# Book, Video, and Film Reviews

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Ablon, Joan. *Living with Genetic Disorder: The Impact of Neurofibromatosis 1*. Westport, CT: Auburn House, 1999, 215 pages, $59.95 hardcover.

Reviewed by Gail Landsman, Anthropology Department, University at Albany, State University of New York.

In *Living with Genetic Disorder*, medical anthropologist Joan Ablon provides a descriptive study of the experience of living with neurofibromatosis 1 (NF1), a condition once mislabeled, and still often associated in the minds of both the public and those with the condition, as the "Elephant Man's" disease. Indeed, the misdiagnosis of NF1 as the Elephant Man's disease is one of many factors Ablon presents as influencing the impact of NF1. Much

recent social science and bioethical literature on genetic disorders has addressed issues of prenatal screening. Ablon focuses, instead, on the experiences and coping patterns of 54 adults already diagnosed with, and adapting to the stigma of, a specific disorder.

While somewhat short on theory, the book is nevertheless rich with the voices of those living with NF1. Ablon categorizes the narratives of interviewees around specific themes, including psychosocial issues, diagnosis, school years, employment, marriage and childbearing, gender, etc., but otherwise lets the voices speak for themselves. This is a weakness of the book for those who might wish for more in-depth cultural or political analysis of genetics, disability, and the body, for instance, but is a strength for those who would wish to gain insight into the diversity of the experience of living with a genetic disorder.

We learn that some affected persons are happily married to supportive spouses whose love is constant, while others have lived lonely, despairing, withdrawn lives or have married, with dismal results, the first person who came along for fear of later rejection. Some persons with NF1 are very accomplished in their professional lives, while others have a history of failure at jobs and/or have had few educational opportunities. Some face life with a positive and persistently hopeful attitude, while others are paralyzed by the biological uncertainty and stigma associated with NF1 in a society with rigid prescriptions for beauty. Many persons have high self esteem despite visible skeletal differences and disfiguring tumors, while others suffer from a poor self-image. And some attribute most of their problems to NF1, while others believe any particular disappointments in life would have happened to them anyway.

Ablon's documentation of the diversity in the experience of neurofibromatosis 1 may make it difficult to draw generalizations, but it points to an important lesson consistent with a disability rights perspective: that persons cannot be defined, and need not define themselves, by disease. Rather, the experience of any disease or disorder is always in a particular context that involves factors including gender, family acceptance and support, age, individual personality, utilization of support groups, and access to financial, educational, and medical resources. Thus, "NF1 must be seen as one factor within a context of many others" (p. 144). Yet, it is also the case, Ablon wants us to know, that the condition of NF1 poses certain obstacles that other genetic disorders she has studied, such as achondroplasia, do not. Most disabling among these obstacles, she argues, are the often undiagnosed learning disabilities affecting more than half the people in her study, disabilities that, when not addressed adequately, negatively affect performance in school and success in the work world. In general, however, Ablon found that the severity of disease symptoms was not significantly correlated with a person's adaptation. The most important factor mediating the impact of NF1 appears to have been the presence or absence of a supportive family.

Ablon's findings may offer little that genuinely surprises Disability Studies scholars, but the diverse experiences she documents, and the voices she enables us to hear, deepen our understandings of human desires and strategies. For medical personnel working with persons affected by genetic disorder, the book will prove especially valuable.

Altman, Barbara M., and Barnartt, Sharon N., eds. *Expanding the Scope of Social Science Research on Disability*. Stamford, CT: JAI Press, Inc., 2000, 242 pages, $78.50 hardcover.

Reviewed by Corinne Kirchner, Ph.D., American Foundation for the Blind, New York, NY.

This book introduces a series that aims for broad social science involvement in building the knowledge base on disability. The editors start with a down-to-earth challenge by subtitling their opening chapter "An Invitation to Social Science to `Get It'" (p. 1). There, Altman and Barnartt scope out research questions from an array of disciplinary perspectives and they follow up with nine chapters written by 13 authors who represent at a minimum, by my tally, economics, history, psychology, anthropology, political science, sociology, law, and communications.

Unfortunately, before I can focus on content, the book's price demands attention. Even for a hardcover, the price is hardly down-to-earth. Books like this have two likely uses: (1) as a variegated reader for students, and (2) as a journal-like resource for researchers. The cost is a deterrent for both categories, especially given a rather modest page count and the absence of an index. Since the range and provocativeness of the book's material are promising, I hope publishers will "get it" that the planned series' viability probably requires more reasonable pricing.

A purchaser's investment will be best rewarded by reading all chapters, and I mean "rewarded" in the sense of gaining quality information, not just quantity of pages. I have already noted the disciplinary diversity. The wide-ranging subject matter includes, among other topics, fascinating analyses of a century of perceptions of mental retardation, the framing of disability by contemporary news media, the legalistic framing of ADA Title III issues, U.S. electoral politics among people with disabilities, and, at a basic social science level of conceptualization, "gender contradictions and status dilemmas" (p. 85) in disability.

Furthermore, as the editors emphasize, the methodological variety deserves attention in its own right. Among the qualitative examples are a thematic analysis of historical documents, case studies of judicial decisions, and an "institutional ethnography" of an innovative health care delivery project. On the quantitative side, whereas familiar techniques are applied to well-known data sets in the economists' analysis of labor market transitions and the political scientists' analysis of electoral behavior, both groups of authors pay exemplary attention to the limitations in their data sources. Two other quantitative analyses employ more novel data. One is a content analysis of 500+ print news stories and the other uses discharge records from a national sample of community hospitals to detect patterns of disability-related "intentional injuries."

Space does not permit raising the few quibbles I have within chapters on which I have some expertise, but that would be beside the point anyway. The value of this book is partly to stimulate such critical response, but especially to expose readers to topics and methods that they would not otherwise seek out, all within the large and growing arena of social scientific Disability Studies.

Bertling, Tom, ed. *An Intellectual Look at American Sign Language*. Wilsonville, OR: Kodiak Media Group (P.O. Box 1029-B4, Wilsonville, OR 97070), 2001, 107 pages, $19.95 softcover.

Reviewed by Lois Bragg, Gallaudet University, Washington, DC.

Tom Bertling's latest offering is more of the same tiresome rant he has been dishing up through Kodiak since his 1994 debut: an irrational, amateurish diatribe against American Sign Language, this time focused on English literacy. His thesis is that ASL is responsible for low literacy rates among Deaf Americans.

Actually, however, literacy rates for Deaf school leavers do not correlate with whether or not they know or use ASL but, rather, with the socio-economic class and educational level of their parents, Deaf or hearing, signing or speaking. The challenge for educators, thus, is how best to replicate in a public classroom the kind of stimulating and secure environment that educated, financially-comfortable parents provide.

Many parents and educators (myself included) believe that an early grounding in ASL will provide most Deaf children with the kind of socialization, stimulation, and security necessary to acquire English literacy. Others are skeptical of the bilingual approach, believing that, for many deaf youngsters, especially those with hearing parents and any exploitable residual hearing, total immersion in English is the better route. It will not be long before we have further data on both these approaches, as the children now enrolled in ground-breaking bilingual schools, and those who are undergoing English immersion with the aid of the new technology provided by cochlear implants, come of age.

Meanwhile, no one interested in these questions will find any reason to read the ironically entitled *Intellectual Look*, neither the pages Bertling has written himself nor those written by other contributors. As an author, Bertling tends to garble his arguments, confusing, for example, a "native" language with

a "natural" language (p. 32), and he demonstrates no notion of, let alone familiarity with, any linguistic research, as, for example, when he refers to Harlan Lane's rip-roaring polemical tracts as "scholarly material" (p. 21).

As for the other contributors, Otto Menzel depends on "straw man" arguments, as when he asserts, incredibly, that the Deaf community "believes English is unnecessary" (p. 52), and Ed Scouten evinces astonishing ignorance of linguistic principles, as when he calls ASL a "gestural surrogate" and English "an orthographic language" (p. 74). The piece co-written by Thomas Balkany, Annelle V. Hodges, and Kenneth W. Goodman is by far the most disturbing, however, in its insistence that Deaf leaders and scholars "mislead people purposefully" (p. 83) in order to retain their professional hegemony over an ignorant Deaf community, and in its assertions that most Deaf people cannot make intelligent decisions for themselves because we are "incapable of accessing moderately sophisticated published information in the lay media" (p. 82) and because of "the prevalence of psychological disorders" among Deaf people (p. 87)!

