

INTRODUCTION

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It has become a commonplace to claim that disability is on the rise in the modern world. Such recognition arrives as we and our families age and modern medicine ensures the viability of children who, only a few decades ago, would not have lived into adulthood. Those who sound this alarm would seek to spoil our attachments to more progressive historical models in which disability, apparently, does not take part. As a marker of our contemporary “decline,” one might cite the predictable “nicks and dents” of aging now compounded by the obesity epidemic with concomitant rises in diabetes, osteoporosis, and heart disease. Asthma is often identified as one of the leading disabling conditions resulting from urban growth and environmental pollution. Furthermore, it would be truthful to observe that the upsurge in wars and civil strife around the world has produced millions of men and women who have been permanently injured by land mines, machetes, bullets, bombs, and beatings. Similarly, in developing countries, one might also argue that populations continue to experience the ravages of presumably eradicated diseases such as tuberculosis as well as newer epidemics such as HIV/AIDS. Finally, given the stresses of contemporary life in industrial and developing countries alike, depression has become the number two cause of disability in the world.

Yet this catalogue of contemporary disability sources does not touch on the true significance of disability, particularly with respect to the degree to which people with disabilities exemplify the dynamic variability, vulnerability, and mutability that exist across individuals, populations, cultures, and histories. Perhaps the most surprising observation of all is that disabled people persist in record numbers despite continuing prophecies from medicine, genetics, and rehabilitation about the ultimate eradication of congenital and acquired

impairments. In this post-eugenics era, disabilities remain with us but the lived experience of disability has undergone radical changes. Consequently, at its most basic level, the *Encyclopedia of Disability* serves as a reminder that regardless of who we are, where or when we live, disability is with us.

Based on this perspective, the *Encyclopedia of Disability* was conceived as an effort to bring current knowledge of and experience with disability across a wide variety of places, conditions, and cultures to both the general reader and the specialist. An encyclopedia is an introduction to a topic that leads a reader through subjects of interest to greater depth and breadth of understanding and provides the reader with a road map to other sources of information. In this work, the entries, bibliographies, websites, search strategies, cross-references, chronology, visual images, and primary source (original) material will conduct the curious reader along a path to a clear understanding of the definitions, fundamental concepts, basic history, diversity, cultural contexts, experiences, health care issues, environmental constraints, helpful accommodations, social movements, laws and policies, and theories and practices in the disability arena. Furthermore, the encyclopedia seeks to demonstrate that our largely negative view of disability must be challenged by the significant contributions to all cultures made by disabled people and committed allies—in art, in politics, in cultural production, in private and public life. May this encyclopedia improve the reader’s understanding and appreciation of the world of disability.

The *Encyclopedia of Disability* was conceived in a broad context. While there has been much research on disability, the research presented in these volumes has usually been approached from an interdisciplinary perspective whenever possible and broken into

manageable topics for investigation. For example, the descriptions of public health show how it aims to improve the quality of life by minimizing the effects of diseases, living conditions, work, and the physical and social environments on mortality and disability. The discussion of medicine focuses on diagnosis of disabling conditions, prevention, and treatment. A number of entries describe the multitude of therapies that are designed to operate individually and in concert to return disabled people to as full and complete a life as possible. The overview of rehabilitation engineering concentrates on assistive technologies aimed at accommodating the environment to the individual and the individual to the environment. Disability studies refuses the equation of disability with inferiority and instead aims its analytical lens at the social obstacles that produce disability as a devalued experience. To do so, disability studies examines the definition, meaning, and representation of disability in various social and cultural contexts by incorporating the voices of disabled people and disability communities into the discussion. The history of medicine's contribution is in placing medical conditions and disability into a historical and cultural context to unveil the shifting determinants of disease and difference. Contributors from the fields of sociology, psychology, and anthropology apply analyses that help us better understand disability as a product of interactions between bodies, environments, and belief systems. Economists draw our attention to the monetary and social costs of disability and the benefits of supporting disabled people and helping them reintegrate into society. Lawyers, government officials, and policy makers consider how the modern state can best respond to the reality of variation across populations. Philosophers and ethicists ponder the value of human life, physician-assisted suicide, and human rights to test contemporary culture's commitment to all citizens despite ability levels. The encyclopedia also demonstrates that disabled people and their families are concerned with how they can exercise full citizenship in a society, have a high quality of life, and contribute as active members in a world that often rebuffs such efforts.

