

Rights Are Still Right: The Case for Disability Rights

by Anita Silvers

A growing philosophical backlash suggests that rights may not be right. For those of us within whose earlier lifetimes patients had no rights, and women only sharply curtailed ones, this prospect is worrisome. Of even more concern to me, as a person with a disability, is the related thought that we should abandon extending rights to the disabled before people like me can be fully caught up. For without having recourse to rights, how are we to rectify the neglect and exclusion people like us have suffered because we are intellectually, physically, or emotionally impaired?

Proponents of feminist care and communitarian theories have argued that relying on rights fails precisely in the case of the disabled. Communitarians, for example, believe that, in general, people's acquisition of virtuous dispositions offers more collective benefit than their exercise of rights. They hold that disabled people do better when non-disabled people are motivated by other-related virtues because rights derive from—and therefore ultimately cannot overcome—self-interested concerns.

In a related argument, feminist care theorists point out that, while rights theories treat individuals as independent, some disabled people—and especially people with intellectual disabilities—could not survive independently. These theorists argue that for people who do not have the ability to claim or

exercise them, rights are of little value. In this theoretical context, the case of disability, and intellectual disability in particular, is advanced to demonstrate the shortcomings of pursuing moral and political progress by expanding rights.

The editors of *The Human Rights of Persons with Intellectual Disabilities: Different but Equal* appear not to have heard that rights may not be right. This is good, for the essays collected here offer important insights into the practical aspects of bringing about the liberation of people with intellectual disabilities worldwide. Most of the volume's nineteen essays attempt to place disability rights in the larger context of the international human rights movement.

Generally speaking, the essays explore how the thesis of Article I of the Universal Declaration of Human Rights, namely, that all humans have equal and inalienable claims to dignity and freedom, offers people with intellectual disabilities equality of respect and treatment that is not merely homogeneous treatment. The relevant principle, "different but equal," challenges governmental as well as nongovernmental organizations not only to develop legislation, but also to implement practices that result in genuine, concretely experienced improvements in disabled people's lives. This means that human rights advocates must learn to think of the disadvantages of disability not in medical terms, but in terms of a political power

problem that can be solved by giving the disabled some control.

But how do intellectually disabled people get and take control? The human rights approach to achieving this goal begins by launching a transnational program to expose biased and inhumane treatment of people with intellectual disabilities. The next step is to articulate an international standard of their rights and to have it ratified by treaty, while pursuing whatever constitutional or statutory protection of them can be invoked in litigation, nation by nation. Some chapters report on how these latter efforts have fared in differing venues, while others hypothesize about how they should fare.

There are five sections to the volume, covering, in turn, what people with intellectual disabilities need in terms of their rights as human beings, how international and comparative law may be applied to redress violations of intellectually disabled people's human rights, national approaches to nondiscrimination protection for the disabled, integration of equality and difference in social policy, and the assumptions and ambitions of the intellectual disabilities rights movement.

This last section is eclectic but exciting. It contains some of the most informative writing available on the subject of what should be done morally and politically for intellectually disabled people. It opens with a chapter by Mitchell Levitz (who with his friend Jason Kingley co-authored the autobiographical *Count Us In: Growing Up with Down Syndrome*). Levitz, a person with Down Syndrome, gives us a concrete account of what self-determination has meant to a person with an intellectual disability. The next chapter, by Eric Rosenthal and Clarence Sundram, details the successes and setbacks of the efforts of a United

The Human Rights of Persons with Intellectual Disabilities: Different but Equal. Edited by Stanley S. Herr, Lawrence O. Gostin, and Harold Hongju Koh. Oxford: Oxford University Press, 2003. 578 pages. Paper \$49.95.

Nations Convention on Disability Rights to achieve an international treaty committing member nations to recognize these rights. Ronald Slye considers the recommendations for the United Nations and international nongovernmental organizations made by the 1995 Yale Law School Conference called "Should Difference Make a Difference?" The declaration that emerged from that conference ends the book.

Two facts, drawn from very different places in the volume, reveal the barrier of inattention that disability rights activists need to overcome. With over 600 million members, the disabled constitute one of the world's largest minority groups. But there are "only 28 people throughout the entire U.N. system working on issues of specific concern to persons with disabilities" (p. 520). Of course, one could argue that disabled people get enough international attention through the efforts of the World Health Organization. But attending to their concerns chiefly through WHO is to treat them as patients rather than as citizens, and to focus their claims as rights-bearers on the health system rather than on society as a whole.

Two essays bear special mention in connection with the conundrum that disability rights presents for public health. Adrienne Asch, Lawrence Gostin, and Diann Johnson consider whether programs for preventing disability contravene respect for people with disabilities. They are concerned with prenatal testing to prevent the birth of people with disabilities, but explicitly not about postnatal measures to prevent or cure disabilities. They advance what they call "speculative observations" about the "effect significant reductions in the prevalence of persons with disability would have on humanity" (p. 335). Included in these considerations are the importance of maintaining diversity in physical and mental capacities in societies and the adverse effect that "a substantial reduction in the number of people with disabilities" could have

on the disabled who remain. But these arguments also apply to postnatal disability prevention and cure. If one effort at eliminating disability raises red flags, why not the other? The authors' specialized answer about ensuring that mothers-to-be are accurately informed about disability, so that they are not panicked by its prospect, does not reach to the broader question of proper versus wrong ways of achieving a disability-free population.

A problem related to bringing the values of medicine in line with respect for people with disabilities arises in a second article, "Cross-Cultural Perceptions of Disability: Policy Implications of Divergent Views," by Alison Dundes Renteln. This article questions the U.S. courts' respect for disability as understood by Hmong parents who refused corrective surgery for their child with hip dysplasia and club feet. The court first ordered the surgery to prevent the child from spending later life in a wheelchair, but backed off after a psychiatric report. The child feared that, were he to be cured of a condition he believed he bore as a penalty for his ancestors' wrongdoings, bad things would befall his siblings and he would be responsible. It is by no means clear that the moral model of disability deserves precedence over the medical model, even in cultures in which it is the prevailing view.

The solution to reconciling medicine with cultural differences in attitudes to disability cannot, I think, lie in trying to build respect for disabled people into the values of medicine. Medicine does not place a high value on people remaining as they are, for medical knowledge is generally sought in attempts to make people better. Instead, disabled people should be treated as citizens, and not as patients, except in those medical contexts where nondisabled people are also thought of as patients. The problem lies not with the medical model itself, but with the medical stereotyping of disabled people in their lives beyond the clinic. I found

John H. Noble's chapter, "The Economics of Equality: An Exploration of Country Differences," thought provoking in this regard.

Several chapters point the way forward for people with intellectual disabilities. "Liberty, Due Process, and the Pursuit of Happiness," by Michael W. Smull and Luciene Parsley, contains a wonderful account of how people with intellectual disabilities who cannot speak nevertheless can have their preferences acknowledged and respected. "Self-Determination, Autonomy, and Alternatives for Guardianship," by Stanley Herr, is another account of people who are citizens with intellectual disabilities. The aforementioned chapter by Mitchell Levitz offers readers the experience of an individual with an intellectual disability (Down Syndrome) writing as a citizen.

This volume is dedicated to the memory of Stan Herr, who, in addition to his research and teaching, litigated some of the most important disability rights cases of the past three decades. Herr's dedication to disability rights, and his successes in obtaining recognition of them, spring from many of the book's pages. Like Herr, the book is replete with passion, principles, and important facts. As Herr made the world a better place, the world of scholarship is better for having this globally ambitious book on the rights of people with intellectual disabilities.