Unless you are doing research on the disgust and resentment that teachers, physicians, and audiologists can feel for the Deaf people they serve, this is a book to ignore.

Brown, Dale S. *Learning a Living: A Guide to Planning Your Career and Finding a Job for People with Learning Disabilities, Attention Deficit Disorder, and Dyslexia*. Bethesda, MD: Woodbine House, 2000, 368 pages, $18.95

softcover.

Reviewed by Mary G. Maciel Klinger, SUNY Empire State College, Corning, NY.

Almost everyone at some time in his/her life has had to deal with the phenomena of job hunting. It is a time-consuming, difficult, and often humbling process. This book has been written to assist people with learning disabilities and dyslexia (whether high school student, college student, or adult) who are thinking about developing careers and looking for jobs. However, it is not just another "how-to" book, far from it. This book not only helps people with learning disabilities and dyslexia cope with the challenges of the job hunt, but it also highlights what the author calls the "LD Traps." The author explains that, if your sole disability is attention deficit disorder, this book may be useful; but she notes that there are other published works on ADD, and she includes a list of titles.

This book is outstanding. It pinpoints the major difficulties for people with learning disabilities and dyslexia embarking on a job search and gives detailed strategies to overcome these. However, it is much more involved than that. The book addresses in a straightforward manner the complications inherent to the LD population and the search for a career. At the outset of the book, Brown explains her own experiences with learning disabilities and creates a book that, as she says, "is meant to serve as a coach" (p. xxiv), and it does. Reading this book is much like having a knowledgeable friend over for coffee to help plan one's career and job search.

Brown assists the reader in dealing with long-term planning, accommodations in both education and the workplace, as well as research, resumes, and interviews. She takes this one step further, which is why this book is so outstanding. Brown deals with those pitfalls with which people with learning disabilities and dyslexia often deal: self-esteem, motivation, social skills, and perceptual problems - those areas that tend to be weak because of lifetime experiences with society. There is also a wealth of excellent resource information available in this book.

I recommend this book, particularly for those with learning disabilities and dyslexia. This user-friendly resource can give a person the needed information and strategies to overcome the anxiety of finding an appropriate place in the work world.

Brown, Steven E. *A Celebration of Diversity: An Annotated Bibliography about Disability Culture*. Las Cruses, NM: Institute on Disability Studies (2260 Sunrise Point Rd., Las Cruces, NM 88011; <SBrown8912@aol.com>), 38 pages, $10.00 softcover.

Reviewed by Joy E. Weeber, North Carolina State University, Raleigh, NC.

A Celebration of Diversity arrived for review when I was developing my first university Disability Studies course, so it seemed appropriate to assess it through that lens. Brown situates his bibliography within the struggle to redefine disability as a collective community experience worthy of celebration. While he does not claim the bibliography is comprehensively contemporary, the entries are reviewed through the lens of disability community consciousness. Given the current proliferation of disability culture today, it is a work that will be "in progress" for some time.

Entries are divided by medium: print, film, video, radio, etc.; with print materials subdivided by genre, such as non-fiction, fiction, poetry, children's, articles, etc. Publishers, addresses, and prices are included with each entry, as well as suggestions on how to locate those that may be out of print. The selected list of web sites adds further scope of information useful for those seeking information about contemporary work by disabled artists and writers.

As a budding educator, I found this bibliography helpful as a resource for course development. The strong suit of this bibliography is that the materials chart a historical flow of events and cultural perspectives on disability that led to the development of disability culture. I found myself wishing for content categories, though, which would make the information more accessible as an academic tool. So, I will share categories devised from my developmental psychologist's idiosyncracies that helped me to classify the materials and to identify where they might be useful in a syllabus.

Some entries describe historical perspectives and policies relating to disability while others illustrate those perspectives through cultural forms. A third, related kind of entry offers critical analyses of such materials from the disability community perspective. A fourth type of entry primarily articulates the disability community's redefinition of the disability experience, which, in turn, is illustrated by those entries that are redefining disability in the plethora of cultural forms that exist today. A final kind of entry articulates the cultural struggles of other disenfranchised people, paralleling the disability community's struggles, providing a bridge of understanding as we teach students from multiple cultural experiences.

Although the usefulness of this bibliography would be enhanced in future promised editions by content categories and

consistent descriptions, it is still a useful tool for people beginning to study disability culture seriously.

Corker, Mairian, and French, Sally, eds. *Disability Discourse*. Buckingham, England: Open University Press (Distributed by Taylor & Francis, Inc., 47 Runway Rd., Suite G,

Levittown, PA 19057-4700; 1-800/821-8312), 1999, 238 pages, $29.95 softcover.

Reviewed by Beth Haller, Towson University, Towson, MD.

The relationship between disability and the communication of it is only beginning to be explored, but Corker and French have assembled a wonderful collection of essays on the topic in this book. The essays revolve around three main themes - personal narratives, disability identity, and cultural discourses - which make for varied approaches to the topic of disability discourse.

For example, in the personal narrative section, Sandy Slack explains that "I am more than my wheels" (p. 28). She communicates an important transition through the telling of her experience of moving from non-disabled physical education teacher, whose focus was on movement, to a wheelchair user, who must learn to deal with numerous barriers. She explains how her vision of the world has changed and how that causes miscommunication with non-disabled people: "What I am seeing is different from what non-disabled people are seeing. We are coming from separate reference points and often move in a different direction. I may see the mountain and they may see the hump" (p. 31). In a similar fashion, Sally French's personal

narrative discusses her experience as a visually impaired person trying to communicate in a sighted world.

The disability identity section presents scholarly interpretations of how people with disabilities come to understand themselves. Anthony Hogan discusses the experiences of adults in Australia who acquire hearing losses. Their experiences illustrate that, although their communication changes due to their deafness, they are still bound by the social rules of the larger hearing society - an ableist society that may devalue sign language and other alternative means of communicating. Other essays in this section present the communicative experiences of English schoolchildren with disabilities, parents of children with disabilities, people with learning disabilities, people with Asperger's syndrome, etc. The international breadth and the disability breadth of the essays in this section are a true strength of the book. They strongly reinforce that disability identity comes from human communication and interactions with society, not from a specific disability.

The final section on cultural discourses covers topics such as disability and rhetoric, disability in film representations, disability and the Chinese language, mental retardation, and an emancipatory disability research paradigm. One interesting historical essay in this section explores the impact of Joseph P. Sullivan, whom author Brad Byrom says, shifted the discourse of "crippledom" in the Progressive Era in turn-of-the-century America. Sullivan, a polio survivor, tirelessly advocated for the right of people with disabilities to obtain an education. Byrom illustrates that "in some ways the strategies Sullivan developed mirrored methods of more recent disability rights activists, particularly in his rejection of pity" (p. 160). This essay gives crucial insight into the development of Twentieth Century disability discourse.

Disability Discourse is an important book that could be a reader for college courses in disability studies, communication and disability, disability history, or disability and literature. Mairian Corker provides a concluding essay in the book that analyzes the new disability discourse in the language and meanings within disability rights movements in the United States and the United Kingdom. After her analysis, she argues for the discourse of disability rights to leave a monolithic, single-issue approach and, instead, to embrace "cross-fertilization of discourses of otherness" (p. 206), which will strengthen both academic disability studies and the rights movement itself.

Field, Martha A., and Sanchez, Valerie A. *Equal Treatment for People with Mental Retardation: Having and Raising Children*. Cambridge, MA: Harvard University Press, 1999, 453 pages, $49.95 hardcover.

Reviewed by Megan Kirshbaum, National Resource Center for Parents with Disabilities, Through the Looking Glass, Berkeley, CA.

