

STATEMENT OF CONCERN

COVID-19:
Human rights,
disability
and ethical
decision-making





This Statement of Concern is made by internationally recognised independent experts in the area of human rights, bioethics and disability who have come together to emphasise key human rights principles and standards that need to underpin ethical decision-making in the context of disability and the COVID-19 pandemic.

People with disability are at much greater risk than the general population from the COVID-19 pandemic, and in particular, older people with disability, First Peoples with disability, people with intellectual disability, people with psychosocial disability and those with chronic health conditions, co-morbidities, dependence on ventilators and compromised immunity.

These risks have been outlined by people with disability, their representative organisations, advocates and allies in international and national ‘calls to action’ for governments to ensure disability inclusive public health, social and economic responses to the pandemic.¹

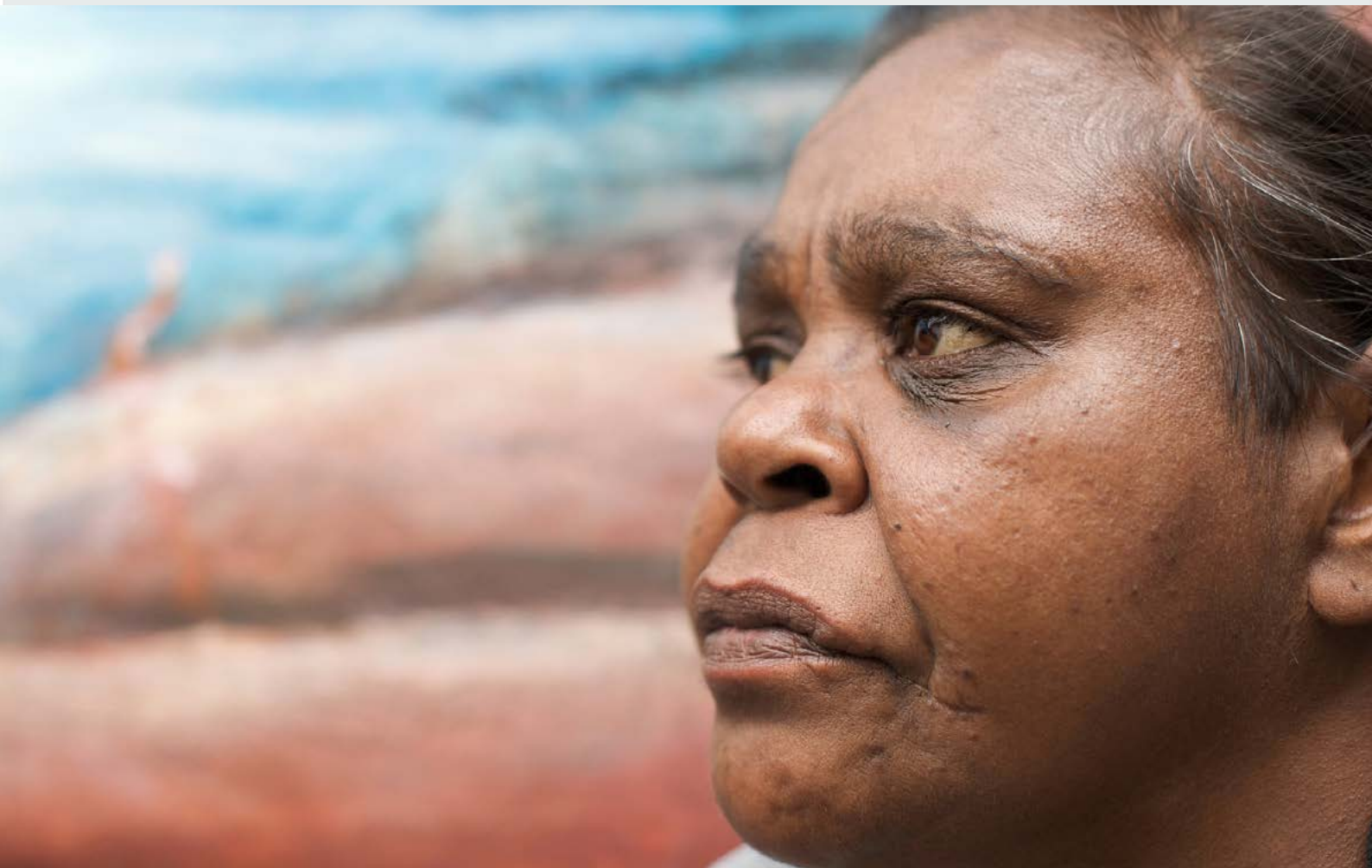
We welcome the development of the *Management and Operational Plan for People with Disability* (the Plan) as part of the *Australian Health Sector Emergency Response Plan for the Novel Coronavirus (COVID-19)*.² This must be a strong Plan based on human rights principles to inform ethical decision-making to address the healthcare issues raised in ‘calls to action’.

