

Editorial

What is the Future of Disability Rights?

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I have been Associate Editor for Research and Essays for the Review of Disability Studies for over a year now. In that time I've been impressed and encouraged by the skill and commitment of the people at the University of Hawaii's Center on Disability Studies who edit and publish the journal. I have enjoyed, tremendously, the opportunity to get to know them, and other new members of the Editorial Board.

The Editor in Chief, Megan Conway, has been particularly good at not only continuing the good work done by previous editors of RDS but in building understanding among a disparate group of Associate Editors and creating a vision for the future of the journal. During much of the time I've been associated with the journal, she, and others at the Institute, have done a tremendous amount of work in keeping the journal going and in helping us integrate into the operation of the journal.

The result, as you can see in this issue, is representative of work being done across the board in disability studies and rehabilitation, which is possible due to the excellent level of contributions from authors but importantly to the commitment of the editing staff. I hope you will enjoy reading this journal and I encourage any of you not already subscribed to subscribe to it as well as to contribute to it.

I also would like to ask us all to think about the future of disability in our world through two older (but still capable of providing surprises) perspectives: technology and disability rights. Forty years ago, in the USA in particular, a number of advocates and organizations were consciously using the Declaration of Independence as a template for why disabled people's rights were inalienable, even if rights were at the time not well-established in US law or practice. Their efforts have led to (in the USA) an environment where disability rights in education and the community are based on Federal and state or local laws. An unanticipated consequence of basing rights and services on government-created laws results in a situation in which rights granted by a government can, logically, be taken away by a government. At the same time, the United Nations has (since 1948, at least) issued several "declarations" identifying human rights, and most recently the Declaration on the Rights of Individuals with Disabilities, based on a strong natural rights approach (that is, that certain rights are inalienable, even if not always exercisable, as in the Declaration of Independence). But, what happens to disabled people in an environment where technology, perhaps gene editing (currently occurring as CRISPR) or future genetic therapies can eliminate conditions like Down Syndrome, cystic fibrosis, and so on? Should a majority in a political system be permitted to take away the right to be as one is, as (say) a person with Down Syndrome? Another way to put this is to think about uses for technology of this sort that many of us might not think of as desirable: for example, should parents be able to prune any genetic condition that they wish?

The Deaf community is faced with technology that promises a “cure” for deafness, leading to a smaller and perhaps marginalized Deaf community. Why couldn’t parents be able to edit genes for height, or body type, or hair color – or even (should they be pinpointed) genes that might contribute to sexual orientation?

Many of these discussions have been going on for years, but they will become more common and more important over the next 5, 10, or 20 years, as the ability of human beings to direct the future of themselves and their offspring moves from fiction and speculation to reality. No doubt, the pages of the Review of Disability Studies will contribute to the debates.