This book presents an analysis of past and present legal doctrines and policies regarding the reproductive rights of individuals with intellectual disabilities and it recommends a number of reforms. It is particularly thorough in its analysis of sterilization while only the final third of the book addresses legal issues relevant to parenthood. I recommend that the volume be read especially by advocates and legal professionals concerned with disability and reproductive rights or the rights of parents with disabilities. I certainly hope that it will be read by attorneys and judges involved in family law and child protection,

and that it will be included in the curriculum of law schools.

As the Custody Specialist at the National Resource Center for Parents with Disabilities, it provides me with a useful historical and conceptual framework, helps locate legal precedents relevant to particular cases, and offers analyses that can contribute to improved public policy and practice. Despite its usefulness, the book is an arduous read, often quite repetitious, and could have benefitted from more editing. The treatment of legal material is more thorough and expert than the presentation of research, evaluation, or intervention with parents with intellectual disabilities. A number of issues are raised that would be interesting to develop in dialogue with specialists regarding such parents who are from other disciplines. For example, the authors emphasize the need for equal treatment of parents labeled with mental retardation, but they have only a brief discussion about the relation of equality and "assistance" or accommodation.

I have found that the need for adaptation is a pervasive problem in current practice - in legal proceedings, evaluation, and reunification services - affecting custody by parents with intellectual disabilities. To illustrate, the authors apply the idea of equal treatment to the interval between removal of a child and termination of parental rights, saying the time period should be the same for all parents. As an expert witness, I recently argued that one adaptation parents with cognitive disabilities may need is a longer time-frame to demonstrate their benefit from reunification services.

Overall, I found the book to be thought-provoking and an important contribution to the dialogue about the rights of parents with disabilities: the interface of family law and disability law.

Fletcher, Jacky. *Marching to a Different Tune: Diary about an ADHD Boy*. London, England: Jessica Kingsley (Distributed by Taylor & Francis, Inc., 47 Runway Rd., Suite G, Levittown, PA 19057-4700; 1-800/821-8312), 1999, 122 pages, $16.95 softcover.

Reviewed by Peggy Quinn, University of Texas at Arlington, Arlington, TX.

The title of this book accurately describes its intent and its product. It is a series of entries over a period of four years as the main actor, Stefan, moves from childhood to early adolescence. The book details the activities of Stefan as well as the frustrations of his parents and siblings in dealing with his amazing repertoire of adventures.

His parents are continually seeking professional and bureaucratic assistance. They appear to follow through on recommendations to the best of their ability. At the end of the four years, and the book, however, the family and Stefan seem little closer to being able to manage his behaviors and assist him toward appropriate assimilation into the larger society.

Overall, I found the book to be rather distressing. In some cases, the entries were humorous. In others, it seemed an almost endless catalog of injuries, property damage, and upsets for the family, neighbors, school, and any other setting in which they found themselves.

For families seeking confirmation that they are not alone in dealing with a child with ADHD, this book is reassuring. If, however, they are hoping to find solutions to their own difficulties, or the comfort of knowing that someone else has successfully negotiated the various situations faced by families of children with ADHD, the book is a disappointment.

Freedman, Michael R., Rosenberg, Samuel J., and Divino, Cynthia L. *Living Well with Asthma*. New York, NY: The Guilford Press, 1998, 223 pages, $34.95 hardcover, $14.95 softcover.

Reviewed by Hanoch Livneh, Portland, OR.

Asthma can be a stressful experience in the lives of individuals who suffer from it. In their book, Freedman and his colleagues have adopted what they refer to as a holistic, "biopsychosocial management" perspective on asthma. The approach undertaken by the authors is "to guide (the reader) past the pitfalls of adapting to asthma through information and inspiration" (p. 3). To this end, the authors organize their book into four parts that focus on: (a) the basic medical features of asthma (symptoms, triggers, etiology); (b) psychological and other personal/experiential aspects of asthma; (c) familial aspects, including transgenerational issues and sexual concerns; and (d) social and vocational aspects, including doctor/patient relationships.

A concise appendix listing recommended books and other written and on line resources concludes the book. Selected case examples of individuals who demonstrate successful and unsuccessful coping modes with asthma and its many daily derivatives are appropriately incorporated throughout the text.

The authors of *Living Well With Asthma* have succeeded in providing readers (the book is geared mostly toward those with a recent diagnosis of asthma) with a non_technical, readable, and realistic, yet hopeful, view of the condition and its daily impact on their lives. Moreover, in doing so, the authors have succeeded in dispelling many of the misconceptions and fallacies associated with the etiology, course, and management of this often misunderstood condition. These strengths, however, are periodically compromised by lapses into a preachy and patronizing style and, occasionally, some redundancy in covered material.

Readers and consumers who are more interested in gaining a better insight into the psychosocial correlates associated with asthma may find the book somewhat deficient in this regard. The authors, however, provide thoughtful tips on vocational issues and also offer concrete examples of managing asthma in the workplace.

In sum, despite its weaknesses, the book, when judged in its entirety, is a useful guide for those affected by this chronic illness, their family members, and, ultimately, their care providers.

Kerson, Toba Schwaber, and Associates. *Social Work in Health Settings: Practice in Context* (Second Edition). New York, NY: The Haworth Press, Inc., 1997, 752 Pages, $59.95 hardcover, $29.95 softcover.

Reviewed by Cynthia Fromer, CSW, Southern Westchester Dialysis Center, Yonkers, NY.

My view of disability differs from the view of disability prevalent in the profession of social work. My view stems from being "person in situation." I am a woman with a disability and a social worker.

*Social Work in Health Settings: Practice in Context* (Second Edition) consists of thirty-two case studies in medical social work. The medical model of disability permeates each case study, i.e., disabled person as patient or as person in need of "professional help."

In the chapter titled "Family-Centered Care: Life Span Issues in a Spina Bifida Specialty Care Program" by Wendy Schmid, a person with spina bifida is referred to as a "good walker" until he gained weight and had to use a wheelchair. It is as if using a wheelchair in order to lead a more independent life is somehow a failing on the part of the person with the disability. Further, jargon sometimes obscures the ideas expressed.

The strength of the book is in its breadth of scope and in its explanations of theoretical underpinnings to practice. Each study deftly addresses the interface between policy and

practice.

In a section titled "Differential Discussion," each author discusses what, in hindsight, may have been done differently toward a more positive outcome.

One of the most informative chapters, "He's Schizophrenic and the System Is Not Helping: Reflections of a Troubled Parent and Professional," is written by Mona Wasow. Ms. Wasow is a social worker whose son has been diagnosed with schizophrenia.

Impediments to practice, including the advent of managed care, are explored. This is also a strength of the text. It has a real-world slant.

Although worthwhile as an overview of practice and policy, the text does not convey people with disabilities in a powerful, positive light.

Lago, Colin, and Thompson, Joyce. *Race, Culture and Counselling*. Buckingham, England: Open University Press (Distributed by Taylor & Francis, Inc., 47 Runway Rd., Suite G, Levittown, PA 19057-4700; 1-800/821-8312), 1996, 192 pages, $26.95 softcover.

Reviewed by Christine A. Loveland, Sociology-Anthropology Department, Shippensburg, PA.

This book examines the impact of race and culture on counselling and psychotherapy relationships in a British cultural context. The authors have a critical theoretical perspective; that is, the emphasis is on power asymmetry and inequality, both in society and in counselling. They label groups in British society as "white" or "black" not on the basis of phenotype or appearance, but, rather, they state that "blackness is used to describe those who are not the traditional power holders or members of a dominant majority group in a society" (p. xxi). Most (but not all) of their discussion focuses on therapeutic relationships in which the counsellor is white and the patient or client is black.

Although this is a relatively short book, the authors have an ambitious agenda. They begin with an overview of the historical and cultural factors that have contributed to the formation of a British society they describe as multicultural and multiracial, with 7.3% of British residents, as of 1991, born elsewhere (p.1). They go on to discuss the history of counselling in Britain, the relationship between race and power, and the importance of culture in human communication. As a cultural anthropologist who uses and teaches some of this material, I found this part of the book to be both interesting and accurate.

The middle chapters of the book contain a critique of the theories behind and the content of current counselling practices. They believe that "the current forms and modes of counselling and psychotherapy are not proving to be adequate in response to the changing and contemporary needs of society" (p. 69). They compare Western and non-Western approaches to healing asking if the qualities necessary for successful healing in shamanism might also be useful in psychotherapy.

