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BOOK REVIEW

The encyclopedia of disability, edited by Gary L. Albrecht, Thousand Oaks, CA, SAGE Publications, 2006, 1968 pp., £468.00, ISBN 0-7619-2565-1

This five volume *Encyclopedia of disability* represents a landmark in US American and international efforts to establish the study of disability as an interdisciplinary field of knowledge. Volume 1–4 contains A–Z entries. The fifth volume contains a collection of what are labeled primary sources, a large number of excerpts from texts both classic and present, and a collection of visual images depicting disability. The general editor of the four volumes is the US American disability scholar and sociologist Gary Albrecht. In this review I would first like to present how this encyclopedia is organized and who the authors are. Secondly, I will look into the content by presenting a set of entries in some detail. Thirdly, I will give a critical discussion of the editor's ambition of creating a truly international view on this body of knowledge.

Construction and direction

The *Encyclopedia* utilizes well-developed techniques for information handling in this type of publication project. There are a total of 820 entries covering 1934 large pages and a master bibliography numbering approximately 3650 references. The entries vary in length from only a few lines to ten pages. There is a short list of core references for further reading in nearly all of the entries and a large and a detailed index in the fourth volume.

The 25 topical categories presented as the readers' guide are important when trying to grasp the direction the encyclopedia takes as a project contributing to the establishment of disability as a field of knowledge. The topical categories organize both the entries and the source material. Listing the first ten gives a clear indication that we are very far from a medical textbook: 'Accessibility', 'Arts', 'Biographies', 'Children and Infants', 'Deafness and Deaf Culture', 'Disability *S*tudies', 'Economics and Development', and 'Education'. Only the category of 'Children and Infants' holds any strong relation to medical and psychological knowledge systems (the branches of pediatrics and child psychology). But when we look at the 16 entries listed under this heading, again the socio-cultural themes outnumber the health care themes. As an exemplification, the five final ones can be listed: 'Parental Advocacy', 'Parental Narratives', 'Pediatric Rehabilitation', 'Poster Child', and 'Prematurity'. From this we can conclude that the main profile of the *Encyclopedia* is the grounding of the study of disability in the social sciences and humanities, but with a strong recognition of disability as heavily framed by medical knowledge systems. This is also mirrored in the group of editors.

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There are a large amount of people involved in making the *Encyclopedia*. The team is made up of one general editor, four associate editors, a senior editorial board of nine people, an international advisory board of 60 people, and approximately 540 entry authors. These people represent a truly multidisciplinary group of scholars, but with a central focus on sociology and the humanities. The general editor Gary Albrecht is a sociologist, associate editor Jerome Bickenbach is a scholar of law, Gary Mitchell is a disability studies scholar with an educational background in English and American Studies, Walton O. Schalick III is a pediatrician and historian of medicine, and Sharon L. Snyder is a disability studies scholar holding a PhD in English literature. Mitchell and Snyder are important scholars in the development of disability studies as an academic field in the humanities, and Albrecht and Bickenbach in the social sciences. Bickenbach is also an important architect behind the highly influential International Classification of Deceases (ICF).

The institutional home of the *Encyclopedia* is the Department of Disability and Human Development at the University of Illinois at Chicago. At this centre for disability studies Albrecht, Mitchell, and Snyder were staff members when the *Encyclopedia* was made. Albrecht retired after its completion in 2005 and Mitchell has recently taken on the position as executive director of Temple University's Institute on Disabilities.

A closer look at some entries

My second ambition in this review is to present select entries in more detail. I have chosen one of the main subjects ('Disability Studies'), two of the biographies, (Bengt Nirje and Helen Heller), and two of the small and mid-sized entries ('Stroke' and 'De-institutionalization').

The entry 'Disability Studies' is written by one of the associate editors, Sharon Snyder. It covers 11 pages and it is divided in three parts. The first two, 'Disability Studies' and 'Disability Rights', focuses on disability studies as the theoretical arm of the disability rights movements and its main aim as the critical study of the development and present role of the disability category. The critique of the medical model is identified as belonging to the first generation of scholars. The present generation emphasizes the normalizing practices inherent in policy making and professional practice and their historical legacies in eugenics and policies for improving the human lot. The second subheading, 'Institutionalizing Disability Studies', presents a short overview of centres and journals of disability studies globally, but focuses on the establishment of disability studies in the US. It also discusses the relations to other identity related fields of knowledge such as queer, gender, and ethnic studies. A strong involvement of disabled scholars is taken for granted, an issue deserving closer attention for an international and multidisciplinary readership than given here. The third and final part of the entry is 'Recent Research Trends'. Snyder points out dissemination to third world countries, awareness of media as a powerful tool for storytelling, inspiration from postcolonial studies, and more collaborative work as important such trends. In the source material there is an excerpt from a definition of disability studies by the Hunter College Disability Studies Project. The definition was developed in an attempt to have disability studies included as part of multicultural studies. The attempt failed, but generated much similar activity at universities and colleges across the US. The one page excerpt adds weight to the importance of identifying disability as a social construction and concludes by identifying disability studies as the academic endeavor to address disability as 'a phenomenon that organizes social, political and intellectual experience'.

