

## Book, Video, and Film Reviews

### Book Reviews

Biklen, D., and Cardinal, D.N., eds. *Contested Words, Contested Science: Unraveling the Facilitated Communication Controversy*. New York, NY: Teachers College Press, 1997, 245 pages, \$24.95 softcover.

Reviewed by Sandra McClennen, Eastern Michigan University, Ypsilanti, MI.

Traditionally, it has been assumed that lack of verbal speech is a direct reflection of lack of intelligence. Sign language proved this untrue for people experiencing deafness. Specialized computer applications have proven this untrue for people with physical disabilities who can reliably control as little as one movement or even eye gaze. Each of these assumptions involved initial disbelief on the part of many professionals, who used the traditions of "established knowledge" and the "right way to do research" to buttress their viewpoints.

The current controversy involves the intelligence of people who are non-speaking, minimally speaking, or speech echoing, with diagnoses of autism and/or mental retardation, as well as some people with cerebral palsy (usually athetosis) who do not have a fully reliable movement. A communication access method that has proven successful for some is facilitated communication. It initially requires physical support of the hand or arm, though not guiding, with the eventual goal of independent typing or writing by the individual. Discovered and written about independently by Rosalind Oppenheim in the United States in 1974 and by Rosemary Crossley and Anne McDonald in Australia in 1984, it has aroused a storm of controversy that curiously parallels that following the "discovery" of language and intelligence of those with deafness and physical disability.

*Contested Words, Contested Science* addresses three different, though related, issues: (1) the prevailing controversy over facilitated communication, specifically, whether the words of people communicating with this method of access are their own or those of their facilitators; (2) how researchers investigate something new and controversial; and (3) the larger society's understanding of ability and disability.

Six of eleven chapters describe research in which some or all of the participants demonstrated authorship of her/his facilitated communications. The last chapter summarizes what can and what cannot be said, based on all published research to date, about facilitated communication and the people who use it. Two chapters address the question of investigating something new and controversial, and two chapters address how, without very careful consideration, those of us in power (professionals and academicians) keep those with disabilities, and especially those who cannot speak verbally, voiceless and powerless.

Eugene Marcus, a man who communicates by typing with facilitation, designed one of the research projects. His chapter addresses all three of the issues. He speaks to the question of voice and power particularly eloquently: "Speaking comes easily to most people, and so those of us who don't speak easily are not understood in two ways by those of you who do. First, you are maddeningly slow much of the time at knowing our most basic wants. . . . Nothing can be gotten by just waiting, either. So my nonspeaking siblings and I have become masters of creative problem solving. The second way . . . is that you usually get only a glance at who we really are. You don't see our creative, passionate, spiritual, and laughing sides much. You do see our scared and confused sides, and that makes you scared and confused around us" (pp. 117-118).

### References

- Crossley, R., and McDonald, A. *Annie's Coming Out*. New York, NY: Viking Penguin, 1984.
- Oppenheim, R. *Effective Teaching Methods for Autistic Children*. Springfield, IL: Thomas, 1974.

Charlton, James I. *Nothing About Us Without Us: Disability Oppression and Empowerment*. Berkeley, CA: University of California Press, 1998, 214 pages, \$27.50 hardcover.

Reviewed by Ravi A. Malhotra, Norman Paterson School of International Affairs, Carleton University, Ottawa, Canada.

An occasional complaint in the burgeoning field of Disability Studies is the lack of a sophisticated theoretical framework in much of the literature. Just as an earlier generation of feminist theorists had to struggle to craft a feminist epistemology that made sense of the world from the female standpoint, Disability Studies scholars today still face the arduous task of formulating a comprehensive worldview that analyzes how structural and attitudinal barriers are the primary problem faced by people with disabilities. James Charlton's newly released book, *Nothing About Us Without Us: Disability Oppression and Empowerment*, is an important contribution to that constantly evolving project. Dividing the dimensions of disability oppression into constituent components that Charlton identifies as political economy and the world system, cultures and belief systems, and consciousness and alienation, *Nothing About Us Without Us* contains a thoroughly documented chapter on each one of these topics. Particularly noteworthy are the use of excerpted comments throughout the text from disability rights activists from countries around the world including Zimbabwe, Brazil, and Thailand, and, toward the end of the volume, a detailed typology of disability rights organizations.

The overall quality of the scholarship presented is clearly strong and highly sophisticated. The selective, yet innovative application of the insights of such well known political and cultural theorists as Raymond Williams, Antonio Gramsci, Noam Chomsky, and Ellen Meiksins Wood to disability politics is a refreshing and, sadly, rare experience that one can only hope will become more common in future years. Indeed, Charlton dares to swim against the current fashion of much of contemporary academia, particularly in the humanities, where the obscurities of poststructuralism still retain an iron grip over the curriculum in many universities, when he argues that the politics of the body and cultural politics in general are affected by historical and social processes. Therefore, he convincingly rejects the notion, as many Foucauldians would have it, that the body is the primary site of oppression for people with disabilities.

At the same time, the sheer breadth of topics that this short volume attempts to cover sometimes undermines its presentation. For example, given the avowedly materialist perspective of the author, the section on political economy is frustratingly brief. In fact, one finds oneself wishing that fewer topics had been given a more comprehensive treatment. Another difficulty is the geographic scope of the book. Although the author candidly admits that he is not familiar with certain regions of the world, he is never clear on the intended scope of the project. What results, unfortunately, is an occasionally choppy analysis that jumps back and forth from continent to continent and from First World to Third World.

These quibbles, however, should not distract from Charlton's significant achievement. His typology of disability rights organizations alone should give future Disability Studies scholars much to ponder and debate. Charlton's work ought to be read by all interested in disability oppression and disability rights.

Corker, Mairian. *Deaf Transitions: Images and Origins of Deaf Families, Deaf Communities and Deaf Identities*. London, England: Jessica Kingsley Publishers (Distributed by Taylor & Francis, 1900 Frost Road, Suite 101, Bristol, PA 19007-1598), 1996, 213 pages, \$26.95 softcover.

Reviewed by Stephen F. Weiner, School of Undergraduate Studies and Department of Counseling, Gaudaudet University.

There comes a time when anyone who is a student in his/her particular field begins to see indiscernible shades of grey in any new publication. In the mental health field, working with deaf people, I am so used to reading new publications with similar assumptions by different authors with similar citations. At times, it is hard to notice any real differences in what they say, and, after a while, you begin to scan only the table of contents or the subject index and then the bibliography for any new

information. That just about sums up my thoughts when I received *Deaf Transitions* by Mairian Corker for a book review. After giving a cursory review of the bibliography, I was rather elated to see that it had updated sources and I was intrigued by the unusual amount of tables and illustrations that seemed to support the text. More importantly, the basis for this book is actually interviews or life scripts (narratives), as the author calls them, of eight deaf individuals from diverse backgrounds. The videotaped interviews with seven of the eight individuals lasted between 90 and 150 minutes; one interview was conducted through written responses to open-ended questions posed by the author. While this approach is not unusual, it was nice to see an attempt by the author to conduct interviews covering a wide range of issues pertaining to human development, with an obvious attempt to focus on environmental issues that have an impact on the process of development among deaf people. This book takes a holistic approach towards understanding human development as it relates to deaf people.

The author takes pains to address issues and to introduce the reader to the book with a well-detailed preface, something that other authors would do very well to emulate. It opens with an informative preface about the author and delineates a variety of issues, including a very short introduction to the structure of the book, which is key to preparation for reading this book. Simply, the book is divided into three parts: the first one consists of an introduction to the topic; the second part is composed of anecdotal narratives by eight deaf people from diverse backgrounds, "life scripts" that are supplemented by supporting analyses by the author; and the third part is not a closing, but an open-ended section asking the readers to explore the realm of possibilities when working in the mental health field with deaf people.

Ms. Corker is obviously a libertarian who feels that societal pressures are greater now than ever, forcing people to conform to so-called accepted mores and norms and, thus, eroding diversity and the uniqueness of humanity. Her preferred approach to the study of the issues presented appears to be humanistic psychology, although eclectic themes appear throughout the book. It is clear to the reader that the author is a knowledgeable counselor and that she assumes readers will understand her views and philosophy, which appear in the preface.

Chapter One of this book, which is the first part, is basically an introduction to developmental psychology and to issues faced by deaf people. Generally, it is a detailed and descriptive chapter supported by plenty of citations and references - something worthwhile for any reader new to the field and a review for those who are in the field. Erikson's theory of development clearly dominates the chapter. Portions of life scripts of three people are presented that address identity development; not surprisingly, they address negative stereotypes of deaf people and societal intolerance of people who are different. The rest of the chapter is devoted to supporting the need for uniqueness in identity development. The author concludes with a clear presentation of her views, pointing out key components and issues for creating an ideal environment for identity development. There is a lot of information in this section and any people new to the field should see this as an introduction and the basis for further exploration. For the rest of us who are in the field, it is a place for us to examine critical aspects of her comments and observations. She has presented information in a cogent manner with sources to support it and it is incumbent on us to carefully scrutinize this information before coming to agreement or, if you may, disagreement.

The life scripts of eight deaf individuals take up most of the second section of the book. One learns a lot from these people who provide very insightful comments reflecting their experiences growing up and how they see themselves in relationship to their existing environments. Earlier in the preface, the author explains how the seven videotaped interviews were transcribed. The process was interactive, with interviewees having input to ensure that their stories accurately depicted their reflections of life experience. The eighth "interview" was conducted through written correspondence. I am not sure that written correspondence is as effective as personal interaction. Constant themes in this section relate to development of identity and illustrate background differences among the interviewees - deaf of deaf parents or deaf of hearing parents, ethnicity, religion, and other essential factors that have life-long ramifications. Simply, these factors influenced us to be what we were as children and

they affect the process of constant growth and changes throughout our lifetimes. This section of the book is a real achievement for the author, since she had to tie in the interviewees' experiences with careful analyses, where needed, to clarify issues presented by the interviewees. Some of her analyses incorporate developmental theories and some contain illustrative examples that help the reader to better understand the life scripts.

Futuring seems to be the theme for the third section where the author presents the humanistic view of developmental issues faced by deaf people. However, I found the author's premise - that the interviewees' core issues were in the areas of gender, ethnicity, and sexuality rather than the issue of being deaf - intriguing or, rather, faulty. I disagree with this because their life stories began mostly with relationship problems - not understanding what was happening to them at a very young age - the exceptions to that were deaf children in deaf families. Therefore, the core or first issue for them was one that dealt with being deaf persons in their families. Several deaf psychologists and mental health practitioners of stature have recognized that there are developmental issues unique to deaf people. They recognize that societal expectation does not necessarily agree with our (deaf) views of healthy development of deaf individuals. Simply, the acceptance of the deaf self is a precondition towards the resolution of other issues leading to healthy and holistic living.

*Deaf Transitions* is a book that should be in the library of everyone who is in the field. Mairian Corker did a very admirable job of writing this book because, when one reads it, one can see the organic development of the text that makes it an interesting read rather than a dry academic tome to be used for reference purposes. I can see this book causing lively discussions in classrooms and in professional circles; for this, I thank Mairian Corker for writing the book.

Denzin, Norman, K. *Interpretive Ethnography: Ethnographic Practices for the 21st Century*. Thousand Oaks, CA: Sage, 1997, 325 pages, \$56.00 hardcover, \$26.95 softcover.

Reviewed by Russell P. Shuttleworth, Medical Anthropology Program, UCSF-Berkeley.