The remaining one-third of the book offers practical suggestions for those who work in multicultural settings. Included are an overview of the use and value of film in counselling training, a detailed discussion of the context of the counselling organization (even the type of art work chosen for display is included), a summary of the importance of supervisors in these complex situations, and, finally, a plea for more research on cross-cultural counselling in Britain.

This book offers a well written and concise analysis and discussion of a topic that is important to anyone who works with diverse populations. The authors have a consistent and well articulated theoretical approach, but they also ground their discussion in the practical everyday details that can make or break any therapeutic relationship. I believe that this book would be useful to practitioners in a wide range of medical or disability-related fields. It also would be a valuable resource for the educator or lay person who wants an accessible, but comprehensive introduction to these topics.

Leicester, Mal. *Disability Voice: Towards an Enabling Education*. London, England: Jessica Kingsley Publishers (Distributed by Taylor & Francis, Inc., 47 Runway Rd., Suite G,

Levittown, PA 19057-4700; 1-800/821-8312), 1999, 135 pages, $24.95 softcover.

Reviewed by Dona Avery, Arizona State University, Tempe, AZ.

Slim books: I like them. Thus, I expected the 135 pages of Mal Leicester's book, *Disability Voice: Towards an Enabling*

*Education*, to be an easy four-hour read: perfect for a coast to coast airplane trip or, at most, a week's worth of chapters to read on my lunch hours.

Even better, Leicester operates on the KISS principle: Keep It Simple, Stupid. Her thoughts are so clearly and concisely packaged that her suggestions for an "enabling education" read like an 11th Commandment. The simpler things are, the more obvious, sometimes, the more profoundly they affect us. For instance, it is an absurdly commonsensical notion that one might ask the people who use a service, whether they are satisfied with it or not. That is precisely what Leicester did interviewing eighteen adults with disabilities and ten parents of disabled children who are in the education system currently. While the size of her research sample, like the book in which she interprets the findings, is small, she is able to weave from recurrent narratives of the school experience a message that must be heard by educators and policy makers. *Disability Voice* is a small, but hugely important book, absolutely powerful in its brevity, highly readable for nonacademics - and slim enough to appeal to busy teachers, principals, and college faculty.

Leicester's message, short and sweet: Disability "is not an attribute of an individual, but a condition arising from an interaction within an inadequate social world" (p. 9). Schools are part of that inadequate social world, where "endemic prejudice and wide-scale discrimination of people with disabilities" create an "educational apartheid" that "continues to damage seriously the quality of people's lives" (p. 8). And she is talking all people's lives, whether they reside in the mainstream or on the margins of society, for we are all hurt, from kindergarten upwards, by the "relative lack of a social perspective on disability . . . [and] little disability awareness in [school] practice or provision" (p. 10).

If there were a true policy of inclusion in our schools, on the other hand, we might see progress towards a society where architectural access, public transport, social roles, and leisure activities are equally available to all citizens. We might see far fewer instances of "aesthetic dissonance" (p. 16), that fear or distaste that makes people stare or avert their gaze from the physically different. Let us begin such attitude change in the primary schools, she argues, and let us not stop at colleges and adult education. Let us help adults unlearn oppressing behaviors, let us train new teachers and supervisors and health/welfare professionals to create a world where "a caring justice [combines] with a just compassion" (p. 21). We must "ensure that disability-awareness permeates formal and informal education . . . and informs the mass media and other agents of all informal learning" (p. 29).

The "single most often-expressed point of view" that Leicester heard from her respondents was that true inclusive education "would be extremely educative for mainstream society" (p. 70, emphasis mine). The inference is that, with all the education-reform acts here and abroad, and even with England's DDA and our own ADA, much work still needs to be done. In fact, argues Leicester, "the very legislation which at least addresses the educational apartheid . . . does so in a way which enshrines `disablist' assumptions" (p. 99). The act of assessing or identifying a child as having "special needs," for example, or the process of evaluation known as "statementing" in the UK do not contribute to a child's ego-balance or well-being whether he/she is the "special needs" classified student or the observing peer. Because schools so heavily influence the tone of "personal, social and moral education" for all students, it does seem that, what Leicester calls "radical reorganization" needs to be

enacted (p. 111).

In just over 100 pages, then, Leicester summarizes several disability theories, relates them to the educational system, and proposes radical change. Next, she recommends many incremental improvements on which a whole-school policy of inclusion might focus: increased resources, curriculum differentiation, assessments of "social adjustment" as well as academic achievement, better information and support systems, involving parents as partners in assessment and decision-making, in-service training for teachers and staff, and external help for parents in developing advocacy skills. Clear, straightforward, do-able suggestions: Keep It Simple. Leicester makes her point swiftly and in brief with neither wasted words nor skimpy evidence.

Best of all, though, the author amplifies the voices of people who have been direct "users" of the educational system. One respondent said, of students in the present school system, with its endemic prejudices firmly in place, "Their education in life will be lacking" (p. 93).

Inclusion benefits all. Let us hope that Leicester's slim book inspires heavyweight changes in schools and colleges everywhere.

Marmor, Theodore R. *The Politics of Medicare* (Second Edition). New York, NY: Aldine de Gruyter, 2000, 254 pages, $35.95 hardcover, $16.95 softcover.

Reviewed by Susan Prokop, Associate Advocacy Director, Paralyzed Veterans of America.

The Politics of Medicare puts present day discussions about health care reform in a historical context. As the author tells it, Medicare's story is interwoven with the ongoing debate over universal health insurance: how comprehensive and national in scope reform should be or whether reform is best done incrementally with maximum flexibility given to the states. It also provides a picture of the interplay of forces in support of and in opposition to Medicare's enactment and how this shaped its evolution. Furthermore, the book illustrates the compromises so often required and the importance of legislative and executive branch leadership in achieving major health policy change.

Marmor admits that his book does not explore how people with disabilities experience Medicare. Still, certain philosophical and policy issues he raises in relation to elderly beneficiaries beg questions about their impact on the other segment of Medicare's population. For example, Marmor acknowledges that Medicare debates have left unsettled whether it should pay for all care that is deemed effective or whether this somehow favors the aging population at the expense of younger individuals. Millions of Medicare beneficiaries are themselves young, and the effectiveness of treatments for people with disabilities may be based on a different calculus than that used for the elderly. What is viewed as ineffective for Medicare beneficiaries over 65 may, in fact, be helpful to program participants under 65 with disabilities.

The author also notes that little attention has been paid to "justifying the care the program does and does not finance" (p. 156) even as Medicare's fiscal condition has become a fulcrum of discussion. Medicare does not cover many items and services that could give people with disabilities a measure of independence. This is one of the most regrettable instances of that lack of attention.

Marmor demonstrates how Medicare's politics is central to both narrow health policy disputes and "ideological cleavages" (p. 181) in the American public over the merits of social insurance. Perhaps, a future scholar can use *The Politics of Medicare* as a basis for examining the role of people with disabilities in that dynamic.

Mindess, Anna, Holcomb, Thomas K., Langholtz, Daniel, and Moyers, Priscilla Poyner. *Reading Between the Signs: Intercultural Communication for Sign Language Interpreters*. Yarmouth, ME: Intercultural Press, Inc., 1999, 273 pages, $21.95 softcover.

Reviewed by Sharon Barnartt, Gallaudet University.

Although this book is written for interpreters, it is of wider interest than that. Its topic is deaf culture and the cultural gap between deaf and hearing people. Its focus is on communication issues, rather than on other areas of culture. It defines culture and identifies areas of communication about which

all cultures have something to say. It identifies a core of American cultural values, which it then contrasts to deaf cultural values. In the strongest terms it draws a picture of two cultures with a high potential for conflict and misunderstanding.

The book provides a very comprehensive discussion of paralinguistic, as well as linguistic, aspects of American Sign Language (ASL). Paralinguistic aspects of communication in deaf culture include facial expression, usage of name signs, "facial grammar," hugging, and blunt personal comments, such as "Oh, you have gained a lot of weight."

