Journal Review

Title: Independent Living and Self-Help in 2003: A Global Snapshot of a Social Change Movement

Editors: Barbara Duncan & Jennifer Geagan

Publisher: World Institute of Disability (WID), 2004

Available from WID, 510 16th St., Ste. 100, Oakland, CA 94612

Cost: \$30.00 USD

Reviewer: Katharina Heyer

Readers of this journal will not be surprised by the growing attention to global issues in disability studies. This volume is part of this international trend: aptly entitled a "global snapshot" of the state of the art of independent living (IL); it is a collection of essays from countries across the globe. Specifically, countries covered are the US, Canada, China, Japan, India, Mozambique, South Africa, and the countries of the Latin American region—somehow this needs to parallel the earlier clause. The volume also features analytical essays documenting international efforts to spread the independent living philosophy, including problems this will entail. Editors Barbara Duncan of Rehabilitation International (RI)) and Jennifer Geagan of the World Institute on Disability (WID) intend the volume also to be a progress report since the International Summit on Independent Living (Washington DC, 1999) organized by the US National Institute for Disability and Rehabilitation Research (NIDRR) with assistance by WID and Rehabilitation International. This summit was considered so successful in solidifying an international eye on independent living movements that just a year later WID launched the highly popular *DisabilityWorld*, an online magazine featuring IL-related news from countries around the globe. Many articles in this collection were previously posted on the DisabilityWorld website (www.disabilityworld.org) or in the International Journal of Rehabilitation Research (see www.independentliving.org), which gives immediate access to the essays for those preferring the paperless version. Translated excerpts are included from a Spanish language volume on international IL issues not otherwise available to monolingual readers.

As the independent living philosophy spreads across the globe, one fundamental issue people grapple with is the question of cultural sensitivity and competence. Culture occupies a central place in this volume as well. How can the (Western) notion of "independence" be translated to make sense to other cultures? This does not only apply to non-Western cultures that have different ideas about independence and family life, but also to cultures within the US that will question the urban-based middle-class values imbedded in the IL-philosophy. In her excellent overview of US IL history , for example, Kathy Martinez outlines some pressing issues for what is now considered the second generation of IL activism: poverty, services development for people from rural communities, and the critical examination of "Anglo bootstrap independence and self-

sufficiency" (p. 15) as applied to ethnic communities that value family interdependence and for whom notions of disability pride are so alienating it is "counterintuitive to introduce them" (p. 16). A related issue is the question of personal assistance services (PAS). In the US, PAS is currently based on the assumption that adults with disabilities want to live outside of their parents' home, and that hiring professionals is preferable to relying on family for personal assistance. Again the question is, "whose values are these?" (p. 53) Based on these issues, Independent Living Centers have begun outreach services to Asian, Black, Native American and rural communities. National Technical Assistance Centers have been developed for Latinos, Asians and Pacific Islanders, and Native Americans.

Similar questions are being asked by those in non-Western countries importing the IL philosophy, and this is where the volume both shines and disappoints. Some country reports are extensive and detailed, giving a good overview of history and current issues. Examples of these are the essays featuring Canada, Japan, South Africa, and the Latin American region. Here, scholars and activists can easily access information about policies and organizations, as well as the relevant literature. The essay on India is especially valuable in showing how a non-Western country can generate and implement culturally appropriate forms of independent living and self-help. It allows us to follow nine young Indian women for two years as they fashion their own self-help group and independent living community while undergoing a vocational training program in prosthetics.

When it comes to less well-studied countries, however, the volume promises more than it delivers. For example, the chapter on China consists of a brief, technical study of quality of life issues of hospitalized adults with spinal cord injury. It is a case study that needs to be placed in a larger context: as is, it does not tell us anything about the state of independent living in China. Similarly, the chapter on Mozambique is full of general statements on community-based rehabilitation, but tells us nothing about local approaches or organizations, with the exception of a curious mention of a traditional healer housing adults with mental disabilities to administer "spiritual treatment towards recovery" (p. 85). While it is doubtful this is to be interpreted as an example of a culturally appropriate adaptation to the IL principle, curious readers are left in the dark about what it all means. Readers interested in these studies cannot follow up with the authors—there is no information (contact or otherwise) about the contributors, which is a serious oversight in a volume so concerned with international cooperation.

The volume's primary strength lies in its more comprehensive essays that trace larger analytical themes, such as the development of the IL philosophy in the United States (Ch. 1) and the ways it has informed the international community (Ch. 7). Another essay in this category features the UK's "Action on Disability and Development", a development organization that supports IL in twelve of the world's poorest countries in Africa and Asia. This essay makes a strong case for the inclusion of disability in the planning and implementation of larger developmental projects, in the same ways that gender issues are already being addressed. At heart lies the recognition that poverty cannot be eliminated without addressing the needs of disabled people (p. 59), and this essay gives compelling examples of how this inclusion has worked in practice. The volume concludes with an extensive timeline of major milestones in independent living communities all over the world, along with an international review of IL literature

featuring a large number of online articles. Both are excellent resources for further study and discovery.				