As a form of inquiry into the ways of life of people with disabilities, ethnography has much to offer. Both for Disability Studies researchers schooled in ethnographic methods and for those who are contemplating doing a disability ethnography, Norman Denzin's recent work provides much food for thought. Denzin presents ethnography as a project in transformation. Traditional and modernist ethnographers assume cultural meanings are connected to observable actions in the world. The ethnographic analyst's task is to "show how culture and social structure were mapped into the mental structures of the persons studied" (p. xv). Since the 1970s, however, interpretive researchers have increasingly criticized studying human groups and situations in realist and objectivist terms. In his book, Denzin advocates the ethnographic use of innovative and critical practices drawn from such diverse areas as performance, the new journalism, and crime fiction, the processes and products of which are more appropriate to our postmodern situation of contradiction, ambiguity, difference, violence, multinationals, disjuncture, and global economic and discursive systems.

Anyone familiar with some of Denzin's earlier books on qualitative research methods (see, for example, Denzin, 1989) will find this one much improved in terms of organization of materials. While Denzin's rather bland style of writing never quite matches his obvious fervor for the ideas and practices he advocates using, his work, nevertheless, should challenge the thoughtful among us to take stock of our ways of doing ethnography as we approach the 21st Century. He begins by reminding us that we are in the midst of a triple crisis: representation, legitimation, and praxis. The connection between lived experience and the representational text has been rendered problematic. The criteria for evaluating and interpreting qualitative research is also undergoing major upheaval, with the extreme postmodern position being that there are no criteria for judging its products. The related crisis of praxis asks, "Is it possible to effect change in the world, if society is only and always a text?" (p. 4). As researchers, our response to these crises reveals where we stand between two seemingly opposed visions for the craft of ethnography: the modernist vision committed to a realist epistemology and a poststructural, critical social science.

Denzin engages these crises on multiple levels throughout his discussion of the various foci that relate to his primary aim of developing an interpretive ethnography for the 21st Century. These foci include the work of James Joyce as a model for a new way of writing ethnography; our century's visual regimes of truth, of which the "ethnographic gaze" is a perfect example; the promise of recent interpretive texts written from the standpoint of certain excluded groups (e.g., women and other minority groups) and their inability to transcend realist and positivistic assumptions; a critical, performative cultural studies and performance ethnographic texts; the texts and practices of literary journalists and writers of new forms of detective fiction as models for ethnography; the place of ethnopoetics and personal narratives of the self in the messy text; and the different use of the narrative turn by realists and poststructuralists. In the last chapter, Denzin responds to critics of some of the new ethnographic writing and also his and Yvonna Lincoln's vision for interpretive qualitative research. (For this debate, see Huber, 1995; Snow and Morrill, 1995a, 1995b; and Denzin and Lincoln, 1994, 1995.) Denzin decries the realists for policing the boundaries of science and rebuking the ethnographic experimentalists. He calls for new norms in writing ethnography, new models of truth based on a postpragmatist social criticism, a feminist, communitarian ethics, and a radical sense of democratic journalism in the development of an ethnography committed to the public good.

One problem I have with Denzin's approach is that he wants to theoretically infuse ethnography with so many perspectives and approaches (poststructuralism, neo-Marxist critical theory, postmodern discourse, Foucault's genealogy, interpretive anthropology, poststructural and postmodern feminist discourse, cultural studies, materialist, critical ethnography, and antifoundationalism), yet keep explicit theorizing to a minimum. While I certainly believe the voices of research participants should form a significant part of any ethnography, Denzin's position makes it requisite for readers to be thoroughly well versed in all these perspectives. In addition, in the zeal to unite theory and praxis, there is always the possibility that readers, participants, and even ethnographers may lose sight of the fact that resultant ethnographies are driven yet by implicit theories. Denzin also seems suspiciously over-eager to move out of the Fifth Moment of ethnography (the present), where "we are writing our way out of writing culture," and into the "undefined Sixth Moment" (p. 18). I find his (and Lincoln's) fascination with a linear (but also cumulative) time line and the future of ethnography somewhat obsessive and unnecessary; indeed, the Fifth Moment operates simply as a bridge to a moment that has not yet arrived. Denzin, it appears, wants to be remembered as a visionary, selecting those perspectives and practices from various fields that he believes point to ethnography's future.

Whether or not one accepts all of Denzin's vision for ethnography in the 21st Century (he can be annoyingly prescriptive), certain aspects definitely have implications for people with disabilities. His observation - that the epistemology behind the legitimating criteria of positivist and realist social science is normalizing to the core - is an obvious instance. To take the criterion of generalization, for example - since it is a "normal" population to which generalizations are directed - the "marginal" or nonrepresentative is always studied in terms of the "normal." Yet, showing how societal structures and meanings inhibit access and the free expression of "marginal" individuals or groups certainly does not require use of this criterion. Denzin's discussion of the challenge that standpoint texts mount to normative and realist approaches to qualitative research and where they fall short in this goal is obviously relevant to Disability Studies. He also echoes participatory action research (PAR) in advocating the active participation of those studied in the research process, albeit without some of PAR's realist assumptions. Additionally, disability culture's promotion of diverse, subversive performances (performance art, poetry and prose readings, and even stand-up comedy) that critique oppressive symbolic, social, and political structures is a significant move toward a critical, performative cultural studies. As with research directed by all groups (and their allies) that are considered nonrepresentative of the larger society, however, there is a dilemma for Disability Studies: How do we take advantage of these new ethnographic practices within a formal funding apparatus, a human subject's code, and a policy environment that is still under the sway of a normalizing and objectivist view of social science?

## References

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- Dybwad, Gunnar, and Bersani, Hank Jr., eds. *New Voices: Self-Advocacy by People with Disabilities*. Cambridge, MA: Brookline Books, 1996, 286 pages, \$29.95 softcover.
- Reviewed by Phil Ferguson, Specialized Training Program, University of Oregon, Eugene, OR.

My guess is that not many readers of *DSQ* will be very familiar with the history of the disability rights movement that this book documents. Those who can recite dates and places for the emergence of the independent living movement in Berkeley and Boston should also know the important roles played by people such as Bernard Carabello, Valerie Schaaf, and Ray Loomis. From the perspective of those who were fighting for their freedom from institutional hellholes such as Willowbrook in New York or Beatrice in Nebraska, the importance of the San Francisco/HEW sit-in is matched by the 1974 meeting in Salem, Oregon, that organized the first chapter of People First (the leading self-advocacy organization for people with intellectual disabilities). This is a two-sided coin, of course. Those who know the details of the self-advocacy movement among people with intellectual disabilities should also know the stories that go with names such as Ed Roberts, Judy Heumann, Irv Zola, and others. Everyone should know the struggle involved in getting the regulations for Section 504 promulgated. There are important names and stories in all corners of the disability community. As we try to peer over the horizon at the shape of the disability rights movement in the next century, we must develop a more broadly-shared awareness of the giants of early advocacy on whose shoulders we stand.

This book is an excellent place to start for those who would like a quick survey of the self-advocacy movement for people with intellectual disabilities as it has emerged over the last 30 years. The book is an interesting collection of personal history by the individuals involved, supplemented by more elaborate chronologies and conceptual analyses of the ideas behind the movement. Unlike many other accounts, the book is also refreshingly international in outlook. Besides the United States, the book includes reviews of self-advocacy movements in Sweden, Canada, Great Britain, and Australia.

From that beginning in Salem, Oregon, there now exists a national network of over 700 individual self-advocacy organizations for people with intellectual disabilities. Estimates vary, but there are probably over 17,000 members nationwide. Their triumphs continue at the local and state levels (see the institutional closure lawsuit by Tennessee People First) and their organizational visibility is growing at the national and international levels as well. Their work is important. Despite the book's title, their voices are not really so new. Rather, we are just now beginning to listen.

Harrington, Thomas F., ed. *Handbook of Career Planning for Students with Special Needs* (2nd Ed.). Austin, TX: Pro-Ed, 1997, 451 pages, \$39.00 hardcover.

Reviewed by Andrew Christensen, Boston College.

Employment and economic self-sufficiency remain a central issue for persons with disabili-

ties. While most policy initiatives aimed to increase employment rates for persons with disabilities center around employers, there are, in many instances, two sides to the issue. In order to gain employment, many persons with disabilities must overcome, in addition to their disabilities, underdeveloped job searching skills. This manual is designed for the service provider trying to assist the person with a disability in finding suitable employment.

The situation facing persons with disabilities who want to work has changed considerably since this handbook was first published in 1982, mostly because of technological advancements and the passage of the Americans with Disabilities Act. The book's fourteen chapters by individual authors are divided into five sections. The first section gives an overview of career counseling, which may be particularly useful to the professional with little or no formal training as a career counselor. Subsequent sections focus on disability policy, particulars of the contexts in which most persons with disabilities receive career guidance, vocational planning, and preparation and transition. Four appendices outline the thirteen competencies, as identified in a 1995 government report, central to obtaining employment.

Service providers who consult this book, depending on their background, will find some sections more useful than others. While the handbook touches on all aspects of career planning that affect persons with disabilities, its treatment of these aspects seems superficial. Little effort is made to contrast the job hunting process for persons with disabilities with that for the general population, an obvious reference point. Similarly, the volume could use more overview, most notably an expanded explanation of the book's organization and a discussion of the changes from the first edition. The title is somewhat misleading because most students with special needs will lack the background and preparation necessary to utilize the information as presented in this book.

Jackson, Vera R., ed. *The Abusive Elder: Service Considerations*. New York, NY: The Haworth Press Inc., 1996, 84 pages, \$24.95 hardcover, \$14.95 text (5+ copies).

Reviewed by Debra J. Sheets, Andrus Gerontology Center, University of Southern California, Los Angeles, CA.

The topic of the abusive elder seldom receives attention, in contrast to the considerable concern about the abuse of elders. This book is unusual in describing the types of abusive and disruptive behaviors of elders in geriatric settings, and in examining their impact on programs, staff, quality of life, and staff members.

The book is divided into five sections. The introductory section identifies four common types of abuse (physical, sexual, psychological, and violation of rights) and the barriers to responding to abuse that result in adaptive behaviors. Section II is an uneven compilation of chapters by service providers detailing interventions that work with abusers who are cognitively impaired, sexually inappropriate, manipulative, disruptive, or depressed. This section would have been improved by strong editing and more rigorous attention to content and the state of the literature. Section III consists of a chapter on the role of an ombudsman and the assistance she/he can provide in responding to problem behaviors. Section IV focuses on legal and professional issues associated with abusive elders. One of the strengths of this book is Dr. Villani's chapter, which addresses the importance of education in helping practitioners to recognize and to reduce practitioner abuse. The final section highlights the themes and provides recommendations for responding to the abusive elder. The recommendations provide a good summary of the main points of the various chapters and should prove useful to service providers.

A significant limitation of this book is the uneven quality of the articles and the failure to integrate the sections in a unified manner. The chapters appear to have been written independent of one another, and they fail to reinforce the strategies, recommendations, and approaches that are proposed. In addition, the chapters are quite short and, with few exceptions, fail to communicate more than superficial content. Finally, very few references are provided by the authors as evidence that the approaches they recommend are supported by research.

Overall, the strength of this book lies in its directing our attention to an often overlooked area of abusive behavior - the perpetrator as well as the victim. However, while the book provides an adequate description of the problem, the individual chapters often lack sufficient depth and detail on how to deal with the behaviors of abusive individuals.

Julia, Maria C. *Multicultural Awareness in the Health Professions*. Boston, MA: Allyn and Bacon, 1996, 210 pages, \$36.00 softcover.