This book provides the best discussion of deaf culture that this reviewer has seen, even though its focus on communication does leave out other areas of culture. However, this book is likely to be very controversial. It presents the role of interpreter as that of a bicultural mediator rather than that of a translator or transliterator. In this view, the interpreter is not just a passive translator (if such is even possible), but someone whose role is to facilitate effective communication for all parties. Thus, the interpreter's role can include explaining deaf culture and sign language to hearing people as well as, sometimes, alerting them to aspects of their communication that might be seen as insulting to a deaf person. It may also include informing deaf clients of ways in which their communications might be seen as being inappropriate by the hearing standards of the situation in which the interpretation is occurring. It suggests a number of problematic scenarios and explores a variety of possible ways in which an interpreter might handle such a situation. One example presented is that of a deaf person in a job interview responding to the question "Why do you want this job?" by saying "I need the money." If the interpreter feels that a more job-focused answer would increase the deaf person's chances of getting the job, the book opens the possibility that the interpreter would "step out of role" and say something to the deaf client.

This reviewer used the book in a class that included both deaf and hearing college students. Some of the hearing students were in interpreter training programs. The book was received very differently by the groups. Deaf students thought that it was appropriate for the interpreter to help the deaf client in some situations with additional comments or by using more erudite words with the same meaning when voicing for the client than the client actually signed. The interpreter training students did not agree.

This book is likely to raise the hackles of some hearing readers, whether interpreters or not, but it provides such a good discussion of the non-linguistic aspects of ASL and intercultural communication that it should not be overlooked. It could also serve as an introduction to deaf culture, with some supplementary discussion of other, non-linguistic aspects of deaf culture. Thus, it could be used in other types of interpreter training programs. The conflicts it illuminates may differ in substance from those experienced between ASL and English, but they exist among most language/culture pairs and need to be recognized.

Myles, Brenda Smith, and Simpson, Richard L. *Asperger Syndrome: A Guide for Educators and Parents*. Austin, TX: Pro-Ed, 1998, 148 pages, $28.00 softcover.

Venta Kabzems, Ph.D., Education and Behavior Programming Consultant, Edmonton Public Schools, Edmonton, AB.

Asperger Syndrome is a diagnosis used to describe individuals with significant social communication difficulties who, concurrently, function within the normal range of development in most other areas including cognition. There exist considerable gaps in our understanding of this disabling condition which is considered by many to be part of the autistic spectrum.

Myles and Simpson have written a book that meets its stated goal of being accessible to professionals and lay persons in particular the families of individuals diagnosed with Asperger Syndrome. The information presented is practical and informative. The six chapters cover the defining characteristics of the disorder, educational assessments, educational supports, behavior management (if needed), transition planning, and the familial impact of living with someone with Asperger Syndrome.

The strongest chapters are those on educational management and transition planning. The information contained in several of the tables, such as Table 4.1, Guidelines for Social Story Construction, leaves the reader with clear steps that can be transferred to educational programming in any model of schooling. Transition planning is emphasized not only in the traditional sense from secondary school to post-secondary education or the workplace, but also in its foundations beginning in elementary school. Examples of approaches to transition planning are included in the section on planning for post-schooling, adult life.

The weaknesses in the book include a limited reference to scientific research findings, a fact noted by the authors in the preface. Points are sometimes made via case studies which make for interesting reading, but they are not always generalizable. The chapter dealing with the impact on the family provides descriptions of events in the life of a person with Asperger Syndrome, but it does not include any discussion of the family's responses to these situations, their feelings and so on.

Instances of over generalizations about the syndrome include statements such as "Students with Asperger Syndrome have endless potential when teachers recognize their individual needs and characteristics and structure the environment for success" (p. 51). Such an overriding comment does not fit with the individualized approach used elsewhere in a book that strives to give the reader a feel for what it may be like to work with or to live with a student diagnosed with Asperger Syndrome. The inclusion of a section on the "hidden curriculum" is on the mark, since a primary challenge for these individuals is "reading" the expectations of the group in social and instructional situations. Persons who would find this concise description of Asperger Syndrome useful include teachers, psychologists, family members, developmental pediatricians, pediatric psychiatrists, and job coaches. There is much in the book that is of immediate relevance to professional practice and day-to-day management.

Osgood, Robert L. *For "Children Who Vary from the Normal Type": Special Education in Boston, 1838-1930*. Washington, DC: Gallaudet University Press, 2000, 224 pages, $49.95 hardcover.

Reviewed by Martha L. Rose, Truman State University, Kirksville, MO.

In this study of special education in the United States, Osgood discusses the school system in Boston during the period from 1838-1930 as his spatial and chronological reference points, arguing that the Boston school system is a representative microcosm of the American school system. These decades witnessed dramatic change in social and scientific outlook. The book is in two parts.

Part I is a concise overview of education in general in Boston; the bulk of the book, Part II, traces the development of Boston's special education programs. Osgood organizes the material topically rather than chronologically, e.g., Chapter Six discusses the Horace Mann School for the Deaf, while Chapter Seven is titled "Disciplinary Programs for the Boston Schools." Osgood frames the topic of special education in light of the perennial question of the degree to which disabled children should be fully integrated with their nondisabled peers.

*For "Children Who Vary from the Normal Type"* is a solid historical inquiry. It is well conceived, thoroughly researched, and clearly written. There is a nice balance of primary and secondary material. Quotes from various administrators, for example, enliven and clarify, but do not overwhelm the work. Appropriate black and white photographs, along with clear charts, illustrate the text effectively. The greatest strength of the work is Osgood's command of the complex layers of historical context including the intertwined issues of eugenics, immigration, and mental testing. He is able to analyze, yet leave intact, the perspective of the mid-Nineteenth through mid-Twentieth Century. There was, for example, little differentiation between children with discipline problems and children with mental retardation during the time period. Where the evidence is missing, he makes intelligent surmises, but he never pushes conclusions beyond what the evidence will bear. The book ends with guarded optimism for the potential of full integration.

The weaknesses of the book concern production rather than content. The notes to each chapter are grouped at the back of the book making for cumbersome reading. Worse, there is no separate bibliography. These are minor complaints. Historians, education professionals, and scholars of Disability Studies will benefit from reading this fine historical study.

Owen, John M., and Rogers, Patricia J. *Program Evaluation: Forms and Approaches* (International Edition). Thousand Oaks, CA: Sage Publications, 1999, 320 pages, $78.00 hardcover, $25.95 softcover.

Reviewed by Raymond E. Glazier, Ph.D., Director, Abt Associates Center for the Advancement of Rehabilitation and Disability Services, Cambridge, MA.

This book is a far cry from the small Sage paperback "cookbooks" that each address a specific social research method. It is a substantial treatise that not only pulls together in a single volume most of the "state of the art" of the field, but also advances its frontiers by redefining program evaluation and its role in the implementation of social change.

The authors demonstrate a command of the evaluation literature and also draw from the literature on change management in putting together a typology of evaluation forms around which the bulk of the book is organized with a chapter on each of the five forms. (Note that, here, "evaluation forms" refers to the types of evaluation, not, as in common parlance, data collection instruments.) Just as importantly, Owen and Rogers discuss in detail the social, political, and economic contexts of program evaluation, as well as the theoretical foundations and practical implications of program evaluations of all sorts before moving

on to those five "how to" chapters.

Many of us have been accustomed to thinking of program evaluation simplistically, only in terms of either formative/process or summative/impact evaluations, the former documenting program implementation and the latter assessing the ultimate accomplishment of the intervention's objectives. The typology that Owen and Rogers set forth, first in easily comprehended tabular form, includes: 1) Proactive evaluation, synthetic in nature, which helps planners define the intervention and mobilize support for it; 2) Claricative evaluation, development of program logic which helps create and communicate a vision that empowers others to act and to create short-term wins; 3) Interactive evaluation, documenting the innovation which can inform program evolution; 4) Monitoring evaluation, usually based on quantitative performance indicators which helps program administrators with "fine tuning" and program improvement; and 5) Impact evaluation, end-point analysis which tells policy makers how well the intervention accomplished its objectives and contributes to a judgment about whether program costs were justified.