However, 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 life-saving 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.³

This has demonstrated an underlying, pervasive and often unquestioned devaluing of people with disability that is termed ‘ableism’.⁴ We are concerned, along with people with disability about similar ableist practices and protocols being replicated in Australia. We are further concerned, given the greater risks faced by older people with disability and First Peoples with disability, that when ableism intersects with ageism and / or racism, it can result in aggravated forms of discrimination and specific human rights violations that often mean lower quality services, particularly when resources are scarce.⁵

We recognise the significant challenges faced by the National Cabinet, the State and Territory health care systems, and medical and health care professionals across Australia. We value and appreciate the efforts being undertaken by frontline medical practitioners and workers, and the difficult decisions that may need to be made about prioritising critical and intensive care resources.

In this context, we believe it is critical that nationally consistent human rights principles and standards underpin ethical decision-making frameworks to protect the rights of all people with disability in Australia during the COVID-19 pandemic.



Human rights and disability

Australia ratified the *Convention on the Rights of Persons with Disabilities* (CRPD)⁶ in July 2008. The CRPD frames the body of existing international human rights law as it pertains to people with disability. The CRPD is partly reflected in domestic law through the *Disability Discrimination Act 1992* (Cth),⁷ State and Territory anti-discrimination legislation, the human rights laws that operate in Victoria,⁸ the ACT⁹ and Queensland,¹⁰ and various other laws, such as the *National Disability Insurance Scheme Act 2013* (NDIS Act).¹¹

The CRPD establishes principles and standards outlining the obligations for implementation. This includes principles and standards that are relevant for health care and medical decision-making:



Equality and human dignity¹²

People with disability are equal in their humanness and are subjects of rights; being subjects of rights they are of equal value and worth. Human dignity is the ultimate foundation of all human rights and fundamental freedoms. The CRPD recognises ‘disability’ as socially constructed and values ‘impairment’ as part of human diversity and human dignity. It reaffirms that people with disability are entitled to the human rights due all human beings on an equal basis.

Non-discrimination¹³

People with disability are due all human rights and fundamental freedoms without discrimination on an equal basis with others. People with disability are treated equally before the law and receive equal benefit of the law. People with disability may require individualised supports to exercise their human rights and to not experience discrimination.

The CRPD also recognises the diversity of people with disability and intersectional discrimination that can be experienced because of this diversity, including in relation to race, colour, sex, language, religion, political or other opinion, national, ethnic, Indigenous or social origin, property, birth, age or other status.¹⁴

Right to life¹⁵

People with disability have an inherent right to life on an equal basis with others. To enjoy the right to life, people with disability must be provided with the health care and social services that are essential for their survival. They should not be arbitrarily denied health care or medical treatment on the basis of impairment.

Equal recognition before the law¹⁶

People with disability are equal before the law and can exercise their legal capacity on an equal basis with others. To enjoy this right, people with disability may require supports to express their will and preference, and these supports should be based on personal choice, be proportionate and be appropriately safeguarded. People with disability have the right to make decisions and provide consent in relation to their healthcare and treatment, and not have decisions made for them in their 'best interests'. Some people with disability may need individualised support to express their will and preference, including identifying trusted people to assist them.

