



Cathy Bodine

SERIES EDITOR Gary L. Albrecht

ASSISTIVE TECHNOLOGY AND SCIENCE

Disability KEY ISSUES AND FUTURE DIRECTIONS

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ASSISTIVE
TECHNOLOGY
AND SCIENCE

The SAGE Reference Series on Disability: Key Issues and Future Directions

Series Editor: Gary L. Albrecht

Arts and Humanities, by Brenda Jo Brueggemann

Assistive Technology and Science, by Cathy Bodine

Disability Through the Life Course, by Tamar Heller and Sarah Parker Harris

Education, by Cheryl Hanley-Maxwell and Lana Collet-Klingenberg

Employment and Work, by Susanne M. Bruyère and Linda Barrington

Ethics, Law, and Policy, by Jerome E. Bickenbach

Health and Medicine, by Ross M. Mullner

Rehabilitation Interventions, by Margaret A. Turk and Nancy R. Mudrick

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ASSISTIVE TECHNOLOGY AND SCIENCE

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Series Introduction

The SAGE Reference Series on Disability appears at a time when global attention is being focused on disability at all levels of society. Researchers, service providers, and policymakers are concerned with the prevalence, experience, meanings, and costs of disability because of the growing impact of disability on individuals and their families and subsequent increased demand for services (Banta & de Wit, 2008; Martin et al., 2010; Mont, 2007; Whitaker, 2010). For their part, disabled people and their families are keenly interested in taking a more proactive stance in recognizing and dealing with disability in their lives (Charlton, 1998; Iezzoni & O'Day, 2006). As a result, there is burgeoning literature, heightened Web activity, myriad Internet information and discussion groups, and new policy proposals and programs designed to produce evidence and disseminate information so that people with disabilities may be informed and live more independently (see, for example, the World Institute of Disability Web site at <http://www.wid.org>, the Center for International Rehabilitation Research Information and Exchange Web site at <http://cirrie.buffalo.edu>, and the Web portal to caregiver support groups at <http://www.caregiver.com/regionalresources/index.htm>).

Disability is recognized as a critical medical and social problem in current society, central to the discussions of health care and social welfare policies taking place around the world. The prominence of these disability issues is highlighted by the attention given to them by the most respected national and international organizations. The *World Report on Disability* (2011), co-sponsored by the World Health Organization (WHO) and the World Bank and based on an analysis of surveys from over 100 countries, estimates that 15% of the world's population (more than 1 billion people) currently experiences disability. This is the best prevalence estimate available today and indicates a marked increase over previous epidemiological calculations. Based on this work, the British

medical journal *Lancet* dedicated an entire issue (November 28, 2009) to disability, focusing attention on the salience of the problem for health care systems worldwide. In addition, the WHO has developed community-based rehabilitation principles and strategies which are applicable to communities of diverse cultures and at all levels of development (WHO, 2010). The World Bank is concerned because of the link between disability and poverty (World Bank, 2004). Disability, in their view, could be a major impediment to economic development, particularly in emerging economies.

Efforts to address the problem of disability also have legal and human rights implications. Being disabled has historically led to discrimination, stigma, and dependency, which diminish an individual's full rights to citizenship and equality (European Disability Forum, 2003). In response to these concerns, the United Nations Convention on the Rights of Persons with Disabilities (2008) and the European Union Disability Strategy embodying the Charter of Fundamental Rights (2000) were passed to affirm that disabled people have the right to acquire and change nationalities, cannot be deprived of their ability to exercise liberty, have freedom of movement, are free to leave any country including their own, are not deprived of the right to enter their own country, and have access to the welfare and benefits afforded to any citizen of their country. As of March 31, 2010, 144 nations—including the United States, China, India, and Russia—had signed the U.N. Convention, and the European Union Disability Strategy had been ratified by all members of the European Community. These international agreements supplement and elaborate disability rights legislation such as the Americans with Disabilities Act of 1990 and its amendments, the U.K. Disability Discrimination Act of 1995, and the Disabled Person's Fundamental Law of Japan, revised in 1993.

