



AUSTRALIAN CENTRE FOR
CHRISTIANITY AND CULTURE

WISDOM FOR THE COMMON GOOD

How do we decide who gets the ventilators? Polio, ethics and the age of COVID-19

Genevieve Jacobs

Riot ACT: <https://the-riotact.com/how-do-we-decide-who-gets-the-ventilators-polio-ethics-and-the-age-of-covid-19/369606>

April 2020



Charles Sturt
University

When we discuss global pandemic history, it's most often the Spanish Influenza. But victims of a much more recent pandemic say COVID-19 raises deeply rooted concerns about who receives treatment and on what basis. For decades, poliomyelitis rolled around the world in repeating epidemic waves, bringing with it absolute terror for parents who feared their children would be struck down. Like COVID-19, polio was a terrible lottery. It could mean death or lifelong paralysis, with the hovering threat of calipers, crutches, prosthetic boots or the iron lung, a huge tank-like respirator. And until the arrival of the Salk vaccine, there was no cure for the disease. It's estimated that at least 20,000 to 40,000 people had paralytic polio in Australia and that up to four million Australians could have been infected.

One of them was Roger Beale. With a distinguished APS career behind him as Secretary of the Department of the Environment, Sport and Territories and later Department of the Environment and Heritage, he also chaired a review of Australia's Quarantine and Biosecurity Arrangements, was a Commissioner of the Climate Commission and now sits on the Australian Centre for Christianity and Culture's board of directors. In 1948, he was a polio-afflicted two-year-old whose parents were desperate to ensure he had the best chance at life. They were living in South Africa where the growing tide of apartheid was already prompting unease. But the promise of radical post-polio therapy in Australia was a key decider for the family's move here.

Roger's mother had heard about Sister Elizabeth Kenny, an Australian nurse whose approach to polio patients was the diametric opposite of prevailing wisdom. "Instead of constraining patients, she advocated very active remediation as soon as the crisis had passed," Roger says. "It took place outdoors if possible, involving hydrotherapy, exercise and stretching programs. It could be painful but there was a profound difference from the immobilisation and institutionalisation of conventional polio treatment."

Equally significant was the message that these patients' lives had value. Roger's parents rejected any notion of separate schooling and different treatment. "Everything was to be mainstream and I made my own way in the world, for which I am eternally grateful, but that was not the conventional approach," he says. "My parents had to fight for it all the way."

Other patients were not so fortunate. They were hospitalised or institutionalised for long periods, treated as different from other people and regarded with fear because the disease vector was so poorly understood. "I had a huge fear of institutionalised disregard," Roger says. "It haunted the rest of my childhood, that sense of worry about abandonment, that you were in infectious-care hospitals where you were very much alone. As a young child that is a devastating feeling."

It also underpins one of his major concerns about COVID-19: that if we are gripped by a major health crisis where resources are under intense pressure, generations of polio survivors and others who are disabled may be arbitrarily excluded from intensive care or ventilator support. “That great fear of dying alone, that our lives are of no value, is a searing issue,” he says. His deep personal concern is that treatment and resource allocation should be underpinned by a clear ethical framework. If hospitals are overwhelmed by COVID-19, should discrimination on the grounds of age or disability be prevented in the same way that ethnicity, race, gender, religion, social status and wealth are already precluded? And how should that weigh up against utilitarian principles that prioritise the greatest good for the greatest number of people?

Roger’s point is that these will always be anguished, dreadful decisions with far-reaching consequences. But they must be made within clear and established ethical guidelines rather than on an ad hoc basis in the middle of an emergency. “For me personally, a fundamental part of my Christian faith is that Christ was there for all in a non-discriminatory way, and particularly for people with broken lives,” he says. “Governments are very understandably anxious about whether they are seen to be playing God, but we make ethical decisions all the time that means some will live and some will die.

“When I ran transport, we knew that if you reduced speed limits by 10 km/h proportionately you’d save hundreds of lives. But we don’t do it because it would be inconvenient. Yet we spend a lot more time and money saving people from being eaten by sharks than in almost any other way, for example.”

So how would you decide who gets the ventilator?

Media release

COVID-19 Statement of Concern:

Human rights, disability and ethical decision-making

Internationally recognised Australian experts in the areas of human rights, bioethics and disability have today released a Statement of Concern 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.

There are much greater risks from the COVID-19 pandemic for people with disability; in particular, for older people with disability, First Peoples with disability, people with intellectual or psychosocial disability, those with chronic health conditions, co-morbidities, dependence on ventilators and compromised immunity.

Ms Rosemary Kayess, Vice-Chair, United Nations Committee on the Rights of Persons with Disabilities stated, “We welcome the development of the Management and Operational Plan for People with Disability as part of the Australian Health Sector Emergency Response Plan for COVID-19. However, we are concerned that any increasing demand on critical health treatment and intensive medical care will require decisions to be made about life-saving treatment that could seriously undermine the rights of people with disability.”

Professor of Bioethics, Jackie Leach Scully further outlined, “We are aware of international experience during this pandemic that shows that health directives and medical decision-making protocols demonstrate an underlying, pervasive and often unquestioned devaluing of people with disability. We are concerned, along with all people with disability, about similar ableist practices and protocols being replicated in Australia.”

Ms Robin Banks, former Tasmanian Anti-Discrimination Commissioner continued, “We believe it is critical that nationally consistent human rights principles and standards underpin any ethical decision-making frameworks to ensure the protection of the rights of people with disability.”

Signatories propose the following 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.

The signatories provide this Statement of Concern acknowledging the significant challenges faced by the National Cabinet, the State and Territory health care systems, and medical and health care professionals across Australia, and thank them for their efforts.

Signatories:

Robin Banks

Human Rights Lawyer and former Anti-Discrimination Commissioner, Tasmania

Andrew Byrnes

Professor of Law, Faculty of Law, University of NSW
Research Associate, Australian Human Rights Institute, University of NSW

Kevin Cocks AM

Former Queensland Anti-Discrimination Commissioner

Megan Davis

Expert Member, United Nations Expert Mechanism on the Rights of Indigenous Peoples, UN Human Rights Council
Professor of Law, UNSW Law

Graeme Innes AM

Former Disability Discrimination Commissioner

Rosemary Kayess

Vice-Chair, United Nations Committee on the Rights of Persons with Disabilities
Senior Research Fellow, Social Policy Research Centre, University of NSW
2019 Australian Human Rights Medallist

Ron McCallum AO

Emeritus Professor and former Dean of Law, University of Sydney
Former Chair, United Nations Committee on the Rights of Persons with Disabilities
Senior Australian of the Year 2011

Jackie Leach Scully FAcSS, FRSA

Professor of Bioethics
Director, Disability Innovation Institute, University of NSW

The Statement of Concern is available here:

<https://dpoa.org.au/statement-of-concern-covid-19-human-rights-disability-and-ethical-decision-making/>

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).