Right to health¹⁷

People with disability should enjoy the highest attainable standard of health, and be provided with health care and health services without discrimination. People with disability should have access to the same range, quality and standard of free and affordable health care on an equal basis with others, as well as to specialist health services required because of impairment. Health care should be provided on the basis of free and informed consent, and there should be no discriminatory denial of health care, health services and food or fluids on the basis of impairment.

Situations of risk and humanitarian emergencies¹⁸

People with disability should be afforded all necessary measures to ensure their protection and safety in situations of risk, and be included in responses to emergencies, including public health emergencies and situations of risk.

Participation of people with disability and their representative organisations¹⁹

People with disability, including children with disability through their representative organisations should be closely consulted and actively involved in the development and implementation of legislation and policies and other decision-making processes that affect people with disability, including in relation to health care.



The background of the page shows a blurred view of surgeons in an operating room. They are wearing blue scrubs and surgical caps, with their backs to the camera. The room has a sterile, clinical appearance with a door and some equipment visible in the background.

Framework of human rights principles for ethical decision-making

1. Health care should not be denied or limited to people with disability on the basis of impairment.
2. People with disability should have access to health care, including emergency and critical health care, on the basis of equality with others and based on objective and non-discriminatory clinical criteria.
3. Health care should not be denied or limited because a person with disability requires reasonable accommodation or adjustment.
4. Health care should be provided on the basis of free and informed consent of the person with disability.
5. Health care should not be denied or limited based on quality of life judgements about the person with disability.
6. Ethical decision-making frameworks should be designed with close consultation and active involvement of people with disability and their representative organisations.

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This Statement of Concern was commissioned by: People With Disability Australia (PWDA); Women with Disabilities Australia (WWDA); National Ethnic Disability Alliance (NEDA); Australian Federation of Disability Organisations (AFDO); First Peoples Disability Network (FPDN); ACT Council of Social Service Inc. (ACTCOSS).