In the United States, the Institute of Medicine of the National Academy of Sciences has persistently focused attention on the medical, public health, and social policy aspects of disability in a broad-ranging series of reports: *Disability in America* (1991), *Enabling America* (1997), *The Dynamics of Disability: Measuring and Monitoring Disability for Social Security Programs* (2002), *The Future of Disability in America* (2007), and *Improving the Presumptive Disability Decision-Making Process for Veterans* (2008). The Centers for Disease Control have a long-standing interest in diabetes and obesity because of their effects on morbidity, mortality, and disability. Current data show that the incidence and prevalence of obesity is rising across all age groups in the United States, that obesity is related to diabetes, which is also on the rise, and that both, taken together, increase the

likelihood of experiencing disability (Bleich et al., 2008; Gill et al., 2010). People with diabetes also are likely to have comorbid depression, which increases their chances of functional disability (Egede, 2004).

Depression and other types of mental illness—like anxiety disorders, alcohol and drug dependence, and impulse-control disorders—are more prevalent than previously thought and often result in disability (Kessler & Wang, 2008). The prevalence of mental disorders in the United States is high, with about half of the population meeting criteria (as measured by the *Diagnostic and Statistical Manual of Mental Disorders*, or DSM-IV) for one or more disorders in their lifetimes, and more than one-quarter of the population meeting criteria for a disorder in any single year. The more severe mental disorders are strongly associated with high comorbidity, resulting in disability.

Major American foundations with significant health portfolios have also turned their attention to disability. The Bill and Melinda Gates Foundation has directed considerable resources to eliminate disability-causing parasitic and communicable diseases such as malaria, elephantiasis, and river blindness. These efforts are designed to prevent and control disability-causing conditions in the developing world that inhibit personal independence and economic development. The Robert Wood Johnson Foundation has a long-standing program on self-determination for people with developmental disabilities in the United States aimed at increasing their ability to participate fully in society, and the Hogg Foundation is dedicated to improving mental health awareness and services. Taken in concert, these activities underscore the recognized importance of disability in the present world.

Disability Concepts, Models, and Theories

There is an immense literature on disability concepts, models, and theories. An in-depth look at these issues and controversies can be found in the *Handbook of Disability Studies* (Albrecht, Seelman, & Bury, 2001), in the *Encyclopedia of Disability* (Albrecht, 2006), and in “The Sociology of Disability: Historical Foundations and Future Directions” (Albrecht, 2010). For the purposes of this reference series, it is useful to know that the World Health Organization, in the International Classification of Functioning, Disability and Health (ICF), defines disability as “an umbrella term for impairments, activity limitations or participation restrictions” (WHO, 2001, p. 3). ICF also lists environmental factors that interact with all these constructs. Further, the WHO defines impairments as “problems in body function or structure such as significant

deviation or loss”; activity limitations as “difficulties an individual may have in executing activities”; participation as “involvement in a life situation”; and environmental factors as those components of “the physical, social and attitudinal environment in which people live and conduct their lives” (WHO, 2001, p. 10). The U.N. Convention on the Rights of Persons with Disabilities, in turn, defines disability as including “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” In the introduction to the *Lancet* special issue on disability, Officer and Groce (2009) conclude that “both the ICF and the Convention view disability as the outcome of complex interactions between health conditions and features of an individual’s physical, social, and attitudinal environment that hinder their full and effective participation in society” (p. 1795). Hence, disability scholars and activists alike are concerned with breaking down physical, environmental, economic, and social barriers so that disabled people can live independently and participate as fully as possible in society.

Types of Disability

Interest in disability by medical practitioners has traditionally been condition specific (such as spinal cord injury or disabilities due to heart disease), reflecting the medical model approach to training and disease taxonomies. Similarly, disabled people and their families are often most concerned about their particular conditions and how best to deal with them. The SAGE Reference Series on Disability recognizes that there are a broad range of disabilities that can be generally conceived of as falling in the categories of physical, mental, intellectual, and sensory disabilities. In practice, disabled persons may have more than one disability and are often difficult to place in one disability category. For instance, a spinal-cord injured individual might experience depression, and a person with multiple sclerosis may simultaneously deal with physical and sensory disabilities. It is also important to note that disabilities are dynamic. People do experience different rates of onset, progression, remission, and even transition from being disabled at one point in time, to not being disabled at another, to being disabled again. Examples of this change in disability status include disability due to bouts of arthritis, Guillain-Barré Syndrome, and postpartum depression.