The idea for the *Encyclopedia of Disability* was hatched during 1999–2000 in conversations with Rolf Janke of Sage. The intent was to provide a resource that would be available in all of the major libraries of the world to scholars, disabled people, disability advocates and allies, and the general public. To be

useful to a wide audience, the encyclopedia needed to have breadth and depth and be written for a general audience. The project was also an opportunity to encourage creative people in different but related fields, all interested in disability, to talk with each other. Another desideratum was to make the encyclopedia as international as possible since disability is an issue that knows no national or cultural boundaries.

After signing the contract for the encyclopedia on September 10, 2001, an international editorial board of 74 editors from the Americas, Europe, Australasia, India, Japan, and China, who were all experts in their own subfields of disability, was constituted. After much discussion, the members of the editorial board and the publisher agreed that the encyclopedia would span five volumes: four consisting of alphabetically listed entries and a fifth composed of primary source materials representing the field of disability broadly defined across history and cultures. Volume V is organized into chronological categories that allow the breadth and depth of cultural thinking about disability to become evident for the first time.

The task of identifying the entries to appear in the encyclopedia was the next exercise in creativity. The major journals, books, government documents, and Web-based disability discussion groups in the world were searched for themes and topics. These were organized into lists and circulated. The editors iteratively added terms and suggested authors. The authors, in turn, often proffered other terms and authors. Great effort was taken to have a considerable number of authors from outside North America to provide balance to the work. Another source of global representation was to include internationally focused entries on most of the key concepts in the encyclopedia and to provide cross-cultural examples wherever possible. Yet, even in the wake of these commitments to achieve an international representation of disability, the encyclopedia cannot claim to be exhaustive to any degree. Because of the global, historical, and conceptual reach of the *Encyclopedia of Disability*, it is virtually impossible to cover every topic, person, and event. This is a mere introduction in many ways to myriad differences that characterize the world of disability. The editors decided to organize the entries hierarchically from large crosscutting concepts such as disability models to smaller entries such as those on individual people. At this point, the editorial board was divided into areas of expertise such as health and medicine, mental illness, cultural studies, rehabilitation,

disability studies, rehabilitation engineering and assistive technology, law and social policy, and history, and teams were formed to oversee and deepen these areas and headwords.

A list of suggested authors for all of the terms was then formed and authors were invited to participate. With few exceptions, the editors and authors who were invited to participate in the project eagerly did so; all were experts in their own areas. Each entry is based on the personal expertise of the author, and further readings and websites are listed at the end of most entries. The draft of each entry was reviewed by the editor in charge of that group, by the general editor, and in the case of the more important or contentious entries, by other reviewers as well. Revisions were made based on these comments. At a later stage, entries were cross-referenced with other entries in Volumes I through IV to guide the reader in an exploration of a topic.

The covers of the five volumes were selected to represent disability in various historical periods and cultural settings. The jacket art provides an index to the cultural, historical, and representational diversity of disability imagery. The cover of Volume I, *Tree of Hope—Stand Firm!* (1946), portrays one of Frida Kahlo's many self-portraits as a disabled Mexican woman of color. In the painting, her identity is split. One image proudly holds her back brace while the other image portrays her impairment as if exposed as a medical specimen. The cover of Volume II, by Hieronymus Bosch, *Extraction of the Stone of Madness (The Cure of Folly)* (ca. 1475), depicts a fifteenth-century representation of treatment for mental illness in medieval Europe. The portrait assembles all of the constituent professions of the time—barber, friar, nun—as they treat a patient who looks out anxiously toward the audience as a tulip is extracted from his head. The cover of Volume III depicts the Chinese physician Hua T'o as he seeks to heal necrosis on the arm of the warrior Guan Yu in the fourteenth century. The work, created by the famous Japanese printmaker Utagawa Kuniyoshi in 1853, emphasizes the disparity that exists between social rituals of gaming that continue even as one receives serious medical attention. The cover of Volume IV, showing the early-fifteenth-century Nigerian King Oba being supported by his two personal assistants, captures the king's effort to explain sudden paralysis in his legs. Rather than confessing his incapacity, Oba argues to his subjects that he has become one with the revered mudfish of his

