmful.³⁶ Emerging evidence indicates that patient empowerment and engagement is effective in reducing rates of low value care. Techniques include the use of multidisciplinary teams, and patient decision aids to support patients to share in decision-making.³⁷ This is consistent with WWDA's continual calls for supported decision-making for people with disability in all areas of life, an approach that aligns with the CRPD. We refer in this regard to the WWDA *Position Statement: The Right to Decision-Making* and note that women and girls with disability are frequently excluded from participating in decisions that affect their lives on a daily basis, including as active agents in their own health care.³⁸

Enablers identified by the Strategy

- 22. The Consultation Paper provides for a number of 'enablers', said to form the foundation for action in the health system to address climate change. WWDA agrees that workforce capacity building, research, communication and engagement, collaboration and monitoring and reporting are important focus areas. The Strategy must take an intersectional approach to each of these enabling factors, implementing a gender-responsive and disability-inclusive lens. This includes by:
 - further developing the skills and capacity of the healthcare workforce to address the needs of people with disability including in relation to the impacts of climate change;
 - investing in and supporting research on current and emerging climate risks for people with disability, and how efforts to strengthen the resilience and sustainability of the health system can improve healthcare for people with disability;
 - engaging with people with disability and their representative organisations to ensure actions to address the health and health system impacts of climate change are not only widely understood, but informed by people with disability;
 - collaborating with people with disability to facilitate working partnerships to strengthen climate resilience; and
 - ensuring that measuring, evaluating and reporting on the impacts of actions taken includes data that is disaggregated by gender and disability.
- 23. Climate mitigation and adaptation measures must be disability inclusive. They must be effective for, implemented, and accountable to people with disability.³⁹ This necessitates that people with disability

and the organisations that represent them be involved in the co-design and co-production of such measures. Indeed, the CRPD requires that people with disability participate in the creation of climate change strategies. However, people with disability are often inadequately consulted during policy-making processes or left out entirely. This results in policies, strategies and decisions that do not reflect or meet the needs of people with disability. Australia's responses to COVID-19 and the Black Summer Bushfires are recent examples of the failure to respond to the needs of people with disability in emergency situations. In this regard, we refer to the Report of the Royal Commission on *Public hearing 12: The experiences of people with disability, in the context of the Australian Government's approach to the COVID-19 vaccine rollout,* ⁴⁰ and our response to the Royal Commission's *Response to Emergency Planning Issues Paper.* ⁴¹

- 24. Indeed, in the context of decisions during the COVID-19 vaccine roll-out, the Royal Commission found that the Department of Health's decision-making process was 'not consistent with reasonable expectations of an Australian Government agency making a decision affecting the health and wellbeing of the community, specifically the health and wellbeing of people with disability' because the Department: 42
 - did not seek any advice from any person with relevant expertise in the health of people with disability, and specifically intellectual disability;
 - did not consult with or seek any advice from the Advisory Committee on Health Emergency Response to Coronavirus (COVID-19) for People with Disability;
 - did not seek advice about the impact of changing priorities for people with disability living in disability residential settings;
 - did not consider whether some people in disability residential accommodation were exposed to a similar level of risk as aged care residents;
 - took no advice as to whether the decision was consistent with the Australian Government's obligations under the *Disability Discrimination Act 1992* (Cth).
- 25. The Royal Commission also found that the:⁴³

failure to make public the decision to deprioritise the vaccination of people in disability residential settings meant that people with disability and Disability Representative Organisations were unaware of the Government's change of course...

26. In order to respond effectively to a crisis situation, people with disability and their representative organisations must have access to up-to-date information. In order to ensure that Government responses to crisis are effective, they must be informed by, and co-designed with, people with disability. Co-design involves the sharing of power and decision-making authority. It also requires providing the necessary resources, funding and support to facilitate genuine participation.

RECOMMENDATIONS

1. Amend the Principles and Objectives of the Strategy to provide for a human rights-based approach to climate change and health and ensure that this approach is the foundation of all decision-making.

- 2. Ensure that initiatives to strengthen the healthcare system and reduce greenhouse gas emissions fundamentally recognise and address health inequities. For example:
 - a. Review and assess models of care for their accessibility and implement models of care that are responsive to the needs of marginalised communities.
 - b. Where digitised healthcare services are used, address digital exclusion and ensure that services are accessible by improving infrastructure and availability, and educating healthcare professionals on the inclusive and equitable use of digital technologies.
 - c. Promote mixed models of service delivery to allow choice between digitised and face-to-face healthcare.
 - d. Address and eradicate the barriers that people with disability face to obtaining adequate preventative healthcare. This includes by investing in training and education for healthcare professionals.
 - e. Abolish substitute decision-making regimes and mechanisms, including in the healthcare system, and implement mechanisms to facilitate patient engagement as means to reduce low-value care and promote the realisation of human rights.
- 3. Engage in genuine consultation, co-design and co-production with people with disability at all levels and in all phases of the Strategy, including ongoing monitoring and evaluation.
- 4. Consistent with the CRPD and reflecting the critical role of Disabled People's Organisations and independent advocacy organisations (including in times of national disasters and emergencies), provide long-term support, including core support and resources for disability advocacy and information services, research, and capacity building.
- 5. Consistent with recommendations from the Committee on the Rights of Persons with Disabilities, consult with people with disability and their representative organisations to establish nationally consistent emergency management standards to be implemented across all levels of government, that ensure inclusivity across diverse impairments and that cover all phases of emergency management preparation, early warning, evacuation, interim housing/accommodation and support, recovery and rebuilding.
- 6. Consistent with recommendations from the Committee on the Rights of Persons with Disabilities and in close consultation with representative organisations, establish a fully accessible and inclusive mechanism to engage with people with disability in the implementation and monitoring of the Sendai Framework.
- 7. Implement the directives for States as set out in the Resolution adopted by the United Nations Human Rights Council on 12 July 2019, including by:
 - a. Implementing policies aimed at increasing the participation of persons with disabilities in climate change responses; and
 - b. Adopting a comprehensive, integrated, gender-responsive and disability-inclusive approach to climate change adaptation and mitigation policies.⁴⁴

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