

## *New Zealand Bioethics Journal* Special Issue on Disability Ethics

### FROM THE EDITOR'S DESK

Bioethics, as a discipline, relies on contributions from a range of other disciplines and groups. When considering the range of backgrounds from which bioethicists come, we find philosophers, lawyers, health professionals and many others. The moral issues and dilemmas with which bioethics grapples are situated in increasingly wide fields of endeavour, both scientific and in everyday living. Bioethics, as a relatively young discipline, continues to grow and develop as it draws on scholarship, empirical science, and perspectives from an increasing number of areas.

Many of the 'favourite' cases or moral dilemmas encountered in the teaching of bioethics and in the clinical examples of medical ethics centre around the issue of disability, although seldom framed as such. Should the disabled baby live? When is a life deemed not worth living? Should expensive treatment be provided for a disabled patient? Should disabled parents be supported to have and raise children?

When I undertook graduate study in bioethics some years ago, coming from a strong background of personal experience of disability and a research career in disability studies and research, I was amazed at how out of touch bioethics appeared to be with scholarship, research, and perspectives relating to disability. I set myself a personal goal of trying to do my part to redress this serious limitation.

I wish to express my sincere thanks to the Bioethics Centre at the University of Otago for supporting the achievement of this goal, rather than dismissing me as a 'politically correct troublemaker'. For me, the publication of a Special Issue of the *New Zealand Bioethics Journal* on 'Disability Ethics' represents a significant goal on the journey to taking seriously the moral journeys of disabled people, rather than conceptualising their lives as moral dilemmas for other people.

This Special Issue sets the stage for a continuing dialogue in the New Developments Section by describing recent New Zealand government strategies pertaining to disability and noting some contemporary areas of particular relevance to bioethics and the disability community. Owen Hughes identifies some objectives from the New Zealand Disability Strategy, which he sees as having particular relevance to bioethics. It is interesting to note that none of the 15 objectives of the Strategy refer to the prevention of impairment itself, but instead refer to the prevention of the disabling experiences that often accompany bodily impairments. The central consideration of a rights perspective is stressed. The bioethics community may be challenged by the author's conclusion that 'debate on disability and ethics (should) be led by disabled people'.

In the first of the articles, Rhonda Shaw and Martin Sullivan suggest that the dialogue around disability and bioethics needs to be informed by social sciences scholarship in the area of disability. These authors view their contribution as a 'work in progress' and welcome ongoing discussion. While acknowledging the enormous contribution that a social model of disability has made to the lives of disabled people (see the New Zealand Disability Strategy) Rhonda and Martin argue for a disability ethics to consider both the social construction of disability and the embodied experiences of disability. This perspective challenges both disability scholars and bioethics scholars to engage in study and debate together.

In the second article, Christopher Newell makes some of these challenges real by providing the unique narrative of an insider's dual perspective on both disability and bioethics. He notes the practical barriers to access, which even well-meaning ethicists omit to consider. While the latest Conference of the Australasian Bioethics Association in Queenstown was not

totally inaccessible, for those delegates who used wheelchairs, access to the Conference rooms was through a small kitchen – a route that would have clearly rendered the venue unacceptable to those of us who walked!

Christopher's paper challenges bioethics to reconsider the broader issues which can benefit from disability knowledge and perspectives – 'notions of humanness, health and ethics'. I would add to his list the issues of autonomy, dependence, and competence.

Jayne Clapton's article helps to explain why an historical perspective is essential to informing our consideration of disability ethics. Much of this history is unknown or not considered within bioethics. The holocaust experienced by 200,000+ disabled children and adults (and by extension, their families) in Hitler's Germany is a fact which receives little attention and no memorials. As the ultimate outcome of eugenics beliefs, is it little wonder that disabled people are concerned about the motivations and applications of biotechnological advances? If disability is a tragedy and a burden, how can its prevention or removal be conceived as anything but a virtue? If disabled people are not (enabled to be) economic contributors, why should they continue to consume economic goods all their lives, or in Hitler's words – why should 'useless eaters' be supported to live? Jayne's paper challenges us to remember history in order to examine basic issues of citizenship, human rights, and societal diversity.

Finally, the case presented for response is one that challenges us on many fronts. While the United Nations Convention on the Rights of the Child clearly outlaws discrimination against disabled *parents* (Article 2), as well as disabled children, our society does not take this seriously. In New Zealand, disabled

parents (not just those with intellectual disabilities) are not recognised in public policy and its funding arrangements, as sometimes needing public support for them in their *parenting* role. Too often, their need for support is reconceptualized as an issue of child protection, rather than family support, with negative outcomes for both the child and her biological family.

The invited commentaries on this hypothetical case provide food for careful reflection. These thoughtful responses from experts within the relevant disciplines pertinent to the case may challenge some readers. The belief that 'those sort of people should not be allowed to have children' is still alive today, while usually concealed under other virtuous-sounding clichés. Framing such cases as a 'conflict of interests' fails to consider adequately the individual circumstances of each family, and that the child's best interests are usually best assured by ensuring the wellbeing and healthy functioning of her family.

My hope is that readers of this issue of the Journal will open their minds and hearts to the important contributions that can be made to the discipline of bioethics from disabled people themselves, from disability research, and from scholars in disability theory. It is my expectation that future contributions to the Journal will continue and expand this initial conversation.

Anne Bray  
Guest Editor

#### Acknowledgement

I would like to thank Neil Pickering for his unfailing courtesy, support and wise advice to me in undertaking this editorial task.