Reviewed by Diane Weiner, UCLA American Indian Studies Center, Los Angeles, CA.

What can I say? I admit it, I am one of those folks who often judges a book by its title or cover. Using this criterion, this book would have been left on the shelf - simple title and dull cover. What a mistake I would have made! Maria Julia has edited a fine collection of essays that provokes health professionals and researchers alike to reconsider the impact of inter- and intra-cultural diversity on health beliefs and approaches.

In her frank and cogent introduction, Julia asserts that many health professionals have limited "cultural awareness, understanding, sensitivity, and competency in dealing with the variety of ethnic subcultures in the United States" (p.x). Her goal, as well as that of her co-authors (social workers, nurses, counselors, and academics), is to describe the "uniqueness" (p. xi) of individuals and their ethnic groups in order to assist health providers with the revision of existing services and the development and operation of future programs. And, for those of us who are not in the position to make macro level health reforms, each chapter offers practical micro level tips for the provision of culturally sensitive and/or competent care.

The health constructs and treatment behaviors of eight particular ethnic groups are discussed: African-Americans, Amish, Appalachians, Arab Americans, Asian Americans, Hispanics, Orthodox Jews, and Native Americans. Each author follows cultural information with descriptions of current health circumstances and with numerous ways to alleviate these conditions. Significantly, no ethnic group is treated as an isolate nor as a static entity. In her chapter on Arab Americans, Anahid Devartain Kulwicki acknowledges the historical, political, linguistic, religious, economic, and gender differences within the Detroit, Michigan, Arab American community. These distinctions highlight the necessity for the care of individuals who may not fit a particular health profile or ethnic/social stereotype held by a provider.

I was particularly fascinated by the chapters on the Amish (Gretchen H. Waltman) and on Orthodox Jews (Daryle Spero), two groups whose populations are quickly and seemingly quietly expanding through increased birth rates. Waltman and Spero eloquently offer cost-effective guidelines to aid clients and their families with the prevention and treatment of acute and chronic conditions.

The final chapter of the book by Shary Scott Ratliff expands on these ideas and on those of the other authors; this writer challenges her readers to embrace interethnic mediation and negotiation of philosophies as part of the health delivery experience. Again, this approach embraces practical suggestions.

This text will be useful in the classroom for health providers and medical anthropologists. Project directors, researchers, and providers might also want to place this book on an accessible shelf.

Kauffman, James M., and Hallahan, Daniel P., eds. *The Illusion of Full Inclusion: A Comprehensive Critique of a Current Special Education Bandwagon*. Austin, TX: Pro-Ed, Inc., 1995, 364 pages, \$29.00 softcover.

Reviewed by Phyllis Rubenfeld, Hunter College of the City University of New York.

The authors whose work is collected in this volume do not believe that disabled students can be adequately served in the general education classroom, in part because, as they see it, collaborative teaching simply does not work. Full inclusion of disabled people in the larger culture is a doomed philosophical position, they contend, one that serves as an excuse for dumping disabled kids



in regular classrooms without services. They confidently state that many parents now complain that their disabled children were routinely placed in general education classes and that it was only their own aggressive advocacy that forced their schools to come up with essential resources, such as self-contained classes. They offer no supportive data to buttress this position, and, indeed, it is hard to see how they could, since much of the actual data available on the topic suggests that the opposite is the case.

What the authors represented here fail to realize is that special education is a program, not a location. They also do not appear to understand that what inclusionists seek is freedom from segregation, not the loss of appropriate services to facilitate learning. They seem to believe that, as long as there are disabled students, there will be a need for special education in self-contained classes. While they are quick to condemn those educators who believe in inclusion as naive and wedded to out-of-date research, they fail to recognize that their own assumptions and beliefs are unsupported with factual evidence.

Finally, although the volume includes a chapter on the "Culture of Disability" written by the editors, little in it suggests that they have much understanding of that culture. They would have done better to have found a person who had actually experienced life in a special education classroom to write the chapter, rather than writing it themselves, which alone would have strengthened their argument. As it stands, however, the best the authors can produce is a collection of all the usual arguments against inclusion without any new data to support their position - this, despite their criticism of inclusionists for having done the same.

Kaye, H., Stephen, and Longmore, Paul K. *Disability Watch: The Status of People with Disabilities in the United States*. Volcano, CA: Volcano Press, Inc. (P.O. Box 270, Volcano, CA 95689; 1-800/879-9636), 1997, 90 pages, \$14.95 softcover.

Reviewed by Marcia J. Scherer, Institute for Matching Person and Technology, Webster, NY.

This short 1997 monograph is jam-packed with data and information about the status of people with disabilities in the U.S. Authors H. Stephen Kaye and Paul K. Longmore have selected five major topical areas as follows: demographics, employment, social integration, barriers to independence, and transportation. Additionally, there is an introduction by Paul Longmore, Director, Institute on Disability at San Francisco State University, that provides an important substantive springboard for the topical, data-filled chapters. There is also a brief conclusions chapter where many areas in need of additional, focused attention are discussed.

This is an indispensable guide for anyone interested in disability policy and systems change. Researchers, demographers, educators, advocacy groups, and leaders in a wide variety of organizations and agencies will find it packaged in a very easy-to-use format with liberal pull-outs of key points, myths and facts, and graphic presentations of data. While the authors have provided a comprehensive "slice of life" regarding living with a disability in 1997, their desire for clarity and conciseness have resulted in some gaps. To select one example near and dear to my heart, the importance of assistive technologies in the areas of employment, social integration, barriers to independence, and transportation are given only cursory mention. While there are many texts and organizations dealing exclusively with assistive technologies for persons with disabilities, there is no bibliography provided to lead the interested reader to these other resources. The same is true for other, specialized areas. Perhaps, when an updated edition is published, as surely will occur in our fast-paced world, a bibliography of key resources in relevant specialized areas can be appended. This would go a long way to helping the interested reader put some detailed flesh on the excellent skeleton provided by Kaye and Longmore.

Klimas, Nancy G., and Patarca, Roberto, eds. *Disability and Chronic Fatigue Syndrome: Clinical, Legal and Patient Perspectives*. New York, NY: The Haworth Medical Press, 1997, 132

pages, \$23.96 hardcover, \$14.95 softcover.

Reviewed by Tanis Doe, Pearson College, Victoria, BC, Canada.

This volume was simultaneously published as the *Journal of Chronic Fatigue Syndrome*, Volume 3, Number 4, in 1997. Given the current debate on the classifications and definitions of disability, impairment, and handicap, this book is a good illustration of how "disability" can be "un-constructed" by legal and regulatory disability determinations. The subtitle implies that it is multi-disciplinary because it presents papers from medical practitioners, attorneys, and consumers (called "patients" in this text). However, the overall impression one gets from reading all nine papers is that the "patients'" perspectives are included to add credibility to the work of the professionals - almost like case histories - to prove a point. This was unlikely the intention, but it appears to be a consequence of spending the first 86 pages explaining how difficult it is to demonstrate the existence of disability among people with Chronic Fatigue Syndrome (CFS).

The book provides a lucid example of how some people with disabilities must fight to have their situations recognized as disabling and how they are often most stigmatized by the lack of physical evidence and by the widespread belief that Chronic Fatigue is a mental illness or a symptom of malingering. The doubt cast on the validity of disability among people with Chronic Fatigue Syndrome probably explains why so many of the papers attempt to prove its existence. The patients' perspectives focus on how difficult it is to navigate the stormy waters of disability determination with the Social Security Administration and long-term disability insurance carriers. Limits of two years, clustering CFS with psychiatric disabilities that are excluded, or outright denying the existence or disabling nature of CFS are common examples of fights people face when applying for insurance benefits. The very nature of having Chronic Fatigue Syndrome makes it far more unlikely for a person to have the stamina to pursue second opinions, appeals, legal aid, or political assistance.

One might hope that the book would bring answers to the difficult puzzle of CFS and disability, but the papers do not succeed very well. They reveal that, in controlled experiments, neuropsychological assessments and laboratory tests do not consistently identify deficits of Chronic Fatigue Syndrome and that claimants for Social Security and disability benefits are unlikely to be able to meet the strict tests of "disability."

While it is continuously acknowledged that people with CFS exhibit cognitive difficulties associated with memory and concentration, extreme exercise fatigue, and a number of auto-immune irregularities, the testing reported of people without CFS, and of people with other "diagnoses" such as allergic rhinitis and depression, show there is rarely clinical indication of CFS-related deficits on tests. The one test that was described that did seem to offer some "objective" evidence of CFS was an oxygen consumption measurement during exertion, but it lacked statistical validity. Even though the professional papers focus on medical identification and measurement of CFS and "disability," the final two papers, from patients' perspectives, really reinforce the fact that most medical and legal efforts are geared to disproving CFS in patients or, conversely, to proving that people with CFS should be working and are not entitled to disability benefits.

I do recommend this book, particularly to those interested in the intersection between illness/impairment and disability/handicap. It does not offer hope to people with CFS, but it does offer insight into social and economic implications of current policy and medical definitions of work disability.

Kuusisto, Stephen. *Planet of the Blind*. New York, NY: The Dial Press, 1998, 194 pages, \$22.95 hardcover.

Reviewed by Beth Franks, Hobart and William Smith Colleges, Geneva, NY.

Stephen Kuusisto was born three months prematurely. In 1955 the connection between the use of large amounts of oxygen in incubators and retinopathy of prematurity had not yet been made. As a consequence, Stephen's eyes were permanently damaged.

Although legally blind, Kuusisto spent most of his life passing as sighted. Without benefit

of white cane or guide dog, wearing thick, often blue-tinted glasses, Kuusisto walked, ran, and bicycled - sometimes stumbling, sometimes falling, but always traveling at high velocity. Entering the world precipitously, Kuusisto has continued to rush through life. This in itself is not unique, but, when combined with a visual impairment, the result is a compelling journey. And Kuusisto takes you with him every step of the way. Open the book anywhere. You encounter luminous prose and metaphor-rich language that invite you to enter the worlds Kuusisto travels. From pre-IDEA (Individuals with Disabilities Education Act) schooling to disability activism, from rural New Hampshire to New York City, from passing as sighted to gloriously guided (Corky, his Labrador retriever, now goes with him everywhere), Kuusisto himself lives in the land between - guiding his readers from one world to another with great dexterity.

To this work, Kuusisto brings both poetry and exuberance. His inclination to fling himself head-long into life, his intelligence, and his talent both shaped and were shaped by experience and schooling. His parents faced the difficult decision of placing him in either an institution for the blind or a public school without special assistance and chose the latter. Thus began Kuusisto's conflict-ridden and contradictory relationship with schools, scholarship, and schooling.

No special provisions were made for him in elementary, junior high, or senior high school. Forced to sink or swim, Kuusisto swam. Like most children, school became both his social world and his gateway to learning. Although many of his educational experiences were aversive (he even became anorexic during adolescence), the world of scholarship attracted him. He attended college and graduate school; he traveled in Europe; he worked as an assistant professor; and he won a Fulbright Scholarship. Until a freak accident further limited his already marginal vision, Kuusisto lived independently. This accident (his eye was cut by a bookmark) moved him into a new borderland. Describing his current status, Kuusisto says, "I live in the 'customs house' between the land of the blind and those who possess some minor capacity to see" (p. 11). No longer passing as sighted, Kuusisto still navigates among those different worlds.

The book's title, *Planet of the Blind*, captures the multiplicity to be found within its covers. The literary reference to H.G. Wells ironic short story, "Country of the Blind," grounds the book in the field of literature. With this foundation, Kuusisto points forward. A mere country no longer sufficient, Kuusisto aims for the planets and stars beyond. Poet, sight-impaired visionary, and author, Kuusisto has written a memoir well worth reading.