The Australian authors have made a very conscious effort in this edition to reference U.S. and other non-Aussie sources and programs. The use of many British spelling conventions and the predominance of Australian programs and evaluation efforts as examples often remind the reader of this book's origin in Melbourne. But that also serves as a powerful signal that the program evaluation literature is global in nature, reflecting common policy, planning, and program implementation concerns in a world that seems to be shrinking every day. The usefulness of this book, both to the program evaluation practitioner and as a classroom text, is enhanced by the posing of program evaluation design exercises based on scenarios set forth at the close of certain chapters. The method of presentation encourages independent thought and fosters a deeper understanding of the concepts presented.

*Program Evaluation* would be a useful text around which to build a program evaluation course at either the undergraduate or graduate level. Its profuse use of case examples and its discussion of trends enhance its utility. But this reviewer had hoped to find included a discussion of Logic Model technique, a relatively new tool for program planning and qualitative evaluation.

Phelps, LeAdelle, ed. *Health-Related Disorders in Children and Adolescents: A Guidebook for Understanding and Educating*.

Washington, DC: American Psychological Association (P.O. Box 92984, Washington, DC 20090-2984; 1-800/374-2721), 1998, 761 pages, $59.95 hardcover non-APA members/affiliates, $49.95 hardcover APA members/affiliates.

Reviewed by Keith Storey, Associate Professor of Education, Chapman University, Concord, CA.

This book is "intended as a reference tool for service providers who collaborate with medical professionals" (p. 3). The book is divided into 96 chapters that each address a specific medical condition. Each chapter has an overview section of specific medical conditions, an outcomes section addressing consequences of the medical condition, and a section on psychoeducational implications. In addition, each chapter has good resources in terms of organizations, books, and journal articles related to the topic.

The book meets its intended goal. The chapters are well written, informative, and to the point. Though only an overview of each medical condition is provided, the resources in each chapter will make it easier for readers to find more information. Readers will find the chapters on the more low-frequency conditions helpful if they encounter them in their professional or personal situations. In addition, there is a strong overview chapter on the role of school-based professionals in health-related services that nicely summarizes child advocacy, direct service, and coordination of services.

Problems with the book include non person-first language, the use of inappropriate terms such as "handicapped," "handicapping conditions," and "emotional suffering." Also lacking is discussion of support groups, self-determination, self-advocacy, role models, and mentoring. Though outside the purpose of the book, there is also no consideration of larger societal influences such as the disability rights movement, legislative issues, or legal rights, which would have made the book more informative for readers.

Robillard, Albert B. *Meaning of a Disability: The Lived Experience of Paralysis*. Philadelphia, PA: Temple University Press, 1999, 207 pages, $59.50 hardcover, $19.95 softcover.

Reviewed by Patricia Sisco, National Chair of the Canadian Association of Independent Living Centres.

Each person who encounters a disability deals with it in his or her own unique way. Robillard, a Professor of Sociology, who

encountered amyotrophic lateral sclerosis in middle life, chose to find meaning in his disability by writing an ethnomethodology of his illness - a detailed analysis of his interaction with people, particularly in the area of communication. This autobiography traces Robillard's experience with the disability from the time he noticed the first symptoms to the point when he was almost completely paralyzed and unable to utter his own words.

He used ethnomethodology "not because it was a useful paradigm, one among many theoretical models, but because I was convinced that it alone addressed the concerted, bodily accomplishment of ordinary tasks, such as caregiving" (p. 31).

After reading the book, the reader is left with a detailed description of all the places to which Robillard traveled and the universities in which he taught, as well as considerable detail

on all the significant people in his life. It is through this thread that Robillard weaves his own unique story of his disability. He discusses his physical deterioration, showing what added physical supports he needed so that he could carry on with his career. He discusses the attitudinal barriers that are constantly present. He also writes openly about his anger, expressing that he "could not build the sequence of care with them through speech" (p. 31). Through all of this, we are left with a picture of a man who has great fortitude and perseverance. The more severe his disability was, the harder he worked to achieve his goals.

Robillard wrote openly about the people he liked and about those who performed their duties in a way that deserved respect. He particularly liked those who took the time to communicate and to follow his direction in caregiving. He also wrote about those who were completely insensitive. He was able to express vividly how he felt when his presence was ignored or when someone would unthinkingly turn his wheelchair away from the crowd so that he could not even communicate through eye contact. He wrote extensively of the degradation he received, particularly from hospital nurses, who would refer to him as a "bad boy" (p. 35) if he called for help, if he insisted they take the time to communicate, or if he wanted questions about his health answered.

The book is simply written, but has many levels. There is the story of the busy professor; there is the story of a man's body slowly deteriorating and all that that encounters; and there is the story of the psychological implications this all has on all those who have to face a person with a severe disability, either as a caregiver or just a passerby. There is a fair amount of repetition, which can be annoying, but he writes with such great preciseness and accuracy that one does not mind re-reading parts of the story.

This book should be read by those working with people with disabilities, those teaching in the area of Disability Studies, and by people with disabilities.

Roth, Nancy L., and Fuller, Linda K., eds. *Women and AIDS: Negotiating Safer Practices, Care, and Representation*. New York, NY: The Haworth Press, 1998, 350 pages, $39.95 hardcover, $19.95 softcover.

Reviewed by Betsy Johnsen, J.D., Client Services Director, AIDS Legal Referral Panel, San Francisco, CA.

In the two decades since "the gay disease" first stigmatized urban white males, AIDS is still seen only occasionally in other American contexts. But AIDS has always affected women. Many female IV drug users and sexual partners of HIV-infected men have died; and, as society's caregivers, women help friends, lovers, and sons, as well as patients and clients, deal with this incurable disease. Yet, they are under-reported and unrecognized; and, thus, women, especially women of color, receive little information on safe sex practices, and they get inadequate medical care for their own HIV infections or support for their activities as caregivers. And, despite the explosion of cases outside urban gay enclaves, the media still ignores women and their relationship to the epidemic.

This book recognizes these gaps and may be the first to link all of these issues from a communications perspective. Roth and Fuller, both communications experts, group the dozen chapters contributed by academicians and medical professionals under the rubric of "negotiation."

This umbrella works, largely because women must use communication skills in lieu of physical, social, and economic equality with men. The first section, on negotiating safer sex practices, explores how women involved in drugs, women who are Latina or African American, and even women who are college students need different skills to prevent HIV transmission. The cultural research demonstrating this is often fascinating.

African American and Latin cultures, for example, vary widely in who makes sexual and reproductive decisions; verbatim quotes demonstrate how women use this knowledge when it counts. This section also touches on other issues, such as the importance of accepting solutions that are less than 100% effective. The section on negotiating care offers some diverse practical advice, such as how to give someone her AIDS diagnosis. But, other than the chapter on getting women into research trials, no chapter directly addresses how an HIV-infected woman can get care for herself today. This is particularly important, since most AIDS service organizations are still oriented toward urban gay men.

The last section, on representation, it is hoped, will stimulate care. In one chapter, women producers and directors of AIDS films/videos offer creative ideas on how to control media when you are on the right side of the camera. Every chapter is supported by extensive references, which provide excellent source material for everything from ethno-anthropology to medical ethics, and from protest literature to economic theory.

I recommend this book to people interested in numerous topics, especially the impact of race and culture on disease transmission, and media representations of disability. And, of course, communications.

Saltman, Richard B., Figueras, Josep, and Sakellarides, Constantino, eds. *Critical Challenges for Health Care Reform in Europe*. Buckingham, England: Open University Press (Distributed by Taylor & Francis, Inc., 47 Runway Rd., Suite G, Levittown, PA 19057-4700;1-800/821-8312), 1998, 440 pages, $34.95 softcover. Reviewed by Dennis Lang, Disability Studies Program, University of Washington, Seattle, WA.

This book is one in a "State of Health Series," which is "intended to be accessible to students and informed lay readers as well as to specialists" (p. viii). This volume concerns the very complex field of health care reform in Europe.