Disability Language

The symbols and language used to represent disability have sparked contentious debates over the years. In the *Handbook of Disability Studies* (Albrecht, Seelman, & Bury, 2001) and the *Encyclopedia of Disability* (Albrecht, 2006), authors from different countries were encouraged to use the terms and language of their cultures, but to explain them when necessary. In the present volumes, authors may use “people with disabilities” or “disabled people” to refer to individuals experiencing disability. Scholars in the United States have preferred “people with disabilities” (people-first language), while those in the United Kingdom, Canada, and Australia generally use “disabled people.” In languages other than English, scholars typically use some form of the “disabled people” idiom. The U.S. version emphasizes American exceptionalism and the individual, whereas “disabled people” highlights the group and their minority status or state of being different. In my own writing, I have chosen “disabled people” because it stresses human diversity and variation.

In a recent discussion of this issue, DePoy and Gilson (2010) “suggest that maintaining debate and argument on what language is most correct derails a larger and more profound needed change, that of equalizing resources, valuation, and respect. Moreover, . . . locating disability ‘with a person’ reifies its embodiment and flies in the very face of the social model that person-first language is purported to espouse. . . . We have not heard anyone suggest that beauty, kindness, or even unkindness be located after personhood.” While the debate is not likely over, we state why we use the language that we do.

Organization of the Series

These issues were important in conceiving of and organizing the SAGE Reference Series on Disability. Instead of developing the series around specific disabilities resulting from Parkinson’s disease or bi-polar disorder, or according to the larger categories of physical, mental, intellectual, and sensory disabilities, we decided to concentrate on the major topics that confront anyone interested in or experiencing disability. Thus, the series consists of eight volumes constructed around the following topics:

- Arts and Humanities
- Assistive Technology and Science

- Disability Through the Life Course
- Education
- Employment and Work
- Ethics, Law, and Policy
- Health and Medicine
- Rehabilitation Interventions

To provide structure, we chose to use a similar organization for each volume. Therefore, each volume contains the following elements:

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The Audience

The eight-volume SAGE Reference Series on Disability targets an audience of undergraduate students and general readers that uses both academic and public libraries. However, the content and depth of the series will also make it attractive to graduate students, researchers, and policymakers. The series has been edited to have a consistent format and accessible style. The focus in each volume is on providing lay-friendly overviews of broad issues and guideposts for further research and exploration.

The series is innovative in that it will be published and marketed worldwide, with each volume available in electronic format soon after it appears in print. The print version consists of eight bound volumes. The electronic version is available through the SAGE Reference Online

platform, which hosts 200 handbooks and encyclopedias across the social sciences, including the *Handbook of Disability Studies* and the *Encyclopedia of Disability*. With access to this platform through college, university, and public libraries, students, the lay public, and scholars can search these interrelated disability and social science sources from their computers or handheld and smart phone devices. The movement to an electronic platform presages the cloud computing revolution coming upon us. Cloud computing “refers to ‘everything’ a user may reach via the Internet, including services, storage, applications and people” (Hoehl & Sieh, 2010). According to Ray Ozzie (2010), recently Microsoft’s chief architect, “We’re moving toward a world of (1) cloud-based continuous services that connect us all and do our bidding, and (2) appliance-like connected devices enabling us to interact with those cloud-based services.” Literally, information will be available at consumers’ fingertips. Given the ample links to other resources in emerging databases, they can pursue any topic of interest in detail. This resource builds on the massive efforts to make information available to decision makers in real time, such as computerizing health and hospital records so that the diagnosis and treatment of chronic diseases and disabilities can be better managed (Celler, Lovell, & Basilakis, 2003). The SAGE Reference Series on Disability provides Internet and Web site addresses which lead the user into a world of social networks clustered around disability in general and specific conditions and issues. Entering and engaging with social networks revolving around health and disability promises to help individuals make more informed decisions and provide support in times of need (Smith & Christakis, 2008). The SAGE Reference Online platform will also be configured and updated to make it increasingly accessible to disabled people.

The SAGE Reference Series on Disability provides an extensive index for each volume. Through its placement on the SAGE Reference Online platform, the series will be fully searchable and cross-referenced, will allow keyword searching, and will be connected to the *Handbook of Disability Studies* and the *Encyclopedia of Disability*.