LaBrake, Tammy. *How to Get Families More Involved in the Nursing Home: Four Programs that Work and Why*. Binghamton, NY: The Haworth Press, 1996, 103 pages, \$19.95 hardcover.

Reviewed by Debra J. Sheets, Andrus Gerontology Center, University of Southern California, Los Angeles, CA.

As more of us live into old age, we can expect to spend some time, whether briefly or perhaps more permanently, in a nursing home. This book argues for the importance of getting families involved in the nursing home and provides very practical suggestions and examples on how to implement four different kinds of programs that will encourage participation.

Ms. LaBrake recommends offering more than one program in order to reach different families and she notes that family programs should be tailored to the unique needs of each nursing home and the families of the residents. The four programs that LaBrake discusses are educational workshops, support groups, council meetings, and holiday socials. Each of these programs is described in a step-by-step format that includes the purpose of the program, hints for getting started, what you need to begin, and ways to plan for success. Among readers of *DSQ*, the book will be especially useful to those who are interested in transforming the institutional atmosphere of so many nursing homes.

The limitations of the book are two-fold. First, the perspective of the book assumes that residents are dependent on family members for advocacy on their behalf. This approach ignores the disability literature, which emphasizes the importance of empowering residents to articulate their needs and to shape the environment in which they live. Secondly, the narrow focus on nursing homes

limits the audience for this useful and quickly read book, when many of the programs described could easily be implemented in other common housing settings for elders, such as assisted living facilities.

Whatever the limitations of this book, its strength is that it provides a blueprint for developing programs that promote family involvement and for making changes for the better in nursing homes. The more that families actively participate in the nursing home community, the higher the quality of life will be for residents.

Little, Jan. *If It Weren't For the Honor - I'd Rather Have Walked: Previously Untold Tales of the Journey to the ADA*. Cambridge, MA: Brookline Books, 1996, 274 pages, \$15.95 softcover.

Reviewed by Jonathan M. Young, NRH Research Center, Washington, DC.

*If It Weren't For the Honor* is a memoir of Jan Little's life experiences as a person with a disability (polio) and a professional working in disability-related fields. Her predominant message is that people with disabilities, decades before passage of the Americans with Disabilities Act of 1990, had lived active and productive lives that contradicted society's presumptive link between disability and life as a "shut-in" (p. 116). People with disabilities, she explains, have "all the same characteristics and goals as any other citizen randomly selected from the crowd" (p. 155). Little builds on this narrative focus to argue that public attention to "disability leaders" has deflected much-deserved credit away from ordinary people with disabilities who have made drastic changes at the individual and local level.

The book follows Little's life from the details of contracting polio, through grade school and college education, to the path of her career. She gives particular attention to her world-wide travels as a wheelchair athlete. At times, her descriptions of sites seen and foods eaten appears unrelated to the subject of "disability." But perhaps that is precisely her point: By talking about people with disabilities doing everyday sorts of things, she illustrates the "normalcy" of being a disabled person. This theme continues as she discusses her career as a journalist and her various roles in promoting improved assistive technology. Along the way the reader meets many people who entered Little's life. Some of these individuals receive considerable attention - Tim Nugent, for example, who made early strides in obtaining access to college education for disabled students at the University of Illinois, Champaign-Urbana, campus.

Readers who are attracted to the book to learn more about the "journey to the ADA," the history of how the ADA came about, will probably be disappointed. One begins to feel as if the ADA is exploited for marketing purposes, for the book scarcely mentions the ADA by name after the introductory material: ten times by this reviewer's count. Moreover, according to Little's comments on the ADA, someone unfamiliar with the law might well conclude that the ADA is, at best, relatively unimportant and, at worst, doing more harm than good.

Little first mentions the ADA (significantly, not until page 139) to suggest that fear of litigation discourages people from assisting disabled persons. Later, she tells the reader that the ADA might not have been necessary "if more friendly discussions had been held between authorities of both the public and private sector and people with disabilities. It could have even resulted in using common sense" (pp. 165-166). Little identifies only two groups of people who benefitted from the passage of the ADA: lawyers, and people with disabilities who "were able to charge companies and legal firms pretty good prices to speak at their seminars or act as consultants" (pp. 218-219). In her final chapter, Little states that the ADA has exacerbated the problems of health care for people with disabilities because it excludes health insurance companies from coverage (p. 261). One wonders: Why bother talking about the journey to the ADA?

Actually, this does not appear to be Little's concern. In her foreword, she warns that her opinions are not popular with federal agencies. Indeed, federal efforts in disability policy most often emerge in her account as destructive or wasteful; libertarian sentiments meander through the text (e.g., Chapter 21, "While the feds fund, the people do"). Little is more interested in talking about what people have done *outside* the government. For example, she discusses efforts to design wheelchairs

that actually work well for the people who use them, including innovative techniques such as controlling a power wheelchair by sipping and puffing through a tube. This is truly a valuable contribution. Unfortunately, Little appears committed to an either/or interpretation: It was the government *or* the private sector.

This perspective is also evident in her claim that the people she talks about, "rather than the people you've seen on the TV and in the news, made the real changes" (p. iii). Thousands of people from a great variety of occupations and identity groups have made important contributions to improving the lives of people with disabilities: One need not discredit some activities to give credit to others. The President's Committee on Employment of the Handicapped, for instance, provided a common meeting place where disabled activists could launch the influential American Coalition of Citizens with Disabilities.

Little's adversarial posture toward the government is accompanied by a curious nostalgia for the "good old days" of living with a disability: before all the organizations, agencies, stereotypes, "political correctness" (for example, the way the ADA spoke of "disability" instead of "handicap"), and equal opportunity laws. She describes "a natural system that supported me and made it possible for me to succeed" in Chicago (p. 140). And she relates one story of how four male airline employees picked her up with her chair, at a curb too high for her to "jump," and carried her to the opposite sidewalk. Yet, it is precisely this type of dependence on charitable behavior that many people with disabilities believed required federal non-discrimination legislation aimed at greater accessibility and independence. Little, thereby, appears out of touch with much of the disability rights movement (not to mention that neither jumping curbs nor being carried across a street are viable options for people using power wheelchairs).

Disability-related autobiographies such as Little's make important contributions to Disability Studies by documenting personal experiences and supplementing the most commonly-known history of disability. By the end of Little's book, however, one cannot help but feel a little deceived. In the prologue, she offers a page-and-a-half summary of her life (self-described as "pretty boring"). Then she asserts that the rest of her account is "about people *other than me*" (p. xi, emphasis added). Such claims that the book is *not* going to be about her belie the book's content, where the first-person "I" is pervasive.

Aside from subject matter, the book might be improved in a few technical ways. An index would enable readers to search for particular subjects — wheelchair sports, assistive technology, or specific people, for instance. Limited notes might bolster some of Little's sizable claims, which, without reference to any source but personal memory and opinion, are apt to leave readers skeptical. Finally, greater attention to writing style and editing would enhance the work's readability, beginning with the unwieldy, misleading title.

Martin, Ruth R. *Oral History in Social Work: Research, Assessment, and Intervention*. Thousand Oaks, CA: Sage Publications, 1995, 153 pages, \$39.95 hardcover, \$17.95 softcover.

Reviewed by James W. Trent, Department of Social Work, Southern Illinois University at Edwardsville.

The last 100 pages of Martin's book contain its best parts. The section begins with chapters on doing oral history and on analyzing and interpreting narratives (Chapters 4-5), and ends with examples of oral histories (Chapters 6-10). In the fourth chapter, the author provides a list of eleven steps for doing oral history, from selecting a topic to writing the history. She supplements the list with details about each step. In Chapter 5, she discusses the analysis and interpretation of data, and the writing of a report. Much of Martin's discussion boils down to choosing, eliminating, and organizing narratives. Her view of interpretation for "some approximation of historical truth" (p. 69) parallels her claims for oral history's subjectivity, yet its reliability and validity. Of the latter, she writes, "The best truth may be the oral history because it gives the subjective truth of life's events" (pp. 51-52).

The last half of the book contains examples of oral histories that Martin or her students

conducted. Each example concerns an interesting topic, and together they show the diverse directions that oral history research can take. Although disabilities are not among Martin's illustrations, the would-be oral historian can easily connect the examples to Disability Studies. My only quibble with these cases is that the author might have characterized some of them better as ethnographies.

The first two chapters of the book are written for social workers. As a member of that profession, I find the chapters both "necessary" and unimportant. By necessary, I mean that Martin feels compelled to present oral history in the lingo and shibboleths promulgated by the Council on Social Work Education, the principal accreditation body for the profession. So we read about building competencies, enlarging the body of social work knowledge and practice, the ecological and life models, and the like. By unimportant, I mean that the author could convince social workers about the pleasures and professional advantages of doing oral histories without resorting to social work mantras. The social work tail has no business wagging the oral history dog.

Oral history, like all good history, has as its most crucial and most critical purpose the creation of doubt. By doubt, I mean the challenge of comfort and the creation of uncertainty. When we look back, our amazement at past ideas, values, and practices may lead us to see our current values and practices as improvements over the past. Surely our values are more informed and more humane than the values of the past and who would deny our improved professional practices? Yet, as we look carefully at the past and talk to people who experienced past events, our pride and confidence give way to post-modern questions about our assumptions, values, and practices. Were all past practices so bad? Are there some things we did better then than we do now? Is our progress all that progressive? Has reason and prediction merely given us better tools to label and control? This post-modern history pushes doubt about the past into the present, and it forces concern for the future.

When Martin formulates oral history in these post-modern terms, she succeeds in making oral history exciting. When she succumbs to social work artifice, her work is dulled and compromised. Social workers, people interested in Disability Studies, and others can learn from this excellent book, especially if they move past the first two chapters.

Miller, Gale. *Becoming Miracle Workers: Language and Meaning in Brief Therapy*. New York, NY: Aldine de Gruyter, 1997, 251 pages, \$41.95 hardcover, \$20.95 softcover.

Reviewed by Patricia Sisco, A.R.C., Winnipeg, Manitoba, Canada.

This book, written by a sociologist, is about the sociology of a clinic, its organization, and the interpretation of the therapist, the client, and society. More specifically, the book is not so much about psychologists and sociologists, but about brief therapists and practitioners of psychotherapy therapy and family therapy. Miller is interested in the "artful ways in which clients and therapists use language to create therapeutic meaning and in their practical consequences for therapist and client" (p. 7).

Miller begins his book with a brief, superficial discussion of three therapies - psychoanalytic therapy, behavioral therapy, and existential therapy (pp. 3-7). This discussion is very weak and contributes little to the book. However, with this as a backdrop, Miller goes on to describe two forms of brief therapy, one being ecosystemic brief therapy, which emphasizes the social contexts of clients' lives and problems, and the more radical focused solution-based brief therapy which treats troubles as ways of talking about everyday life. The focus of Miller's discussion is on the changing language or institutional discourse of brief therapy. He analyzes both the intellectual contexts for the development of two forms of brief therapy and how brief therapy principles are put into practice in actual therapy sessions at Northland Clinic.

Miller refers to this type of therapy as a radical move from the traditional types of therapy (p. 9). It is interesting to note that many of the characteristics of brief therapy are similar to the counseling for which people with disabilities have been advocating. Miller maintains that the terminology has a significant effect on the outcome of the therapy. One of the main differences is that brief therapists use the word "clients," while other therapists use more medical terms, such as "patients."