Unfortunately, it reads like it is trying for all audiences. I found myself frustrated, both by the amount of minutia (e.g., Chapter 8, "Performance Tied Payment Systems For Physicians") and by the lack of needed content, such as an explanation of each European country's health care system. There is a lot of quality analysis that does not coalesce. This is not unexpected, given that over 30 authors from all over Europe and the U.S contributed the 17 chapters.

The editors conceived this volume as providing policy makers with "evidence-based" health policy analysis. They have grouped the chapters into five sections that cover topics from demand

and supply-side strategies for cost containment to the role of the state, citizens, and society in health care reform. Of the several themes that permeate the book, "limited information" from poor to incompatible data collection contradicts their goal of being "evidence-based."

Other themes that appear frequently include the following: maintaining solidarity (equity) is considered of primary importance in any health care reform; utilizing "market forces" to obtain cost containment compromises both solidarity and effectiveness; the health care system is, for the most part, better in Western European countries than in Eastern Europe or the Commonwealth of Independent States; and rationing of health care services is inevitable. Given that those of us with disabilities are likely to be significant consumers of health care, this latter theme is of great concern. What is also of concern is the unquestionable assumption by the contributors that the increase in percent of GDP utilized on health care services is a negative situation in need of reform.

Scheff, Thomas J. *Being Mentally Ill: A Sociological Theory* (Third Edition). New York, NY: Aldine de Gruyter, 1999, 234 pages, $45.95 hardcover, $22.95 softcover.

Reviewed by Peter Bragg and Barbara Granger, Matrix Research Institute, Philadelphia, PA.

This is the leading book on the social context of mental illness (or "mental illness," as author Scheff suggests at one point in the text). The book in its original 1966 and subsequent 1984 editions provided important support for national mental health law and policy reforms and state-by-state shifts to community-based mental health services, starting with California in the late 60s. This third edition builds on and evolves the concept/theory of "mental illness" being defined as the result of known and yet to be known social matrices, rather than being defined as the consequence of chemical imbalances/disease states, as postulated by the currently dominant biopsychiatric viewpoint. Thus, this book again raises the bar for intelligent debate amongst competing theories of "mental illness." It should be required reading for psychiatrists, for people concerned about mental health and mental healing issues, and especially for people labeled "mentally ill."

Scheff readily acknowledges that his sociological theory is not nearly the full answer to the mystery, "What is mental illness?" He asserts, rather, that there is plenty of evidence to support his theory as a cogent hypothesis. He feels that what E.O. Wilson called a "consilience" (in his 1998 book, *Consilience: The Unity of Knowledge*) of viewpoints/theories from all interplaying realms - sociological, psychological, biological, psychiatric - will be needed to get closer to a universal theory of mental health.

Schou, Kirsten Costain, and Hewison, Jenny. *Experiencing Cancer: Quality of Life in Treatment*. Buckingham, England: Open University Press (Distributed by Taylor & Francis, Inc., 47 Runway Rd., Suite G, Levittown, PA 19057-4700; 1-800/821-8312), 1999, 207 pages, $27.95 softcover.

Reviewed by Rosalind Kopfstein, DSW, Danbury, CT.

Experiencing Cancer allows the voices of patients to tell their stories of cancer diagnosis and treatment so that professionals can sense the impact of the disease on their quality of life. Using extensive qualitative interviews, *Experiencing Cancer* presents valuable insight concerning the day-to-day lives of people receiving cancer treatment. The authors interviewed groups of cancer patients in hospital centers in England, asking about their experiences in the healthcare system, ranging from their initial diagnosis to intervention or to palliative care. The reader is immersed in the intimacies of cancer care from a patient's perspective during all phases of the disease. The first five chapters present the specific narratives and explanations of their study. The last chapter offers a philosophical and political discussion of policy, resource allocation, and recommendations for improving the health care system.

Focusing on quality of life decisions and the illness calendar, Schou and Hewison explain the impact of specific cancer treatments on the lives of these interviewees. The illness calendar, on face value, presents a plan of medical intervention; however, this plan does not take into consideration the social environment of patients' lives. Patients are challenged by the simple, but profound barriers of getting a timely appointment, traveling to the treatment center, waiting and then facing equipment breakdowns, and, lastly, experiencing the side effects of surgery, radiation, or chemotherapy.

The book is well written, using limited medical jargon while incorporating detailed quotes from the patients' narratives. Occasionally, the narratives are repetitive and could have been edited more closely. The authors explain the medical model's approach of ignoring the social environment of the patient, and they underscore information gaps and poor communication between doctor and patient. The underlying theme cautions providers to consider the social and medical impact of the disease, while understanding the patient's social supports, family obligations, and career responsibilities, to truly provide the best quality of health care. The message is clear: See the person and his or her context simultaneously. *Experiencing Cancer* is worthwhile reading for health professionals who wish to focus on the patient as an individual and not on the diagnosis/disease.

Wright, James D., Rubin, Beth A., and Devine, Joel A. *Beside the Golden Door: Policy, Politics, and the Homeless*. New York, NY: Aldine de Gruyter, 1998, 257 pages, $39.95 hardcover, $19.95 softcover.

Reviewed by Richard K. Scotch, School of Social Sciences, University of Texas at Dallas.

While public attention and debate concerning homelessness peaked in the 1980s, during the Reagan Administration, the severity of this social problem is probably greater today than it was two decades ago. The stock of low and moderate priced housing continues to erode across the United States and many other Western nations and many problems associated with poverty remain unaffected by the economic growth of the 1990s. Of particular relevance to DSQ readers is the fact that many homeless people have chronic physical and/or mental conditions that contribute to the complexity of alleviating their homelessness.

*Beside the Golden Door,* the title of which is taken from the Emma Lazarus quotation on the Statue of Liberty that offers refuge to "the homeless and tempest-tost," distills research and policy debates over homelessness into a thoughtful, objective, and generally readable discussion of the many dimensions of this persistent issue. James Wright and his colleagues, sociologists from Tulane University in New Orleans, have been engaged in research on homelessness for many years. In this volume, they address the interaction of poverty, the housing market, and the personal characteristics of homeless people, and critically assess policy positions of both conservatives and homeless advocates in light of available research evidence. The nature and significance of mental illness, substance abuse, poor health, and the breakdown of informal networks of support are analyzed in the context of persistent urban poverty and an urban infrastructure increasingly incompatible with the needs of the poor.

*Beside the Golden Door* has many strengths. It provides a clear discussion of the methodological challenges of answering policy questions about who comprises the homeless population and what the housing market actually offers them. While espousing the view that the fundamental issue of homelessness is the lack of housing, it appropriately weighs the contributions of other social, economic, and personal factors. Although much of the discussion concerns the urban homeless in the United States, attention is also paid to homelessness in the rural U.S., in Europe, and in Central America. Anyone concerned with contemporary social policy and the application of social science to the study of social problems will find this an interesting and useful book.

## Film Clips

Chiten, Laurel (Producer/Director). *Twitch and Shout* [video]. Boston, MA: Fanlight Productions (4196 Washington St., Suite 2, Boston, MA 02131; 1-800/937-4113), 1994, 57 minutes, $275.00 purchase.

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

Perhaps there is something to the visual medium in which photojournalist Lowell Handler earns his living that makes him suited to this project. After my mixed review (in the Summer 2000 issue of DSQ) of his book, I was curious to see this video the production of which takes up a whole chapter in the memoir. The imagistic, MTV jump-cut style of the print memoir never really gave me enough depth or insight into life with Tourette. The documentary is much more powerful.

For one thing, the documentary is not solely about Handler. Not that Handler isn't an interesting subject in and of himself, but the multitude of voices here - from the professional basketball player with Tourette, to the sculptor, to scenes from the bi-annual Touretter's convention is a much wider lens in which to view people who live with Tourette. This is not objectification of disabled people under the proverbial microscope. We see these people at work: Chris, the ballplayer, at practice, his Tourette symptoms integrated with the regular grunts and groans players make; Jim, the sculptor and artist, muttering as he creates; Desiree, the singer, in rehearsal, her Tourette facial tics in full swing. Seeing these people as they are, rather than veiled behind some medical curtain with a psychologist's voiceover, does more to debunk the mysticism of Tourette and constructions of normalcy than many a medical documentary or textbook.

