



Ms Prue Torrance  
Executive Director  
Research Quality and Priorities  
National Health Medical and Research Council  
GPO Box 1421 Canberra ACT 2601

**RE: Consultation draft: An Ethics Framework for Pandemics**

26 October 2020

Dear Ms Torrance

Queenslanders with Disability Network (QDN) thanks the Council for the opportunity to provide a response to the consultation Draft Ethical Framework for Pandemics prepared by the Council. QDN is an organisation of, for, and with people with disability. The organisation's motto is "nothing about us without us" and we operate a state-wide network of over 2,000 members and supporters who provide information, feedback and views from a consumer perspective to inform systemic disability policy and disability advocacy. This response is informed by the lived experience of our members and supporters.

QDN has been actively involved at a State and Commonwealth levels in informing Health and Disability responses during COVID-19 and was involved in consultations in Queensland for the development of an ethical framework for the COVID-19 pandemic. The COVID-19 pandemic has highlighted a broad range of service and system gaps that have existed for people with disability over many decades, particularly in health. Before the pandemic, many QDN members report that outdated attitudes and misconceptions about disability are affecting clinical decisions and compromising their quality of care. It is important that these outdated attitudes and misconceptions are not part of the decision making about clinical care during critical periods of a pandemic.

In developing ethical frameworks to be used in times of emergency, it is critical that the process used is collaborative, and that effective consultation and engagement with health consumers who represent the diversity of the Australian community occurs. Central to this is transparent decision making processes.

In Queensland, the legislative framework includes the *Human Rights Act 2019 Queensland*. Australia is also signatory to the United Nations Convention on the Rights of People with Disability. Both of these are foundational in ensuring the human rights of people with disability including right to health.

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As Dr Ben Guantlett, Disability Discrimination Commissioner Australian Human Rights Commission writes in his forward Guidelines on the rights of people with disability in health and disability care during COVID-19 “ A critical justification for the creation, signing and ratification of the Convention on the Rights of Persons with Disabilities (CRPD) throughout the international community was to acknowledge the specific issues faced by people with disability in society. In particular, there was a need, on occasion, to treat difference differently to achieve substantive equality. There was also a recognised need to plan explicitly for emergency or crisis situations.”

The values and principles which underpin the Ethical Framework need to respond to the legislative frameworks and principles that underpin these Acts and Conventions. They also need to be values and principles that can be easily understood by patients and health consumers. Additionally, key is the principle of patients and their families as partners in healthcare. The National Safety and Quality Health Service Standards outline the standard for partnering with consumers. QDN believes that the values of trust, transparency and open communication are key to shared decision making and need to be considered in this framework.

It is important that the principles of this ethical framework reflect key contemporary concepts and experiences of people with disability. The principle of liberty that is included in this framework assumes that self-determination, and choice are fundamental in everyone’s life. However, for people with disability and many Australians who experience additional disadvantage and marginalisation this not the case. The principle of justice also included in this framework may also be considered an abstract and incongruent principle related to the fact that people with disability often report experiences of unconscious bias of healthcare professionals which influences the decision making and the care that people receive.

QDN acknowledges that it is challenging to develop a framework that enables policy and practice responses at the local level to be considered, ethical and deliver shared and informed decision making and clinical practice and care. It is important that the framework acknowledges the tensions that exist. QDN believes that there may be risks associated with using specific worked examples in the framework document but acknowledge the need for examples to show the decision making approach and it is important that this is considered.

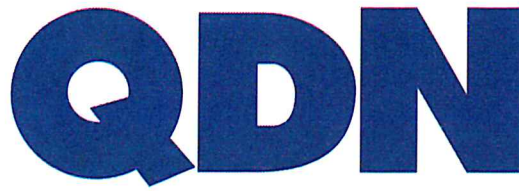
COVID-19 has also driven a rapid and collaborative policy and system response to put in place a number of key policy, strategies and initiatives to ensure people with disability could continue to access essential day to day disability supports, food and nutrition, housing, health care and other essential services. People with disability

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face a range of unique challenges in emergency situations, and it is important that any national ethical framework provides the guidance to ensure people with disability rights to healthcare are upheld during any pandemic.

QDN appreciates the opportunity to provide feedback to this consultation process.

Yours sincerely

A handwritten signature in blue ink that reads 'Paige Armstrong'. The signature is fluid and cursive, with the first name 'Paige' being more prominent.

Paige Armstrong  
Chief Executive Officer