Like brief therapists, people with disabilities are sensitive to the use of language. In the disability rights movement, "client" or, more often, "consumer" is used in place of "patient." Since "consumer" implies control, being called a consumer is usually the first step in taking control of one's life. Like brief therapists, consumers in the disability rights movement recognize that problems are not necessarily deep-rooted, but they focus on the ordinary features of life. These problems usually can be solved in a short period of time.

This type of therapy, as Miller describes it, would seem to be very useful in rehabilitation agencies, provided that the cost is reasonable. Miller maintains that this is a cheaper form of therapy and it fits well into the economic times. The team approach discussed in Chapter 6, however, suggests that this might be a very expensive therapy. The book would have been stronger if the author had included a detailed analysis of the efficiency and effectiveness of the therapy.

In general, this book is interesting, although somewhat rambling.

Null, Roberta L., and Cherry, Kenneth F. *Universal Design: Creative Solutions for ADA Compliance*. Belmont, CA: Professional Publications, Inc. (1250 Fifth Avenue, Belmont, CA 94002), 1996, 325 pages, \$49.95 hardcover.

Reviewed by Michael L.N. Shannon, Universal Design Consultant, San Luis Obispo, CA.

It is always a plus to begin any book with a foreword by experts in the field. That certainly is the case with this one. Ronald Mace was just such an expert. He was the architect who is credited with the term "Universal Design," and he continued his work as one of the experts in that design discipline for many years.

At first glance, there seems to be a basic contradiction between this book's title and its espoused philosophy of Universal Design, since ADA (ADAAG) compliance is based on minimum standards, and Universal Design always leads in the direction of going beyond the least possible compliance and striving for unlimited usage by all, and even a "stretching of the design envelope." That issue for me was never really reconciled and is not aided in its resolution by the fact that Chapter 1 is titled "What is the Americans with Disabilities Act?" This initial chapter could have been used to set the stage for some really important keys to design success, rather than as a summary of the ADA.

The main author, Dr. Roberta Null, comes to the design arena from a lengthy career as an Interior Design educator. Her formal education has been in the School of Home Economics. That very positive point, at least in this book, most likely accounts for the reader's early awareness of a kinship with Human Factors elements throughout. That helps to balance some of the book's shortcomings and possible technical problems. Considering the person first, one of Dr. Null's primary principles in defining Universal Design, is extremely important if the needs and expectations of any user of a facility are to be fulfilled successfully.

*Universal Design: Creative Solutions for ADA Compliance* is heavily dependent on the inclusion of work by a diverse group of contributors. Some of them present key elements of success for anyone attempting to understand and implement Universal Design principles. These contributors are paramount to any degree of success that this book boasts. One such "jewel" is found in Chapter 3, "The Universal Design Process." At that point in the book, contributor Karen Hirsch stresses the importance of "The Oral History Interview" (p. 66). In my opinion, based on studies in the field of Universal Design, that is definitely a key to success.

As a contributor to the 1995 Oakland Society for Disability Studies meeting in the field of architecture and Universal Design, I made known my personal fear of being studied as a "person with a disability" while actually being excluded as a person from the design process. At that time, it seemed apparent to me that architecture and design presentations and their special implications for improved quality of life had not been given enough space on past agenda. Likewise, there was a need to present information, such as Universal Design concepts, to a waiting audience (*DSQ* readers) in a way that they could understand the direction being taken by design professionals as they not only comply with required minimums spelled out in the ADA, but further attempt to implement the desires and expect-

tations of those persons for whom the changes are being made, especially those with disabilities who have been excluded from the built-environment for so long. I had hoped to find some of that in *Universal Design*. That was just not the case.

As the reader continues with this book, it develops into a fair summary of what has been going on recently in the field of design, including product design. That is also a further straying from the intended topic of "creative solutions for ADA compliance."

For a novice who is searching for some basic understanding of Universal Design, this book could be a possible beginning. There certainly are better places to glean knowledge of the Americans with Disabilities Act (ADA). There are some good resources listed in Chapter 10, but that hardly justifies purchasing the book.

Dr. Null is an Interior Design Educator, a professional who has been dedicated to her craft for a long time. Perhaps some of the difficulties in presenting this material comes from an incompatibility with the co-author of *Universal Design: Creative Solutions for ADA Compliance*.

I wish I could make a stronger recommendation in favor of this book at the hardcover price listed, but I cannot. Any book on architecture or design depends heavily on photographic enhancements to punctuate its message. Here the photos are all black and white, in addition to being of poor quality. Most of them are too dark. Even a few color photographs would have been an asset.

Osmond, John. *The Reality of Dyslexia*. Cambridge, MA: Brookline Books, 1995, 160 pages, \$14.95 softcover.

Reviewed by Debra Swoboda, Oklahoma State University, Stillwater, OK.

*The Reality of Dyslexia* is truly a wonderful book on several levels. The book is part chronicle of what it is like to go through life with dyslexia, part training manual for the parents and significant others of individuals with dyslexia, part political treatise on the inadequacies of the school system (in Britain and elsewhere) to assist children with learning disabilities, and part expose on the social, economic, and human costs associated with not recognizing dyslexia as a significant disorder. Utilizing the personal narratives of individuals with dyslexia and their families, author John Osmond presents a highly readable synopsis of the problems arising from dyslexia.

The topic discussed at greatest length in the book concerns emotional problems occurring as a result of living with dyslexia and the family dynamics associated with managing the disorder. Osmond argues that dyslexia is a congenital, genetically-inherited condition, and, as such, the parents of dyslexic children typically manage issues of self-identification, guilt, and resentment while simultaneously struggling to provide the emotional and financial resources necessary for effective advocacy. This examination into the family dynamics associated with raising children with learning disabilities fills a gap in the Disability Studies literature.

The book also persuasively presents how ill-equipped and resistant schools are to providing appropriate resources for children with dyslexia. Personal stories identify the reasons for this inefficacy, including the persistent equation of learning disabilities with failure, the emphasis on a whole language approach to teaching literacy, and the politics of school district funding and policy. The author's take on these issues is an impassioned argument against educational mainstreaming, since the needs of dyslexic children are so great and so uniquely individual. The narratives also point to the need for greater knowledge and consensus about specific learning disabilities, and the author rightfully acknowledges the continuing debate regarding the definition of learning disabilities shaping these issues.

The resounding message of *The Reality of Dyslexia* is the necessity of giving children with dyslexia the understanding, recognition, and support they need, or as Osmond puts it, "a good listening to" (p. 136). Consequently, the text is a valuable resource for parents, educators, and individuals with disabilities, as well as a useful teaching tool on the subject for educators, service providers, and support groups.



Pargament, Kenneth I. *The Psychology of Religion and Coping: Theory, Research, Practice*. New York, NY: Guilford Press, 1997, 548 pages, \$50.00 hardcover.

Reviewed by Amy Ai, School of Social Work, University of Michigan, Ann Arbor.

Both psychology and religion can shed light on coping with disability and chronic diseases as well as other stressful situations. However, there are not many books that systematically approach religion and coping from a psychological perspective. The *Psychology of Religion and Coping* is, thus, a seminal work bridging these topics - theoretically, empirically, and practically. Why a psychology of religion and coping? Through decades of learning and studying in these fields, Pargament became aware of important differences between, strengths and limitations of, and reconcilable linkages between psychology and religion. Different worldviews and methods characterize each, yet both contribute to coping through their own theories, methods, and languages. Psychology guides people to gain control over seemingly powerless conditions, while religion helps them appreciate personal limitations. Thanks to the author's dialectical and pluralistic ways of thinking, exceptionally complex and diverse views related to the above themes are beautifully woven together in his outstanding book.

The book is divided into four parts in a continually insightful psychological perspective. In Part 1, the definition of religion is clarified as "a search for significance in ways related to the sacred" (p. 32) and reaches to its multiple means that lead to its ends, such as spiritual growth, sense of meaning, greater strength, good health, community, and a better world. The new concept of coping, "a search for significance in times of stress" (p. 90), is developed in Part 2. The process of coping flows through appraisals of events, orientations, specific methods, mechanisms, options, and cultural forces to outcomes. The core theory comes in Part 3, an anatomy of connections between religion and coping. The author describes a variety of conditions and reasons conducive not only to convergences, but also to divergences of religion and coping. Going beyond the stereotype of religious coping as a passive approach, Pargament points to its many faces and determinants - situational, cultural, and personal. Conservative and transformative functions of religion in terms of human value are then elaborated exhaustively in relation to coping with catastrophe. The final chapter discusses evaluative and practical issues with respect to both positive and negative aspects of religious coping. In the end, informative guidance and implications for professionals are provided.

The book is valuable to people in a variety of fields: health and mental health professionals, human service providers, social scientists, educators, clergy, leaders of religious communities, and those who work for people with disabilities as well. The significance of the book lies in its reciprocal contributions to both psychology and religion with a focus on coping. A great strength of the book stems from the author's comprehensive and critical vision, challenging conventional views in both fields. Thus, it illuminates alternatives to some polarizations, such as those often present in psychological assessments of religious motivation and treatments of conceptual relationship between religiosity and spirituality. The book uses anecdotes, life stories, clinical experience, and empirical studies. It also recognizes that research in this cross-disciplinary area is still in its infancy. This book will have a great impact on psychological and religious theories, research, and practice in relation to human life and growth through effective coping.

Rostron, Jack, and Fordham, Murray A. *Adapting Housing for People with Disabilities*. Hants, England: Ashgate Publishing Limited (Distributed by Ashgate Publishing Company, Old Post Rd., Brookfield, VT 05036-9704), 1996, 101 pages, \$49.95 hardcover.

Reviewed by Rebecca Ingram, Architect/ICBO Certified Access Specialist, Albuquerque, NM.

*Adapting Housing for People with Disabilities* is an update and an expansion of *Disabled in Rehabilitated Housing*, published by the former National Building Agency in 1978. Directed primarily toward housing professionals in England, this book is a two-part guide for assessing and adapting existing housing to meet the needs of people with disabilities. Although the basic tenets are applicable for housing in the United States, the references to social services, grants, building codes

and standards, and resources are specific to England.

Part One includes comprehensive guidelines for identifying a suitable property and making modifications. The bulleted text format is easy to read and understand; however, the book lacks basic wheelchair clearance and reach range information. As a result, it may be difficult for readers to determine how to meet guidelines that call for "sufficient space" and items "within reach" when actual dimensions are not shown. Where given, the metric dimensions often vary slightly from the American National Standards Institute A117.1-1992, which is the adopted standard in most jurisdictions in this country. This is most likely due to differences in building practices and products. Despite an extensive list of disability organizations, this text is dominated by information about mobility impairment.

The cartoons used throughout the book are amusing and powerful in illustrating why certain courses of action are recommended. In some ways, these are the most useful aspect of the book for an international audience.

Part Two is an assessment survey, consisting of a series of yes/no questions, designed to determine the suitability of a disabled person's existing home and situation. When tabulated, a higher proportion of no's is purported to indicate that rehousing may be the preferred course of action. Although the survey may be very useful as a general checklist, it is inherently flawed as a diagnostic tool. All of the questions are given the same amount of weight without consideration to the cost and degree of difficulty for the required modification. For example, the question of whether the entrance is reachable without stairs holds the same value as the question of whether the doorbell is at a reachable height.