Summed up, the disability studies entry is clearly written from a US American and Canadian point of view and from a standpoint in the humanities. It is supplanted by the subsequent entry: 'Disability Studies: Australia'. This is written by Helen Meekosha and points to the fact that disability studies in Australia is in a sad condition as fragmented and only represented by singular scholars across Universities. She provides an important discussion of the widespread use of the label 'disability studies' and brings in Simi Linton's discussions about what falls into disability studies and what falls into the category of rehabilitation. Meekosha points out how a discipline such as occupational therapy in the disability studies concept can include both de-individualizing social model perspectives and traditional interventionist perspectives. In sum, the two entries depict disability studies in a wide-ranging perspective. The US American scholars and activists are the main definitional powers, no doubt about that, but the concept is difficult to apply precisely to the institutional arrangements of disability as a field of knowledge in other countries. What is lacking in the encyclopedia entries is a systematic discussion of what the demarcation lines are regarding what shall count as disability studies, and the differences between countries. One pressing question is why there is a general entry and one (and only one) country specific entry.

To represent the 189 biographies ranging from Aesop to Jacquline de Pré, I have selected two persons influencing the present situation for disabled people in different ways, Bengt Nirje and Helen Keller. The 'Nirje' entry is written by the psychologist Catherine E. McDonald and labels him as a 'Swedish activist'. The entry covers half a page and points out his role in the development of the normalization concept, both on the national level in a parents association and on the international level as welfare coordinator with the United Nations. The entry also highlights Nirje's formulation of the normalization principle and its international importance. But to gain a full understanding of this, it is important to follow up on the 'See also:' at the bottom of the entry. Here, two entries are listed: 'Niels Erik Bank-Mikkelsen' and 'Normalization'. Just a few pages later, in the 'Normalization' entry, Trevor Parameter presents, over three pages, both Nirje's original formulation in the commonly-cited paper from 1969, the important contact with the Dane Bank-Mikkelsen and the work of Wolf Wolfensberger to export the normalization principle in the treatment of mental retardations worldwide.

The 'Helen Keller' entry also comprises half a page and is written by English literature scholar Georgina Kleege who labels Keller as 'American author and lecturer'. The first paragraph lists Keller's medical history and biography. The second paragraph points outs the role Helen Keller has played as a biography of reference and how this has been criticized. She represents the quintessential overcoming narrative and she kept a distance from the disability movement and supported oralism rather than signing for deaf people. In a concluding sentence, Kleege points out that recently many disability scholars have dived into her life and work to separate myth from reality. In the source material volume there are three pages from Helen Keller's autobiography. In the excerpt Keller tells the story of how she learned abstract concepts such as love. It is accompanied by a picture of Helen Keller and Mark Twain with Keller positioned in a pose that reminds the viewer of her deaf-blindness. This is a good example of the picture material in the source volume which is a rich collection of visual representations of disability, mostly paintings, film stills, and photographs.

The first of the smaller entries I have chosen is ‘Stroke’. It is written by Joel Stein, a medical doctor and chief of a coordinated programme in rehabilitation medicine at Columbia University. It covers two pages. Stroke is identified as one of the most common causes of acquired disability. The second paragraph presents some examples of stroke in the bible and ancient history. In later epochs stroke changed history by affecting world leaders such as Roosevelt and Stalin. Included are paragraphs about risk factors, how stroke biologically causes disability, medical treatment and rehabilitation. The entry closes with a presentation of the latest research findings on brain plasticity and how these have affected treatment programmes for reducing impairments caused by stroke.