Endnotes

- 1 See e.g., Chair, UN Committee on the Rights of Persons with Disabilities & the Special Envoy of the United Nations Secretary-General on Disability and Accessibility, 'Joint Statement: Persons with Disabilities and COVID-19', March 2020, <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25765&LangID=E>; International Disability Alliance, 'Toward a Disability-Inclusive COVID19 Response: 10 recommendations from the International Disability Alliance' (19 March 2020) <http://www.internationaldisabilityalliance.org/content/covid-19-and-disability-movement>; Regional and international organisations of people with psychosocial disability, 'COVID-19 and persons with psychosocial disabilities' (26 March 2020) http://www.chrusp.org/home/covid19?fbclid=IwAR2w-bXj8NyM7Hk21r4W3tx1yWrorKouS0HhGet0vZWjlgvc9Nq1jK_ISwnA; Council for Intellectual Disability, Inclusion Australia, Australian Association of Developmental Disability Medicine, Department of Developmental Disability Neuropsychiatry UNSW, 'Position Statement on Access to COVID-19 Prevention, Screening and Treatment of People with Intellectual or Developmental Disability' (27 March 2020) <https://3dn.unsw.edu.au/covid-19>; Centre of Research Excellence in Disability and Health, 'COVID-19: Policy Action to Protect People with Disability in Australia' (24 March 2020) <https://credh.org.au/news-events/disability-and-health-sectors-need-a-coordinated-response-during-covid-19/>; Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 'Statement of concern – the response to the COVID-19 pandemic for people with disability' (26 March 2020) <https://disability.royalcommission.gov.au/publications/statement-concern-response-covid-19-pandemic-people-disability>; Australia disability organisations, 'An Open Letter to the National Cabinet – Immediate Actions Required for Australians with Disability in Response to Coronavirus (COVID19)' (3 April 2020) <https://pwd.org.au/media-release-now-is-the-time-to-act-on-pandemic-measures-for-people-with-disability/>.
- 2 'Immediate response plan to focus on people with disability during Coronavirus' (Media Release, Greg Hunt, Minister for Health) 3 April 2020 <https://www.greghunt.com.au/immediate-response-plan-to-focus-on-people-with-disability-during-coronavirus/>
- 3 UN Special Rapporteurs and Independent Experts, 'COVID-19: States should not abuse emergency measures to suppress human rights – UN experts', UN news release, 16 March 2020, <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25722&LangID=E>; UN Special Rapporteur on the rights of persons with disabilities, 'COVID-19: Who is protecting the people with disabilities? – UN rights expert' <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25725&LangID=E>; UN Independent Expert on the human rights of older persons, "'Unacceptable" – UN expert urges better protection of older persons facing the highest risk of the COVID-19 pandemic', 27 March 2020, <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25748&LangID=E>; Human Rights Watch, 'UK: COVID-19 Law Puts Rights of People with Disabilities at Risk - Scrutiny Needed to Ensure Rights of People with Disabilities, Older Persons' (26 March 2020) <https://www.hrw.org/news/2020/03/26/uk-covid-19-law-puts-rights-people-disabilities-risk>; Disability Rights UK, 'Fury over Do Not Resuscitate Notices' (3 April 2020) <https://www.disabilityrightsuk.org/news/2020/april/fury-over-do-not-resuscitate-notice>; International Disability Alliance, 'Open Letter to World Health Organisation in response to the COVID-19 pandemic' (2 April 2020) <http://www.internationaldisabilityalliance.org/blog/idas-letter-world-health-organisation-response-covid19-pandemic>; Sheri Fink, 'U.S. Civil Rights Office Rejects Rationing Medical Care Based on Disability, Age' (New York Times, 28 March 2020) <https://www.nytimes.com/2020/03/28/us/coronavirus-disabilities-rationing-ventilators-triage.html?searchResultPosition=2>; Disability Justice Network of Ontario, 'Open Letter: Ontario's Triage COVID-19 Protocol' (7 April 2020) https://docs.google.com/forms/d/e/1FAIpQLSdrK4DFJAe4DWAIpGJc_RXa65N3X12lygGWvqy_xlvLXXKJEw/viewform; Jackie Leach Scully, 'Disablism In a Time of Pandemic: Some Things Don't Change' (Blog, 1 April 2020) International Journal of Feminist Approaches to Bioethics <https://www.ijfab.org/blog/2020/04/disablism-in-a-time-of-pandemic-some-things-dont-change/#comment-334956>.
- 4 See e.g., Campbell, F.K. (2011) 'Stalking Ableism: using Disability to Expose 'Able' Narcissism', in Goodley, D., Hughes, B. & Davis, L. (eds). Disability and Social Theory: New Developments and Directions, Basingstoke: Palgrave Macmillan; Martha Minow, Making All the Difference: Inclusion, exclusion, and American Law (Cornell University Press, 1990), Chapter 2, p. 70-76.

- 5 UN General Assembly, United Nations Declaration on the Rights of Indigenous Peoples: resolution / adopted by the General Assembly, 2 October 2007, A/RES/61/295; UN Special Rapporteur on the Rights of Persons with Disabilities, 'Report on the rights of older persons', 17 July 2019, UN Doc A/74/186 para 8 https://www.un.org/ga/search/view_doc.asp?symbol=A/74/186.
- 6 Convention on the Rights of Persons with Disabilities, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008).
- 7 Australia: Act No. 135 of 1992, Disability Discrimination Act 1992 [Australia], 5 November 1992.
- 8 Charter of Human Rights and Responsibilities Act 2006 (Vic).
- 9 Human Rights Act 2004 (ACT).
- 10 Human Rights Act 2019 (QLD).
- 11 Australia: Act No. 20 of 2013, National Disability Insurance Scheme Act 2013, March 2013.
- 12 Convention on the Rights of Persons with Disabilities, supra n 5, article 3(a) and (e) and article 5.
- 13 Ibid. Article 5.
- 14 Ibid. Preamble (p).
- 15 Ibid. Article 10.
- 16 Ibid. Article 12.
- 17 Ibid. Article 25.
- 18 Ibid. Article 11.
- 19 Ibid. Article 4(3).