Book review

Disability Studies: Past, Present and Future. By L. BARTON, M. OLIVER. (The University of Leeds: The Disability Press, 1997). ISBN 0 9528450 1 6 (pb).
Doing Disability Research. By C. BARNES, G. MERCER. (The University of Leeds: The Disability Press, 1997). ISBN 0 9528450 2 4 (pb).

The Disability Press publishes works in the field of disability studies, which is a blend of sociology, policy studies, and human rights advocacy. The fundamental axiom in disability studies is that disability is not a reflection or result of an individual's developmental or medical condition, but arises from the collective human condition. Therefore, the field emphasizes societal (or social) and cultural views of disability as well as historical and philosophical discourse on such themes as the origins of stigma, disability terminology, and the personal meaning (or construction) of disability. A key aspect of disability studies is the full involvement of persons with disabilities in the field's research and writings; in fact, there are some disability advocates who assert that only persons with disabilities should be active participants in disability studies.

Two good introductory texts provide an orientation to this relatively new field of study. The volume titled, Disability Studies: Past, Present and Future, is an anthology that traces the evolution of this field through papers presented at a 1996 conference and articles first published in the journal, Disability, Handicap and Society (later renamed Disability and Society). The journal was first published in 1986 and during its tenth anniversary year a conference was held in England to celebrate the anniversary. Those papers, reprinted in this book, 'were designed to reflect some (through not all) of the issues and themes that the Journal has been instrumental in both raising and developing'.

Of the 20 chapters in the book, 18 are authored by persons from the UK. Disability studies remains largely the domain of the United Kingdom, as the perusal of the list of contributors will attest, although significant interest in the field is being expressed in North America and Europe. In the US, disability studies is most akin to the largely consumer-led independent living movement which started in the late 1960's as a civil rights movement and reaction to the medical model of disability and its emphasis on cures and the need to overcome limitations.

The collection itself is divided into three parts. The first part presents papers from the conference and establishes the theory undergirding disability studies. Here is where the distinction is made between medical/psychological perspectives and social/cultural perspectives of disability; the evolution from normalization (persons with disabilities should strive to be like non-disabled persons) to empowerment (persons with disabilities have the right to be self-determining and to make their own choices about their lives and to achieve the quality of life each believes is personally best). The second part of the book contains selected papers from the first ten years of the Journal, and the third is focused on current issues and controversies, primarily concerning disability research.

As we strive to individualize rehabilitation services, help people with disabilities achieve their self-determined goals and include them in all aspects of community and society, it is imperative that professional and consumers work together. To do this effectively, perspectives need to be openly shared and discussed. This book has a lot to offer by way of establishing the origins of varying perspectives and framing ensuing dialogue.

Professional and consumer partnership will be increasingly important, not just in the clinical practice of rehabilitation, but in research efforts involving disability and persons with disabilities. Another volume by The Disability Press, Doing Disability Research edited by Colin Barnes and Geof Mercer, is a thirteen chapter text on 'translating disability theory into research practice'. Again, authors from the United Kingdom predominate. The authors of the contributions emphasize an 'emancipatory approach' to the conduct of research, which advocates 'politically committed research' and 'The idea that research should be about changing the world, not simply describing it...[since] research is inherently political (rather than “objective”), and must be guided by the “purpose of emancipation.”' Such a perspective involves the subjects of the research in that research (as opposed to treating them as objects of study) and places the focus of study on environmental, social, and cultural phenomena and not solely individuals' biological conditions and psychological states. The emancipatory approach has fostered the belief among some that disability research is best done by persons with disabilities, but there is a flip side to this argument which says that, if you have a disability, then you had better be doing disability research.

That makes many uncomfortable. For example, I can count on the fingers of one hand the number of psychologists I know who are doing research on spinal cord injury who have a spinal cord injury. I just could not bring myself to advocate that psychologists with spinal cord injuries go only into disability research, or research that disability and no others. To me, that's discriminatory. But this is just one of the ideas and topics raised in the book. As a whole, it is a useful reference for developing an understanding of and appreciation for emancipatory research (which is similar to what we researchers in the US refer to as “participatory action research”) with many in-depth discussions of actual research projects and programs to bring the discussed practices to life.

Both of these books belong on the shelf of disability researchers. While parts of these texts will attract more universal support and agreement than others, the fact is that the research enterprise needs to be more inclusive, conscious of the social and cultural creation of disability, and sensitive to the ideas and needs emerging from the disability community. These texts provide a foundation upon which all of us can begin to examine our inclinations and disinclinations regarding disability research, perhaps to scrutinize the field as a whole and engage in dialogues about the ways we can have more relevance to and impact on the empowerment of people with disabilities and the enhancement of the quality of their lives.

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