The second of the smaller and mid-sized entries I would like to present as an example is ‘Deinstitutionalization’. The four page entry, written by the French historian Henri-Jacques Stiker, starts out with a concise definition. This is followed by the first quarter part of the entry which defines the concept sociologically with examples made from studying institutions such as family, school, and church. To give such a strong priority to this is in my opinion tiring to the reader of an encyclopedia of disability. The next part of the entry covers psychiatric deinstitutionalization indicated by a subheading, the only such in the text. This part of the entry gives a presentation of the psychiatry reforms both in the US and in Europe. The final part of the entry, though not indicated by a subheading, brings up the importance of deinstitutionalization for disabled people in general and concludes that deinstitutionalization is not only about the disappearance of institutions, but their mutation to meet new social demands, i.e. the right to specialized services.

With these examples, my ambition has been to bring a closer look into the fabric of the *Encyclopedia*. The entries are strongly shaped by their authors, and the user of the *Encyclopedia* is left with a question of how the editors have thought about this. The style is in the direction of small essays on the subjects. In total the four entry volumes make up a multi-faceted representation of what disability studies is. But how was this planned and thought out by the editors?

International scope

In the introduction, the editor, Gary Albrecht, states that the ambition of the *Encyclopedia* is to make it as international as possible. The way this is done can be divided into three ideal – typical strategies: country specific, international, and US American only, exemplified by the entries ‘Experience’ (country specific), ‘Polio’ (international), and ‘Physical Medicine and Rehabilitation’ (US American).

‘Experience of Disability’ is made up of a main entry focusing on phenomenological perspectives on the body, disability, and society. This entry is followed by 16 country specific entries covering two–eight pages each. These vary a great deal in aim and scope, but in total they make rich material for the understanding of how disabled people live around the globe and the politics affecting disabled people’s living conditions. One example is the ‘Japan’ entry which gives an interesting presentation of the Green Grass movement of people with cerebral palsy that has acted as a creative, radical and highly influential pressure group since the early 1970s. They introduced ideas of a disability culture as early as 1975. The high number of countries represented is peculiar to the experience entry. The other entries using the country specific strategy have more of a perspective of additions, such as 'Australia' in the 'Disability Studies' entry presented above. Other examples are 'Sweden' in the 'Social Model' entry and 'Gender, International' as an additional entry to 'Gender'.

The 'Polio' entry is written by the Swedish medical doctors and rehabilitation specialists Gunnar Grimby and Katharina Stibrant Sunnerhagen. Over three pages they give an overview of the etiology and of polio, how it spread in the first part of the twentieth century, and how it was halted by the development of a vaccine. Today, many polio survivors in Western countries experience new symptoms in later life, but awareness is limited among physicians. In developing countries, many new cases have appeared lately. The authors refer to the 'Western world', 'in many countries' and 'developing countries' and the entry is truly global in scope. This is a stark contrast to other entries.

The entry 'Physical Medicine and Rehabilitation' is written by the US American professor and health improvement scholar James H. Rimmer. This covers three pages and is an interesting history of the recognition of physical disability in the US medical establishment and among US health authorities. The importance of polio epidemics and surviving WWII veterans were of crucial importance to the development of physical medicine and rehabilitation. But the history told is solely US American. We are introduced to the philanthropic couple Mary and Albert Lasker, the charismatic health entrepreneurs Dr. Howard Rusk and Mary Switzer and a list of important centres and programmes for the development of physical medicine and rehabilitation in the US. The increasing weight of psychological and sociological perspectives on life with a disability is also discussed.

The 'Experience' entry is the only piece with several countries included, but there is a widespread use of the extension ': international' on several entries and some uses of extensions like ': Sweden' or ': Australia'. In most cases it is possible to guess why it is a special entry on a specific country (for example Sweden in the case of the social model), but why some entries are labeled international though, for example, the 'Polio' entry is not, and why the 'Physical Medicine and Rehabilitation' entry is not labeled US is not easy to understand. There is a lack of systematic handling of the ambition of making the *Encyclopedia* as international as possible. That said, it is necessary to underline that the field of disability studies originated among US American scholars and the US has leading experts in physical medicine. A strong representation is obvious, but the balance between the US American and the international points of view should have been handled with more care.

For whom?

In September 2008, *The encyclopedia of disability* cost £468 on Amazon UK and in the editor's introduction it is presented as primarily relevant to libraries. But for most researchers the library is often two or three buildings away, and I see the project as a successful enterprise in the development of the study of disability as an interdisciplinary field of knowledge. Despite a weakness in the handling of the international scope and a few problematic entry texts, the overall impression is strength, breath, engagement, and high quality. I therefore do not hesitate to recommend the *Encyclopedia* not only to libraries, but also to research groups with ambitions to develop in the field of international disability relevant research.

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