Although the survey professes to be written also for use by people with disabilities, there are very few questions dealing specifically with their desires, and the use of the word "client" is prevalent throughout. Furthermore, the section entitled "social situation" is neither comprehensive nor supportive of the assertion in the foreword that one of the most significant contributions of this book is the implicit message that people with disabilities need to have a say regarding their own needs, and that these needs are not peculiar or different. Perhaps, for this book to find an audience in the U.S., this message should be explicit. While this text may well represent an evolutionary step in the social context of England, in this country the building and social services audience is apt to need specific national and local regulatory information, and the person with a disability will likely be put off by the exclusive language of the text.

Changing demographics and the recognition that people often do not fit neatly into categories of "abled" or "disabled" are spurring a realization that the range of human abilities is an ever-changing continuum. The current philosophy in this country is moving toward adapting environments, including housing, for the use of people with and without disabilities rather than toward creating special housing for special people. This seemingly subtle, but important distinction might transform the first paragraph of the introduction from, "Housing provision for disabled people should afford the same standard of comfort, choice and independence as it does for the able-bodied. Ideally, disabled people should be able to continue living in their existing home" (p.1) to *housing for all people should provide the same level of comfort, choice and independence. Ideally, a house should be capable of supporting a lifetime of human experience.*

Seligman, Milton, and Darling, Rosalyn Benjamin. *Ordinary Families, Special Children: A Systems Approach to Childhood Disability* (2nd Ed.). New York, NY: The Guilford Press, 1997, 324 pages, \$30.00 hardcover.

Reviewed by Timothy Lillie, The University of Akron, Akron, OH.

Milton Seligman and Rosalyn Benjamin Darling have combined to produce a superb resource for professionals working with - and for - individuals with disabilities and their families. Special educators, social workers, counselors, physicians, family therapists, and others who need to consider the workings of families of people with disabilities will learn much from this work. It covers the subject with respect and in a scholarly, but not jargon-filled, way. It is both readable and rigorous

- a rare recipe!

In particular, the reader will appreciate the structure of the book. The authors present their overview and theoretical perspective: a social and family systems approach (as described by Minuchin, 1974, or Turnbull and Turnbull, 1997, for instance). This, then, sets the stage for consideration of family members who are often not well-represented in the research or professional literature, but who are important parts of many family systems with members who have disabilities - namely, fathers, grandparents, and siblings. The study of the roles of these relatively neglected family members does not detract from careful consideration of mothers or others, but instead recognizes the tremendous and non-political complexity of families. Seligman and Darling are simply paying attention to some of the actors whose roles have been overshadowed by professional attention toward the immediate, or tip-of-the-iceberg, needs of children with disabilities and their primary (usually female) caregivers. This book does not give simple answers to family issues, but, instead, assumes that each family is complex, and that each system will have its own characteristics.

Particularly useful, I thought, were frequent comments from parents or siblings, meant by the authors to give them a strong voice and to help the authors to illustrate or support a given point or line of research reported. The inclusion of these comments demonstrates that these researchers are among that growing body who recognize the intelligence and competence of parents - and about time, too. I believe this to be an extremely important part of this book - that is, showing parents as competent and able to contribute to the professional effort required when working with children with disabilities and their families.

One small caveat: The authors' discussion of "normalization" is not the same as the "normalization" that may be familiar to some from the writings of Wolf Wolfensberger (1980). Seligman and Darling feel that families will tend to try to obtain a "normalized" life style (that is, one that is similar to the culturally-valued norm) as part of the arrangements they make in their own lives.

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Sellin, Birger. *I Don't Want To Be Inside Me Anymore: Messages from an Autistic Mind*. Translated by Anthea Bell. New York, NY: Basic Books, 1995, 227 pages, \$12.00 (U.S.)/\$16.75 (Canada) softcover.

Reviewed by Patrick McDonagh, Concordia University, Montreal, Quebec.

In 1990, Birger Sellin, a 17-year-old autistic boy living in Berlin, began to write through facilitated communication. This book follows Sellin's developing skills from his initial attempts to the end of 1992, by which point he had become an articulate and, occasionally, even poetic interpreter of his world. It consists of a series of entries that can be read alternatively as a diary and as meditations on autism.

In Sellin's rendition, autism is a terribly frustrating isolation from the rest of the world, making him in his own words an "unperson" (p. 115), a "withoutme figure who has stepped out of the darkness/ of the autistic world to make contact" (p. 225). But his relation to his autism is complex. The title of the book strikes the keynote, the desire to leave behind the isolation: "The loneliness of an autistic," he writes, "is like a great cold of/ earth weighing down on the soul" (p. 84). But his longing to escape is nuanced by his exploration and poetic reconstruction of autism. Sellin fashions himself a "so-called deepsea explorer, of the mind" (p. 119); in relation to those frightened by his condition, he

casts himself as a "dark medieval figure" (p. 162); more playfully, in a letter to his therapist and psychologist, Gisela Ulmann, he is "neanderthal man in person sending greeting to/ gisela/ the clever scientist" (p. 188). Sellin presents a compelling and stimulating commentary on life with autism.

The book's credibility rests not only on its author's expressive voice, unfortunately. Sellin writes by a technique known as facilitated communication, in which an assistant supports and steadies his typing hand; according to critics, the facilitator - perhaps subconsciously - is guiding, rather than simply supporting. For those who do not believe, there is nothing in this book to convince them. Sellin is aware of the issue, writing that "not everyone is right for" facilitated communication, and is sensitive to criticism: "i will write properly as soon as the independent writing/ looks like no one can think oh nonsense he isn't writing/ alone at all it is the person supporting his arm" (p. 95). Alas, proof that Sellin is or is not writing depends on a Catch-22 argument; Cynics would argue that the facilitator is imposing this awareness on him. However, for those willing to believe, or to suspend disbelief, Sellin's book is eloquent and thought-provoking.

Stone, Karen G. *Awakening to Disability: Nothing About Us Without Us*. Volcano, CA: Volcano Press (P.O. Box 270, Volcano, CA 95689), 1997, 287 pages, \$14.95 softcover.

Reviewed by Tanis Doe, Pearson College, Victoria, BC, Canada.

For a parent with a newly-diagnosed child with a disability, for a co-worker of a recently-hired person with a disability, or for any person who has developed a new disability, this is a good general text. It is not specific enough or analytical enough to be required reading at a college or university, but any layperson interested in a perspective on disability issues from a person with a disability would find the text useful. Using a semiautobiographical approach and anecdotes from interviews and excerpts from research, this book pieces together useful information about a very broad topic and makes diversity digestible.

This book can be described pretty well by its table of contents. It starts with some basic definitions and facts about a range of different types of disabilities that people experience. The author has multiple sclerosis, but she researched a number of other disabilities to include in this first section. The next section deals with "practical matters," ranging from housing and transportation to sexuality and suicide. Each of the sections uses stories from individuals with disabilities and their families to illustrate their points. There are some references to statistical and empirical research, but the bulk of the information is derived from personal narratives of lived experiences. For readers with disabilities, the third section will perhaps be the most interesting because it discusses coming into consciousness and acquiring identity as a person with a disability. In this section the author describes her contact with mentors and learning the navigation techniques for surviving the system as a person with a disability. The last section is a brief discussion of spiritual recovery and growth after becoming disabled. An appendix is also included with some helpful hints on accessibility and on advocacy, and a discussion about sex.

Although the table of contents is accurate, and certainly the text does cover the many topics it lists, the book lacks connective tissue to hold the various sections together. The overall message is mainly that disability need not be a tragedy, and that life "A.D." ( after disability) can be fulfilling. While the message is strong, the way it is delivered is somewhat impaired. Since the book is intended for laypeople, it is, appropriately, an easy read; and comfortable, almost conversational, tones are prominent throughout. However, reading from section to section, the primary connection is not an argument, but the consistent voice of the author. The voice is friendly and casual, and it reminds readers on a regular basis that she, too, has a disability and has had experiences similar to those illustrated. Humorous references to getting Ph.D.s in napping, pacing, and "capability," as well as the occasional "whew," supplement the rhetorical questions asked throughout.

As a Canadian reading (and reviewing) this book, I was particularly pleased to see that the author had visited and reported on accessibility and programs in Northern Europe and Canada. She often boasts of the progress and advances made in housing, transportation, and health services for

people with disabilities in those areas. She criticizes the implementation and lack of access for many people with disabilities in the United States despite the ADA and other legislative initiatives. In addition, she points out the double and triple jeopardy of poor women with disabilities and women of color with disabilities.

The author also makes a special effort to ensure that "invisible" disabilities and issues related to pain and fatigue are mentioned. She describes people living with chronic fatigue and environmental illness as well as those with epilepsy and with fetal alcohol syndrome. She ties these back to her own experiences with multiple sclerosis, and she shares her own depression and suicidal ideation. Bringing these issues to the public's attention in a text about disability is an important step toward showing the relationships among "illness," chronic condition, and disability.

Another important inclusion that many writers omit is associated with nondisabled people. As someone who was once nondisabled, Stone discusses her experiences of fear and anger at becoming disabled. She also describes the importance of preventing isolation because losing friends and contacts often happens "after disability." She promotes the inclusion of family, spouses, friends, and community members in the lives and advocacy of people with disabilities. Too often, she relates, the people giving care to and supporting people with disabilities are ignored as consumers, causing their own stress to result in violence or anger towards the person with a disability. Whether talking about sex, about parenting, about violence, or just about living in the community, the author includes people without disabilities as significant actors in the scene.

This text is a welcome addition to the growing pool of material authored by people with disabilities, describing their perspectives as well as drawing in some of the more current political issues. Laypeople and people with recently acquired disabilities will enjoy this accessible text. Disability scholars and academics might be disappointed, but this is a grassroots book written from lived experiences, including visits to several countries, with a message that should be taken seriously: "Nothing about us without us."

Williams, Marie Sheppard. *The Worldwide Church of the Handicapped and Other Stories*. Minneapolis, MN: Coffee House Press (27 N. Fourth St., Suite 400, Minneapolis, MN 55401), 1996, 220 pages, \$12.95 softcover.

Reviewed by Johnson Cheu, Department of English, The Ohio State University, Columbus, OH.

In the wake of James L. Charlton's *Nothing About Us Without Us*, I approached this collection with mixed feelings. On the one hand was my general respect for Coffee House and my joy at any fiction about disability experiences; on the other was a sinking feeling that this book, written by a former social worker, was going to be yet another medicalized objectification of disabled people. I was not entirely wrong about the latter, but I was pleasantly surprised.

To be sure, the narrator here is a social worker. But the stories are decidedly not Jerry Lewis-esque in their messages. In the opening title story, she ends by listing all the "handicaps" and writing, "No formal church was ever founded, because they *were* a church - 'The Worldwide Church of Jesus Christ-All-of-Us-Handicapped.' And everyone belonged" (p. 22). Her assessments of issues are never easily resolved. Of assisted suicide, she writes, "A lot of people blame the doctors for the weird thing that has happened in our culture; they say the doctors force people to stay alive past the point at which nature and God intended them to die. But it is not entirely the doctors' fault, you know. It is also partly your fault; you and the doctors are in collaboration. In the days of your youth and health, you have told the doctors that you want to live forever. . . . You keep contributing to medical research. You keep paying taxes for it. You are crazy; and they (the doctors) are, I think, the helpless, caught creations of your terrible insanity. Of course, as members of humankind, the doctors are also insane; I said it was a collaboration" (p. 55). Her stories are generally complex and intriguing.