Handler and the others do their share of historicizing and informing. But here it is simply done through a brief voiceover by Handler, or through an interview. The fact that only 15-25% of Touretters possess the particular tic of blurting out racial epitaphs or obscenities is illustrated through a funny, yet poignant, story of a young woman's attempt to suppress the tic as she is standing behind an African American in a purple sweater while waiting in line at a bank. The misinformation about Tourette (many are not diagnosed until their teen or adult years) and the strain on families is shown in a dinner scene at the Handler household, brief comments from his mother, and other stories related here. Tourette and its effects are given real voices and faces throughout. Voyeuristic, perhaps, but such is the nature of the visual medium.

The last quarter of the documentary is devoted to the issue of sexuality and relationships, what author Anne Finger has called "our deepest oppression." Juxtaposed between an interview with a woman expressing her frustration and longing and another woman broaching this subject at a conference panel, are shots of Handler partaking in sexual wisecracking on Donahue and preparing for his own wedding. Ironically, his own marriage would end in divorce a few years later. But, perhaps, that is a great set-up for a sequel.

Chiten, Laurel (Producer/Director). *Twitch and Shout* [video]. Boston, MA: Fanlight Productions (4196 Washington St., Suite 2, Boston MA 02131; 1-800-937-4113), 57 minutes, $275.00 purchase.

Reviewed by Donna Anderson, Masters in Occupational Therapy Student, Lewiston-Auburn College of the University of Southern Maine.

Lowell Handler is a photojournalist with Tourette syndrome (TS). He has spent much time photographing, videotaping, and interviewing other people with TS, and this video is informative, interesting, and, at times, humorous without being voyeuristic because of the perspective of the videographer. It opens with some definitions that clarify the disorder and it proceeds with interviews with several people Handler calls "fellow Touretters." They talk about the difficulties of living with this unusual neurologic condition that has a number of socially-stigmatizing behaviors, including involuntary muscle tics and twitches, vocal outbursts that may be profane, and obsessive - compulsive behaviors.

The interviewees include an actress, a lumberjack, an artist and sculptor, and a professional basketball player. Common themes in the interviews include the taunting and isolation they experienced as children, their frustration in getting accurate diagnoses, and their difficulty in maintaining intimate relationships. It was interesting to see that, even though all of these people have a disability that varies in its impact on their daily lives, the collective attitude is that TS is part of them, but it does not define them. In fact, the artist incorporates his feelings of perpetual energy into his paintings of horses with a vibrance that is awesome and beautiful while the basketball player blends his tics and grunts into his on-court persona of intimidation.

If there is one criticism of this video, it is in the overuse of distorted images as a videographic effect at the beginning of the video. While the blurred images are effective in representing the tics and constant motion, their overuse is a distraction, albeit a minor one.

I would strongly recommend this film to other students to enhance their understanding of TS and I believe it is a valuable educational tool for the public as well.

Devlieger, Patrick J., and Hertz, Miriam F. (Producers). *The Disabling Bullet* [video]. Chicago, IL: The University of Illinois at Chicago, Department of Disability and Human Development (1640 West Roosevelt Rd., Chicago, IL 60608-6904), 1999, 32 minutes, $15.00 purchase.

Reviewed by Charles D. Palmer, Department of Counselor Education and Educational Psychology, Mississippi State University, Mississippi State, MS.

*The Disabling Bullet* presents a brief, but poignant view of the lives of four men who acquired spinal cord injuries (and subsequent paraplegia) as a result of gang-related violence in Chicago. In 32 minutes, each man tells the story of his life before "catching the bullet," what his daily life is like as an ex-gangbanger who is also paraplegic, the actual conditions in which he was shot, and his philosophic view of life that has evolved as a result of "bullet- induced paraplegia."

The target population (no pun intended) for this video appears primarily to be persons who have newly acquired spinal cord injuries that are the result of gang-related violence. The men tell their stories in their own words, often using street language that will be understood by and will establish empathic connections to others who have experienced gang-warfare. They talk of "gangbangin'," getting high, and drinking as daily activities before their injuries with facial expressions that often appear a mixture of nostalgia and tacit acceptance of their current conditions.

As the video unfolds, it becomes apparent that social service and health care professionals may also benefit from the stories the men tell of their rehabilitation, incidents that were perceived as either beneficial or detrimental to their adjustment. For example, one man ("Antoine") talks about how he was not "goin' along with the program" because the health care workers were trying too hard to make him believe they understood "where he was comin' from." It was not until one the workers told him to "quit feelin' sorry for yourself and git your ass to therapy" that a connection was made between this gang member and the health care system. This is probably the most insightful portion of the video beyond the descriptions of life as a gang member.

This video appears to have limited applicability in general rehabilitation or health care settings. It is directed toward those individuals and health care systems that deal directly with gang-related disability. Although it appears an interesting case study, this video does not present new approaches, perspectives, or interventions for adjusting to or coping with spinal cord injury.

Lynch, Tamara (Producer), and Sweeney, Gail (Director). *A Mind of Your Own* [video]. Boston, MA: Fanlight Productions (4196 Washington St., Suite 2, Boston, MA 02131; 1- 800/937-4113), 1999, 37 minutes, $195.00 purchase, $50.00/day rental.

Reviewed by Timothy Lillie, Ph.D., Department of Counseling and Special Education, The University of Akron.

Billed as "warm and inspirational" and focused on "self-esteem" building as the goal for students with specific learning disabilities (SLD), the film seemed to this reviewer to focus on a deficit model of disability. It does try to show that specific learning disabilities are real and that accommodations can help students to achieve success, but the film consistently locates the disability and the ultimate responsibility for the success of any remediation within the student.

Special summer camps (for children with SLD and Attention Deficit Hyperactivity Disorder), self-contained special education classrooms, and help from Grandma are offered as the ways to provide services for students with SLD. Over and over again, students are told (and tell us) that they are able to be part of the typical world simply by working hard (or by taking Ritalin). To be part of this world, they say, sometimes means dealing with failure as part of "their" disability. One student speaks of overcoming or erasing not just the inconveniences, but the disabling condition itself by comparing it to a rock being worn away by his hard work and the help of his grandmother. The reviewer saw no coherent set of school services presented, though these may have existed. The responsibility for using and benefitting from these services is portrayed as being dependent on the attitude and effort of the individual with a disability. We do not see extra time on a test for another student, for instance; instead, he is shown as accepting that his failure on a math test is a sign that he has not worked hard enough. There is no indication that the teachers are involved in any meaningful way in understanding the nature of this disabling condition and learning how to provide accommodations.

Henry, 11 years old, tells us: "All you gotta do is believe in yourself, work hard, and bring home work every day." That, he says, is sufficient to "beat" the disability. Max is sold on his use of Ritalin - he, apparently, received no accommodations (except the drug). He is now convinced that he can overcome everything else with "hard work" and Ritalin. He specifically credits the Ritalin with gaining him friends. Even though people are all different (he tells us), it is, nevertheless, necessary to fit in (to existing conditions). The other students - Stephanie and Matthew - say much the same things and present much the same attitude.

What is most unfortunate about this film is the simple acceptance by the children of what they are being told. They believe that, if only they work hard enough, all will be well and they will be able to be part of the general classroom environment, once they have fixed the problem. The entire responsibility for change is laid on students with disabilities and their families, a position that is unacceptable to this reviewer and one that should not be present in educational settings these days. One student (a girl) who has trouble organizing and remembering is the subject of a mildly amusing (but still somehow disturbing) segment, one that appears to have been staged, in which she is shown as needing constant direction and even unable to remember to take a shopping list along to the store. Here again, the focus is on what she cannot do and how she is different from other children.

Each student, indeed, is shown approvingly as being good at something. This is mentioned several times, in fact. It is not enough, however, to overcome the emphasis on deficits. Those who have seen the Billy Golfus video, *When Billy Broke His Head . . . And Other Tales of Wonder*, (available through Fanlight Productions, 1-800/937-4113, ironically, the same distributor as the film that is the subject of this review) will recall that Billy begins his story with the words: "This ain't your typical inspirational cripple story." Unfortunately, *A Mind of Your Own* seems to be just that.