The authors of the volumes have taken considerable effort to vet the references, data, and resources for accuracy and credibility. The multiple Web sites for current data, information, government and United Nations documents, research findings, expert recommendations, self-help, discussion groups, and social policy are particularly useful, as they are being continuously updated. Examples of current and forthcoming data

are the results and analysis of the findings of the U.S. 2010 Census, the ongoing reports of the Centers for Disease Control on disability, the World Health Organization's *World Report on Disability* and its updates, the World Bank reports on disability, poverty, and development, and reports from major foundations like Robert Wood Johnson, Bill and Melinda Gates, Ford, and Hogg. In terms of clinical outcomes, the evaluation of cost-effective interventions, management of disability, and programs that work, enormous attention is being given to evidence-based outcomes (Brownson, Fielding, & Maylahn, 2009; Marcus et al., 2006; Wolinsky et al., 2007) and comparative effectiveness research (Etheredge, 2010; Inglehart, 2010). Such data force a re-examination of policymakers' arguments. For example, there is mounting evidence that demonstrates the beneficial effects of exercise on preventing disability and enhancing function (Marcus et al., 2006). Recent studies also show that some health care reform initiatives may negatively affect disabled people's access to and costs of health care (Burns, Shah, & Smith, 2010). Furthermore, the seemingly inexorable rise in health care spending may not be correlated with desirable health outcomes (Rothberg et al., 2010). In this environment, valid data are the currency of the discussion (Andersen, Lollar, & Meyers, 2000). The authors' hopes are that this reference series will encourage students and the lay public to base their discussions and decisions on valid outcome data. Such an approach tempers the influence of ideologies surrounding health care and misconceptions about disabled people, their lives, and experiences.

SAGE Publications has made considerable effort to make these volumes accessible to disabled people in the printed book version and in the electronic platform format. In turn, SAGE and other publishers and vendors like Amazon are incorporating greater flexibility in the user interface to improve functionality to a broad range of users, such as disabled people. These efforts are important for disabled people as universities, governments, and health service delivery organizations are moving toward a paperless environment.

In the spirit of informed discussion and transparency, may this reference series encourage people from many different walks of life to become knowledgeable and engaged in the disability world. As a consequence, social policies should become better informed and individuals and families should be able to make better decisions regarding the experience of disability in their lives.

Acknowledgments

I would like to recognize the vision of Rolf Janke in developing SAGE Publications' presence in the disability field, as represented by the *Handbook of Disability Studies* (2001), the five-volume *Encyclopedia of Disability* (2006), and now the eight-volume SAGE Reference Series on Disability. These products have helped advance the field and have made critical work accessible to scholars, students, and the general public through books and now the SAGE Reference Online platform. Jim Brace-Thompson at SAGE handled the signing of contracts and kept this complex project coordinated and moving on time. Kevin Hillstrom and Laurie Collier Hillstrom at Northern Lights Writers Group were intrepid in taking the composite pieces of this project and polishing and editing them into a coherent whole that is approachable, consistent in style and form, and rich in content. The authors of the eight volumes—Linda Barrington, Jerome Bickenbach, Cathy Bodine, Brenda Brueggemann, Susanne Bruyère, Lana Collet-Klingenberg, Cheryl Hanley-Maxwell, Sarah Parker Harris, Tamar Heller, Nancy Mudrick, Ross Mullner, and Peggy Turk—are to be commended for their enthusiasm, creativity, and fortitude in delivering high-quality volumes on a tight deadline. I was fortunate to work with such accomplished scholars.

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Preface

In today's world, technology has become ubiquitous. Cell phones, tablets, desktops, ATMs, games, and cash registers are all connected. For people with disabilities, technology not only creates access to the world at large, it also creates greater opportunities for education, work, and play. On the flip side, technology *can* make life more difficult for persons with disabilities. Small buttons and keyboards that are confusing, graphics without tag lines to tell the individual what is on the screen, and many other technical aspects can create confusion, frustration, and limited access to the world at large. But these are all aspects that can be dealt with.

This volume explores the history and current status of assistive technology (AT) and accessible mainstream commercial technologies. Its purpose is to share where we are in the life cycle of technology for persons with disabilities; to examine historical aspects and future trends, along with legislative and funding issues. The need for professional development training and outreach to create an informed constituency is also explored. This volume introduces the topic of assistive technology and offers resources and information about where to go to learn more.

In Chapter 1, *Introduction, Background, and History*, we provide a brief overview of the field of assistive technology, which includes both devices and services. This overview of AT devices and services includes definitions, history, and legislation. It discusses the types of AT available for people with communication disorders, impaired mobility, hearing and visual impairments, and cognitive/learning disabilities. It also describes the selection of appropriate technology and training in its use, suggests ways to avoid the abandonment of assistive technology by clients and caregivers, and discusses the principles of clinical assessment and physician responsibility. Finally, it briefly discusses the future in terms of research and development and application of emerging technologies to the needs of people with disabilities.