Not that the stories are without fault. This is a book targeted at nondisabled people, as evidenced by the amount of explanation of various disabilities and programs throughout, which some-

times intrudes upon the story. That is not, of course, necessarily bad. The problem with having nearly everything told through the social worker's point of view is that one is sometimes left wishing to *know* the "disabled" characters; rather than just *about* them. I laughed heartily (and painfully) at the disturbing-to-the-point-of-comical episode in "The Prettiest Girl in Eau Claire" of cajoling the cab company to pick up the blind clientele at the center. It is no-holds-barred "truth-telling" for any of us who have had to wait for cab/van service, or even for wheelchairs at airports. But, in the end, it was the social worker I *knew*; I knew *about* the prettiest girl in Eau Claire.

Still, the stories are, at turns, comical and heart wrenching, confusingly complex and precise, which makes for an interesting read.

### Film/Audio Clips

Bassick, Jane, and Guth, Jamie, Producers. *Stuttering* [video]. Boston, MA: Fanlight Productions (47 Halifax Street, Boston, MA 02130; 1-800/937-4113), 1993, 29 minutes, \$149.00 purchase, \$100.00 rental/week, \$50.00 rental/day.

Reviewed by Miriam F. Hertz, Department of Disability and Human Development, University of Illinois at Chicago.

This video provides a general overview of stuttering, one that is better attuned to the general public than to an audience of professionals or people who stutter. The world of people who stutter is opened to expose some of the difficulties they encounter. Some feel self-conscious, even ashamed, about being unable to communicate in what the fluent-speaking world considers to be normal fashion. These feelings result largely from the intolerance often conveyed by listeners. A primary goal of the video appears to be to give the public enough general information to fairly and courteously treat people who stutter, such as resisting the temptation to complete words or sentences. Another goal is to provide friends, co-workers, and family with some specific information to allow them to be helpful.

The basic approach of the video, and its greatest strength, is to let people speak for themselves. Several people who stutter give insights. John Ahlbach, Past Director of the National Stuttering Project (NSP) and also a person who stutters, is interviewed on his work in helping people who stutter overcome their feelings of shame and isolation by finding support through self-help groups. In other scenes, members of an NSP support group speak candidly before the camera on the experience of stuttering. In still others, a little girl who stutters is filmed, and her family, speech therapist, and teacher are interviewed on her progress with both controlling stuttering and improving self-esteem. A bank executive speaks on how he does not let his stuttering impede him and is shown on camera during one of his many speaking engagements.

The video falls captive to some common problems that occur in discussions of stuttering. First, it does not adequately define stuttering, but rather describes it in tautological fashion, as in a lack of fluency. Second, it exhibits the stereotypes, documented in the scholarly literature, that speech pathologists often bring to their practice with clients who stutter. In speaking of a seven-year-old in her care, a speech pathologist says, "Three years ago when Hadley first came to this building, she was in kindergarten, and she was a student who stuttered. She was quite a moderate to severe stutterer and that was, sort of, the description of her. Now Hadley is an incredible young girl, student, who happens to stutter [less now]." Third, the video celebrates the supercrip ideal. The narrator comments on the "admirable strain of independence and self-sufficiency" in people who stutter.

The video is successful in delivering the pivotal point that stuttering has a physiological cause, not yet fully known, but probably based in neurology. It reports on a new medical technology that is important for research on the causes of stuttering, Positron Emission Tomography (PET), which can be used to scan blood flow in the brain. However, the video does not adequately cover

research on effective treatments or mitigators. There is little information on how to control stuttering, and only limited coverage of specific therapy approaches or programs. The Botulinum Toxin Study, which involves Botox toxin injections in the larynx that reduce stuttering, is reported as not well received by clients because of distasteful changes to voice quality. The Edinburgh Masker, a device that blocks the user from hearing his/her own speech, is portrayed in the video as not liked by a client, and, in fact, it is not widely used at present. Absent from the video, but more worthy of inclusion than the Botulinum Toxin Study and the Edinburgh Masker, are other approaches, such as the Precision Fluency Shaping Program, which teaches skills to clients that help them exercise control over their stuttering.

The video also falls short in addressing the societal response to stuttering. Although unflattering media portrayals of people who stutter are mentioned, and the observation is made that they are depicted as fools by the entertainment media, there is no other discussion of negative attitudes or of how these might be alleviated. There is no mention of the discrimination in employment that people who stutter encounter, and no reference to the applicability of the Americans with Disabilities Act or the feasibility of reasonable accommodations.

All in all, the video *Stuttering* is a worthwhile introductory overview of its subject. It is hoped that other videos will follow to provide some additional depth.

Block, Laurie, and Allison, Jay, Producers. *Beyond Affliction: The Disability History Project* [audiotapes]. Conway, MA: Straight Ahead Pictures (Box 395, Conway, MA 01341; 413/369-4372; disability@straightaheadpictures.org), 1998, 4 hours (four-part series), \$15.00 each/\$35.00 set of four, purchase. (Series posters containing a montage of archival photographs are available for \$12.00.)

Reviewed by Brad Byrom, Department of History, University of Iowa.

As the parent of a child with a disability, Laurie Block has developed an appreciation for the role history plays in the daily events of a disabled person's life. Frequently, Block's daughter is confronted with seemingly odd, but all-to-common reactions to her disability. Such confrontations - the most puzzling of which involve strangers offering her money - have led Block to seek out the historical roots of society's responses to disability.

With the help of Jay Allison, Block's search culminated in a four-part, four-hour National Public Radio series entitled *Beyond Affliction: The Disability History Project*, which aired on NPR stations across the United States earlier this year. Though some scholars might argue that the project reveals more gaps in the historical record than concrete, no blame for this should be hung on Block's shoulders. In fact, Block is to be commended for attempting to fill some of the gaps herself, digging into archives and poring over documents to reveal intriguing conceptions concerning disability in the American past. Further, Block sought out an impressive collection of academic authorities, including historians Martin Pernick, Paul Longmore, and Douglas Baynton, sociologist Irving Zola, and policy expert Edward Berkowitz. These authorities, along with Block's willingness to immerse herself in the evidence of the past, provide the series with a substantial degree of scholarly credibility.

Still, listeners may feel that the strength of the project lies less in its pursuit of intellectual exactness than in its emotional depth - its telling of poignant stories that reveal both the sufferings and the resilience of America's disabled population. Block's interviews reveal a rich, though frequently somber history. In one particularly painful instance, a former foster child tells of the shock of being handed a fundraising leaflet with her picture and the caption "Not This." In another instance, a woman recalls a conversation she had with a doctor during her adolescence in which she was warned that reproduction should be avoided for fear of producing more "like herself." In less capable hands, such stories might have led to a history that was nothing short of morose. Block, however, is careful to balance tales of victimization with stories of defiant courage. The undaunted, positive self-image maintained by individuals faced with a doctor's warped judgment, and the bold acts of protest displayed by disability rights activists reveal the active role played by people with disabilities in shaping their lives and their history. Though, ultimately, this series is far more of a provocation than a finished

work of history, its intellectual honesty and emotional force make it well worth a listen.

Block, Laurie, and Allison, Jay, Producers. *Beyond Affliction: The Disability History Project* [audiotapes]. Conway, MA: Straight Ahead Pictures (Box 395, Conway, MA 01341; 413/369-4372; disability@straightaheadpictures.org), 1998, 4 hours (four-part series), \$15.00 each/\$35.00 set of four, purchase. (Series posters containing a montage of archival photographs are available for \$12.00.)

Reviewed by Leo Credit, St. Mary's Regional Medical Center, Lewiston, Maine, and Lewiston-Auburn College of the University of Southern Maine.

This audio series consists of four 59 minute cassette tapes narrated and produced by Laurie Block for National Public Radio. Laurie is the mother of twin daughters, one of whom was born with spina bifida. The four programs provide the listener with a wealth of historical information on disability in America and the factors that influence this history. Laurie also shares her own family's experiences and perspectives as someone involved in the life of a child born with a disability. She interviews a wide range of individuals, such as disability expert sociologist Irv Zola, political activists and disability rights advocates, disabled businessmen and women, and street people, most of whom have a disability of one type or another. It is obvious to the audience that Laurie went to great lengths to research, interview, and explore the many facets of disability. Throughout the series there are audio clips from radio, television, and movie sources that reflect societal attitudes of the time and effectively reinforce Laurie's narrative. The quality of the interviews and the audio brings the vivid stories and accounts of personal experiences of disabled people to life and provides for visual re-creation in the minds of the listeners.

Although the series covers many areas within the broad context of disability, Laurie effectively identifies several significant common factors that appear to shape the history of disability and that tie the programs together. Language and terminology as well as religion are seen as playing vital roles in influencing the attitudes, thoughts, and actions of society and its approach to disability policy. Also, the media appear to play an integral role in shaping societal attitudes. Examples include silent films spreading the propaganda of eugenics, Hollywood stars' radio and television fund-raising efforts for disability charities, government advertisements encouraging the "hiring of the handicapped," and an article by the Kennedy family announcing that a family member had mental retardation. Each of these had a profound impact on the way average Americans viewed disabled people, and all seemed to mirror the attitudes of society at the time, which, in turn, helped to delineate evolutionary periods in the history of disability in America.

Program 1: Inventing the Poster Child - has Laurie setting out to answer the question, "Why do people give my daughter money?" In answering this question, Laurie provides the listener with data from many sources dating back to the 1870s that outline the prevailing changing attitudes of nondisabled people toward disabled people. For example, Irv Zola explains that, historically, the disabled child has been seen as a "source of inspiration" and as being "providential," as in "The Christmas Carol's" Tiny Tim. Disabled children were later exploited as poster children, objects of pity, in order to raise funds for charities. Finally, by the 1950s, radio and TV advertisements encouraged their audiences to "offer assistance in trying to help them lead productive lives rather than giving them your pity." Laurie concludes that she still does not know why people give her daughter money, but Zola believes that it is linked to the "perceived perpetual needs of the disabled" and the perception that those who help them will be closer to God.

Program 2: What's Work Got To Do With It? - explores the historical roots of employment and disabled people. These roots were influenced by the pension for Civil War Veterans, the advent of the Workers Compensation system of the early 1920s, the Federal Government's comprehensive social welfare program of the 1930s, the Social Security Act, and post-Vietnam era political activism. These and many other factors had an impact on the social welfare of disabled Americans. Laurie clearly demonstrates the significant social change that was precipitated by, of all things, war. It is emphasized throughout this story that function and its connection to societal participation is more



important than physical or mental impairments. Finally, the horrendous irony that persists today of disabled people being torn between the desire to work and to participate fully in society and those systems that promote non-work and dependency is thoroughly discussed.

Program 3: *The Overdue Revolution* - covers the history of disabled people as a political entity and the barriers (political, economic, and physical) that have stood in the way of change. Laurie educates the listener on disability history from the early losing battles of the deaf community to have sign language accepted, to the triumphs of organized demonstrations in 1977 that forced the implementation of Section 504 of the Rehabilitation Act of 1973. In conclusion, it is suggested that, someday, the post-WW II era may be looked upon as a time of access for people from many groups to their basic civil rights, the "rights, duties, and privileges, and the dignities that come with full citizenship."

Program 4: *Tomorrow's Children* - a more personalized program from Laurie's perspective, focuses on the historical relationship and philosophy surrounding prenatal testing, eugenics, bioethics of testing, euthanasia, and abortion. This is, by far, the most powerful program in that it moves the listener to reflect upon his/her own feelings both from a personal perspective and from one as a member of American society. Eva Katel, a philosopher and the mother of a 28-year old severely disabled daughter, discusses the value of disabled people - the same as that of nondisabled people - and suggests that "any time anything of intrinsic value is lost to the world, it is lost to the world forever." She adds that the acknowledgment of a fetus with a birth defect as detected by prenatal testing places an enormous moral choice and responsibility on the woman. "She alone knows the significance of that choice," states Katel. Laurie concludes that, "Through understanding of the unique contributions of the disabled to humankind, we can avoid the mistakes of the past, like acting like Gods."