day that walks on land and swims in water. At a time when physical, sensory, or cognitive disability in a king could mean expulsion or execution, the bronze demonstrates the necessity of quick thinking that often must accompany disabled persons' ability to fend off violent social tendencies. Finally, the cover of Volume V, *Beacon (Bless the Bastard)* (1991) by contemporary U.S. visual artist Tim Lowly, represents a mother deflecting the discomfort of a society unprepared to accept her disabled daughter in a common public context. In contrast, the multiply disabled daughter appears to revel in the sun while possibly imagining alternative futures for herself yet to be thought by the adults around her.

Taken collectively, the jacket images provide viewers entry into the diversity of cultural responses to, and portrayals of, disability at key moments in history. They become a patchwork of moments in the growing mosaic of our understanding of disability as a historical, cultural, and global phenomenon. In addition, there are more than 100 images related to disability in Volume V. These images illustrate the powerful representation and symbolism of disability in diverse societies.

The use of language and concepts is an issue in an international encyclopedia. Disability is often referred to by different terms and concepts. Rather than forcing each contributor to use the same language, the editors decided to let the authors use the terms and concepts of their culture but to explain them when necessary. This preserves the multicultural flavor of the enterprise. Likewise, when authors were writing about contentious issues, they were encouraged to present the various positions and their rationales. In terms of language, for example, the reader will see “persons with disabilities” and “disabled persons.” “Persons with disabilities” is preferred by those who favor “people first” language capturing the importance of the individual in society, and disability as being something *not* inherent in the person. “Disabled persons” is a term used in the United Kingdom and Australia emphasizing minority group identity politics where community and group identity are forces that can be employed to fight oppression experienced in the physical and social environment. Other authors consider disability to be best understood in terms of human differences that should be accepted as such rather than as being seen as regrettable deficits. This position stands against the background where specific disabilities have taken on positive and negative meanings

in various cultures. For example, in some societies, blindness has been associated with the characteristics of wisdom and prescience, which are valued, whereas AIDS and leprosy (Hansen's disease) are often stigmatized.

The Reader's Guide classifies entries into twenty-five thematic categories. In addition, the materials in Volume V are listed in the Reader's Guide to enable readers to integrate the content of entries with the primary source documents in Volume V. To put the concept of disability in a historical and cultural context, a chronology maps disability across time, culture, and geography and is repeated at the end of each volume.

"Searching for and Evaluating Websites," by Anne Armstrong, a University of Illinois reference librarian, describes how to use the references at the end of the entries, how to access and use websites related to disability, and how to assess whether websites and their content are credible. This valuable research tool appears at the end of each volume. In addition, throughout the encyclopedia there are listings of print and electronic references to government documents and data that are rich resources to investigate how disability is measured and treated on an international level. There are

government documents that can be accessed over the Internet by just entering the keywords "disability" and the name of the country. The International Monetary Fund, World Bank, United Nations, and World Health Organization also are fine sources of data and policy initiatives related to disability, much of which can be accessed over the Internet.

May readers discover that the *Encyclopedia of Disability* provides a fascinating entry into the world of disability where minds are expanded, prejudices shattered, and spirits raised. The range of interrelated resources is designed to stimulate curiosity and encourage readers to move back and forth through the five volumes to pursue their interests. Internet references and search strategies assist the user in entering a larger world of online disability resources that are continually being updated and expanded. The encyclopedia is composed as a multidisciplinary, cross-cultural, and historically grounded resource tool that should lead the reader across fields, theories, debates, and practices. The experience of exploring the encyclopedia should answer the questions: What is disability, and why is it important in my life?