

A Thoughtful Look at Disability

by Dena S. Davis

The cover of Tom Shakespeare's book *Disability Rights and Wrongs* is like a Magritte painting: all is ordinary at first glance but dissolves into the surreal upon closer inspection. Here we have a stark photograph of a wheelchair, with almost no context, on a brown floor beside a beige wall. Made entirely of gleaming metal with no upholstery, it is obviously uncomfortable. Oddly for a book that celebrates the autonomy of the disabled, there are no wheels by which the user could propel himself. The only means of movement are the handles on the back, and they are shaped like kitchen knives; there is no way to grasp them without getting cut.

To this (currently) nondisabled reviewer, those handles look awfully sharp. As linguist Mark Aronoff noted in the *Chronicle of Higher Education*, in America disability is entering the realm of the utterly taboo; "the word 'disabled' has become so charged that it must not be uttered or even written, only inferred."

And yet, this book is the antithesis of its cover: utterly sane, deeply contextual, beautifully rational, committed to the autonomy of disabled people (more on nomenclature shortly) while refusing to demonize the nondisabled. In fact, the author is so persuasive and sensible that his conclusions risk seeming obvious; the reader unfamiliar with the politics and history of disability studies is likely to wonder why everyone doesn't think like Tom Shakespeare.

Although *Disability Rights and Wrongs* transcends its British context, it

cannot be understood without it. In the United Kingdom, the "social model" of disability was embraced by disability activists to the point where anything else was heresy. The social model claims that people are not disabled by some inherent mental or physical impairment, but rather that they are oppressed by societal barriers. In this theoretical universe, a person may be "impaired" because she does not have the use of her legs, but she is "disabled" because of societal arrangements such as narrow doorways, a lack of elevators, and so on. "From seeing disability as entirely caused by biological deficits, the radical analysis shifted to seeing disability as nothing whatsoever to do with individual bodies or brains" (p. 31).

The social model, which casts the disabled as an oppressed group akin to women and certain ethnic groups, has obvious political force. But Shakespeare also describes its many difficulties, not least of which is the refusal to deal directly with the range of impairments people experience. Not all of these impairments can be solved by different social and physical arrangements. Shakespeare points out that the political activism in the United Kingdom that forced the adoption of the social model was led primarily by wheelchair users with stable physical impairments. For them, barriers and attitudes are indeed the primary cause of their difficulties. For people with mental illness, however, or conditions that cause pain or fatigue, removing barriers is not the whole answer.

In place of the social model, Shakespeare offers a "critical realist" model that understands disability as an interaction between individual and structural factors. This model accepts impairment as a nonneutral, perhaps even tragic element of some people's lives, while denying that it is "always all-defining and terrible" (p. 63). It also accepts that even if all discrimination were erased, many impaired people would still have lives that are more difficult, exhausting, limited, or expensive. Thus, on the assumption that impaired people are equal in moral worth to the nonimpaired, "compensation and redistribution" are necessary to "promote true social inclusion" (p. 67).

From this balanced stance, Shakespeare tackles some of the most salient issues in bioethics: prenatal diagnosis, the debate about cure, and autonomy at the end of life. Shakespeare provides a careful critique of disability activists' opposition to prenatal diagnosis and selective abortion, which they often characterize as eugenic, discriminatory, or disrespectful. He makes short shrift of the eugenics objection, pointing out that it is scientifically impossible to prevent the existence of most disabled people through prenatal diagnosis (most of us, after all, become disabled later in life), and also that a eugenics conspiracy theory places all power in the hands of the medical establishment, ignoring the individual choices of pregnant women. He also argues against the "expressivist" objection, claiming that the prevention of impairment is not incompatible with respect for the rights and experiences of disabled people.

Shakespeare's engagement with the abortion issue is the one disappointment in this otherwise fine book. Perhaps this is inevitable, given that abortion could be a book in itself. Nonetheless, bald statements that late-term abortions are "repugnant" (p. 93), while first and second trimester abortions are not "morally wrong" (p. 95), simply hang in the air,

Disability Rights and Wrongs. By Tom Shakespeare. Routledge, 2006. 232 pages. Softcover, \$41.95.

devoid of the careful analysis that characterizes the rest of this work.

“Just Around the Corner,” the ironically titled chapter on cure, is fascinating. The section on stem cell research, and disabled people’s decidedly mixed attitude toward Christopher Reeve, was particularly enlightening, especially to someone who strongly supports stem cell research and does not sojourn regularly in the world of disability politics. Shakespeare supports medical research that will prevent or ameliorate some types of impairment, but reminds us that no amount of medical progress will banish “the problems and limitations of embodiment” (p. 116). Further, he reminds us that research is not the only necessity: we already know how to prevent many diseases, such as malaria and tuberculosis; we just lack the will to use our knowledge effectively.

Shakespeare’s stand on choices at the end of life is equally careful. He gives a sympathetic portrayal of groups like Not Dead Yet, which fear that support for assisted suicide is also covert support for

ending the lives of all disabled people. He is realistic about the impact of societal structures and economic arrangements on people’s choices when faced with, for example, the necessity for ventilators or feeding tubes. Nonetheless, based on his position of “consistent support for the choices and desires of disabled people themselves,” Shakespeare has emerged as one of the few disability activists speaking out in favor of legislation that would enable physician-assisted suicide in a small set of narrowly constrained cases applying only to the terminally ill.

The final portion of *Disability Rights and Wrongs* deals with the most subtle and difficult issues of all: questions of love, intimacy, friendship, and care between disabled people and the nondisabled people—family members, paid and unpaid caregivers, charitable associations—with whom they interact. In some ways, Shakespeare paints a bleak picture of a world in which “broader social changes” have “exacerbated” the problems of being impaired. That seems

odd to me, at least for physical impairments, given the ways in which technology such as e-mail, telecommunications devices for the deaf, teleconferencing, accessible public transport, and so on have made the impaired less disabled. With computers, for example, I can now send a document to a blind colleague that is automatically translated into Braille on her end. However, Shakespeare is persuasive in his resolutely unsentimental treatment of the difficulties of friendship and social interaction between nondisabled people and those who are mentally ill or have learning difficulties.

This is a terrific first book on disability issues for those who are new to the field because it traces the history and theory of disabilities theory and activism in a way that is critical but respectful. It will also reward the academic who is already sophisticated in the field because Tom Shakespeare uses his strong voice to present a unique and fearless perspective.