This series illustrates the concept that access to an acceptable quality of life, typically through education and opportunities, has been a common primary struggle for disabled people throughout the last two centuries. Their lack of political empowerment as a minority group limits their success in social order change. Fortunately, during the last seventy years and especially within the last thirty, disabled people have been better able to congregate and to communicate, which has led to some change in society's erroneous attitudes toward them. Yet, despite progress toward equality for disabled people, it is evident that cultural change has and will take longer to achieve.

I found these audiotapes to be very informative to me personally, and I consider them to be an excellent educational tool for others.

Network of Victim Assistance (NOVA), Producer. *Your Safety...Your Rights* [video]. Boston, MA: Fanlight Productions (47 Halifax Street, Boston, MA 02130, 1-800/937-4113), 1996, 17 minutes, \$145.00 purchase, \$50.00 rental/day.

Reviewed by Jack Ennis Campbell, Origins Society, Tucson, AZ, and Ken Laux, DIRECT ILC, Tucson, AZ.

In the cover hype, NOVA promises much, including, but not limited to, "... look, act, and feel more confident; assert your rights . . ." but it is this reviewer's opinion that they fall short of such aspirations. The video lacks a certain pizzazz, which would go along way to enliven and make more believable the very real situations that could have been addressed. I sought a second opinion because I am a 6'1" and 195 lb. former college football player (current quad rugby player) who might be a little jaded when it comes to "look, act, and feel more confident." I asked my friend Ken Laux at DIRECT, ILC, what he thought of the film, as he is a motorized wheelchair user and a trainer of many groups of consumers on disability civil rights, etc. This was Ken's response:

This is an educational film for victims or potential victims of violent crime. As the film's narrator indicates, an estimated five out of six persons will be victims of violent crime. This includes people with disabilities, the target audience of the film. While the subject matter and the information contained within is very useful, the production of the film is lacking.

The narrator lacks animation, which causes the viewer to be disinterested from the start.

The dramatizations also lack animation. The film lends itself to the belief that assertiveness is the only defense available to people with disabilities. While assertiveness is the best defense against any crime, it will not deter the most determined perpetrator. While people with disabilities are subject to sexual abuse, the film does not explore other crimes such as robbery, rape, hate crimes, or even domestic violence.

In the final analysis, NOVA did make a few good points in this film. In the second scenario, in which the person and her friend are going to a movie, the scenes are well acted and believable, backed up by sound practical advice. In scene four, where the "date" or "boyfriend" tries to force the issue of uninvited or unwanted sexual attention, the woman deftly squelches his advance with a bucket of emotional dry ice that is delivered in such a way as to have a very believable impact on her would-be assailant.

Overall grade: C+

In general, I agree with Ken. The video might be a good conversation starter for transition specialists in ILCs who are teaching consumers what to watch out for, college and university offices of services for disabled students, or parents or teachers of 504 students that needed a little outside help in teaching their kids what they might encounter. My advice, rent it. Final analysis: two stars.

Rumpel, Fritz, Writer/Producer/Director. *Interviewing Skills for Job Candidates with Learning or Other Hidden Disabilities* [video]. Cicero, NY: Program Development Associates (5620 Business Ave., Suite B, Cicero, NY 13039), 1997, 25 minutes, \$89.00 purchase.

Reviewed by Mary Klingler, State University of New York, Empire State College, Corning, NY.

This video was created to help people with learning disabilities and those with other hidden disabilities prepare for job interviews. It is extremely successful in its attempt. The viewer meets Bill, a job interviewee, who is confronted with a decision as to whether or not to disclose a hidden disability during an interview. He is hesitant, and, as he ponders his dilemma, he is "visited" by Will, his "subconscious." For the remainder of the video, Will presents Bill with the many possibilities open to people with disabilities as they approach this question.

The focus of the video is self-choice. It discusses many possibilities and strategies in order to help an individual make the decision whether to disclose, when, and how. Strategies include researching the companies by using their public documents in print and on the Internet to help anticipate the organization's reaction to disclosure; getting a job description and using the Job Accommodations Network (JAN) for advice on possible accommodations for the potential position; and connecting with organizations and agencies that can help with questions. The video offers a wide variety of these organizations and their phone numbers.

The video ends with a presentation of eight typical questions used in interviews in a format so that viewers can practice their answers before the interview. There is also a booklet included with the video with helpful suggestions. These questions may never be asked; however, this type of preparation can help the interviewee to gain the confidence and self-esteem needed to be successful in the interview process.

Bill still must make his own decisions, but he is now in a much better position to decide on his direction in the job interview process.

Ward, Phyllis, and Spiro, Douglas, Producers. *My Country: The Civil Rights Movement that Created the Americans with Disabilities Act* [video]. Cicero, NY: Program Development Associates (5620 Business Ave., Suite B, Cicero, NY 13039; 1-800/543-2119), 1996, 60 minutes, \$195.00 purchase.

Reviewed by Beth Haller, Department of Mass Communication, Towson University.

*My Country* achieves such a level of multi-faceted excellence that it should be required viewing by all American citizens. The U.S. Department of Justice had a hand in its creation, but,

except for the use of the national anthem as transition music, it does not come across as any type of government-derived video. It thoroughly explores the intersection of race, gender, and disability in America through the story of three people with disabilities. The understanding that a shared history of discrimination bind together people of many races and abilities is also reinforced by the host, James DePreist, an African American symphony conductor. He happens to be the nephew of famed singer Marian Anderson, and he happens to have had polio. The discrimination that Marian Anderson faced from the Daughters of the American Revolution (the DAR) helps to frame the discussion of continuing discriminatory practices against people with disabilities. It is a very accessible device that really can help those who do not understand disability rights to "get" the connection between historic and present day discrimination.

The three people whose stories are told in the video also reinforce the fact that disability issues are found all over the United States. Kathy Martinez, who is blind, describes her life and subsequent awakening to the disability rights movement as a college student in the 1970s in Berkeley, CA. She now works at the World Institute on Disability in Oakland, CA, as an advocate. She began a group for women living with HIV, and she illustrates that disability advocacy works for all people with disabilities.

Hughey Walker became a paraplegic in the Vietnam War. As an African American in small-town South Carolina, he already knew how discrimination worked. But, in his life as a person with a disability, he works with fairness toward everyone. He successfully became a city council member and now works as a magistrate judge. Through his interactions with his family and friends, we see the normalcy of the disability experience.

T.J. Monroe's story contains the most horror in the video and is featured last. A 42-year-old man with a developmental disability who grew up in an institution in Connecticut, Monroe is now a self advocate and consultant in addition to working as a kitchen manager at a senior center. His wonderful strength of character makes it clear that he changes the lives of the people he meets. He helps others gain their own independence. But his stories of the institution are the clearest indictment ever of the evils of institutionalization. He points out what was called "the hanging tree," where some children and young adults chose suicide rather than continued sexual and physical abuse from the staff. He takes a survivor's balanced view of his youth, however, and has moved on to make sure that others see the hope that exists in an independent life.

The video addresses a myriad of issues just in profiling these three people, from media stereotypes to consumerism to the "supercrip" syndrome in American society. This video provides a true bridge to understanding the many facets of disability rights and the disability experience in America.

Ward, Phyllis, and Spiro, Douglas, Producers. *My Country: The Civil Rights Movement that Created the Americans with Disabilities Act* [video]. Cicero, NY: Program Development Associates (5620 Business Ave., Suite B, Cicero, NY 13039; 1-800/543-2119), 1996, 60 minutes, \$195.00 purchase.

Reviewed by Ken Eastham and Tracy Eastham, University of Southern Maine, Lewiston-Auburn College, Lewiston, ME.

Any person planning to work with or already working with people who have a disability - any disability - must see *My Country*. This film focuses on civil rights issues on which most curricula only touch. The film really solidifies the empathy one may have by showing real people who have struggled so hard for many rights that nondisabled people take for granted. Our country should view *My Country* to get an idea of the struggles and triumphs of disabled people as a result of societal expectations and/or limitations.

*My Country* illustrates the civil rights difficulties people in our society have faced because of discrimination. The film, hosted by James DePreist, is a powerful film documenting the lives of several individuals depicting these two struggles. At the opening, Marian Anderson, a Black performer, is singing the national anthem on the steps of the Lincoln Memorial. Thirteen years after she

sang at the Lincoln Memorial, the barriers for Black people began to fall, but it was another 50 years after her performance before the barriers for people with disabilities really started to come down. The Americans with Disabilities Act (the ADA), signed by President George Bush, assured the 49 million people with disabilities of their rights.

The focus of the film transitions to individuals with disabilities. James DePreist, nephew of Marian Anderson, faced many racial barriers along his road to success as a prominent conductor, and, when he contracted polio, he began to notice the physical barriers that denied him access within our society. DePreist claims the ADA gives individuals who are disabled the opportunity to "battle" the prejudices and become "equated" with the general public.

Kathy Martinez, a blind woman, reflects on her experiences. As a child she was faced with low expectations by those around her. She graduated from high school and went to college in Berkeley, CA. While at Berkeley, she learned how to live with her disability. Not only that, she encountered protests that were raised by disabled people against discrimination and the refusal of the Carter Administration to enforce the Federal Rehabilitation Act, Section 504, which states that "when receiving Federal money, facilities must be accessible to people with disabilities." After three years of protests, Kathy decided to become involved, but feared that she would be kicked out of school and had to conceal her involvement. On April 28, 1977, the Carter Administration backed down to protestors and promulgated the regulations. From that point on, Kathy set out to help individuals with all types of disabilities to become more independent within society. Today, because of the ADA, Kathy is guaranteed that her employer will provide her with the equipment necessary to do her job, and that all facilities will be accessible.

Hughey Walker and Lena Myers are two other people highlighted in this film. Hughey is an individual who grew up in a very racist society in the South. Blacks were banned from working in certain factories and were confronted with signs that said "white entrance only." Hughey joined the Army in 1966. When he returned home more than a year later disabled from a wound, the racist signs were slowly beginning to come down, but inaccessibility for disabled people was still predominant. When his daughter was in elementary school, he had to sue the school to make it accessible for him to visit her classroom. Lena was also faced with physical and attitudinal barriers throughout her life. After her accident, her family members saw her as incapable of being independent, and prospective employers would not even consider hiring her. She ended up starting her own catering business and became quite successful.

T.J. Monroe is the last individual presented in this film. He spent most of his life in an institution. Once released, he became an advocate and worked with people with disabilities nationwide. President Bill Clinton appointed him to the President's Committee on Mental Retardation. Monroe conducts workshops for people with disabilities that help them to become more confident and independent. Their family members attend, too, to support the process. The bottom line of T.J.'s seminar is to assure disabled individuals that they are equal and to encourage them not to be afraid to attain goals and achievements that others take for granted, such as marriage, independent living, and a job.

*My Country* is an exceptional film. It is amazing that disabled people have had to exert so much energy and to fight so hard for the basic rights that all people have. This film demonstrates that societal attitudes may be more disabling than physical impairments. The film reinforces the notion that the abilities of people who are disabled should not be underestimated. People are only disabled by societal stigma and society's unwillingness to include individuals with physical differences.

### **Minutes of the Federal Interagency Subcommittee on Disability Statistics**

The Federal Interagency Subcommittee on Disability Statistics is the only federal group concentrating on disability statistics (including methodology questions) which is completely accessible to interested