

Disability Studies Quarterly  
Spring 2001, Volume 21 No. 2  
[www.cds.hawaii.edu](http://www.cds.hawaii.edu)  
Copyright 2001

## **Book, Video, and Film Reviews**

Biesold, Horst. *Crying Hands: Eugenics and Deaf People in Nazi Germany* (Translated by William Sayers). Washington, DC: Gallaudet University Press, 1999, 252 pages, \$39.95 hardcover.

Reviewed by Carol Poore, Brown University.

This important book is a revision of the author's dissertation which was published in Germany in 1988. As a now retired professor and teacher of deaf students, Horst Biesold has connections to the German deaf community and to schools for deaf people that enabled him to carry out his research. Through these personal contacts and by placing notices in various publications that deaf people read, he managed to collect questionnaires from 1215 deaf people who had been forcibly sterilized as "hereditarily unfit" during the Nazi period. He also interviewed a number of these respondents in German Sign Language and speech, and included in his book many of their statements about the painful, long-lasting psychological and physical effects of sterilization.

This is an invaluable case study of what happened to one of the groups of people with disabilities who were singled out for

elimination in the Nazis' Law for the Prevention of Offspring with Hereditary Diseases which went into effect on July 14, 1933. The book begins with a helpful historical introduction by

Henry Friedlander and chapters on the background of Social Darwinism and eugenics. Biesold is particularly concerned with showing how educators in schools and institutions for deaf

people often supported Nazi racial hygiene practices and reported their own pupils for sterilization. He gives a brief history of the Reich Union of the Deaf of Germany (REGEDE) which subsumed all other deaf people's associations after 1933 and was led by deaf men who endorsed the Nazi program of racial hygiene.

He documents how these deaf Germans took the lead in expelling deaf Jews from their organization and he recounts the terrible fate of deaf Jews in the Third Reich. In contrast to

these deaf collaborators, Biesold was able to uncover several instances in which deaf people tried to resist being sterilized or to help others avoid it. He also documents a number of

cases where deaf people were killed in the Nazis' so-called "euthanasia" program.

Much research remains to be done on the history of people with disabilities in the first half of the Twentieth Century in Germany. Such research is especially important given the

brutality of the Nazis' eugenic programs and in view of the seemingly unstoppable trend towards genetic engineering today. *Crying Hands* presents an essential part of the story of one

group of disabled victims in Germany. We now need more research that focuses on the complexities of the lives of disabled people in Germany before and after the Nazi period in order to understand where efforts to resist victimization existed in the past and still exist today.

Brown, Ronald T., ed. *Cognitive Aspects of Chronic Illness in Children*. New York, NY: The Guilford Press, 1999, 432 pages, \$45.00 hardcover.

Reviewed by Rosalind Kopfstein, DSW, Consultant, Danbury, CT.

*Cognitive Aspects of Chronic Illness in Children* is based on extensive research studies and literature reviews that document the problems faced by children with significant illnesses. This book of seventeen chapters was written for faculty, pediatric psychologists, school counselors, and psychology students to familiarize them with the limitations associated with chronic illnesses in children. The writings are based on four major research studies and extensive literature reviews that document cognitive and behavioral problems faced by such children. The underlying question for the reader is: Why do some children adapt well to their conditions while others adapt poorly?

The book is organized into three sections beginning with an overview of illnesses in children involving the assessment and referral processes utilized by professionals. The second section has nine chapters discussing disease-specific conditions. The last section has five chapters presenting general topics such as returning to school and family issues. The language and writing is fairly consistent, readable, informative, and functional for classroom use. However, the perspective does not focus on the resiliency, the adaptive capabilities, the insights, and the strengths displayed by those who have dealt with childhood illnesses. Underlying themes concern behavioral and cognitive dysfunctions and the deficit model. The emotional aspects of surviving and thriving in spite of a chronic illness are not fully explored.

In Section I the authors encourage pediatricians and psychologists to conduct better assessments and referrals for service to help prevent problems faced by children. Reading the chapter on diabetes in children in Section II, I was surprised at the low expectations assumed for children with childhood diabetes and the belief that no diabetic

could ever attain a high level of education or occupational status. Again, the deficit model prevails.

A chapter in Section III on Family Issues highlights the strains experienced by families dealing with the emotional, financial, and medical battles associated with childhood illnesses. The authors seem surprised that families do cope and adapt well in spite of the stressors placed on them. Another chapter on returning to school is constructive for school systems in creating better environments for children with chronic illness.

The text is a helpful and useful baseline of information for specialists. However, additional readings and presentations are

required that focus on the successes and resiliency of children and families facing chronic illness.

Carroll, Cathryn; and Fischer, Catherine Hoffpauir. *Orchid of the Bayou: A Deaf Woman Faces Blindness: The Kitty Fischer Story*. Washington, DC: Gallaudet University Press, 2000, 272 pages, \$24.95 softcover.

Reviewed by Alexa Schriempf, Department of Philosophy, University of Oregon.

An autobiographical narrative of living as a congenitally deaf woman, *The Kitty Fischer Story* is a marvelous account of a life influenced by deafness, an Acadian-Cajun heritage, race, gender, and, ultimately, blindness caused by Usher's Syndrome. Fischer takes us through her life from ambiguous snapshots of her early childhood to more vivid and compelling accounts of her experiences as a nearly-blind deaf adult.

Her deafness was never misdiagnosed; rather, nearly a year after being born, Fischer's grandmother insisted that "there's something not right about that baby" (p. 6). Home-made experiments of banging pots and pans and a trip to the doctor's eventually convinced Fischer's parents that she was "deaf-and-dumb," a misconception that nearly prevented her education. By

sheer happenstance an aunt discovered the Louisiana School for the Deaf and urged that Fischer be enrolled there.

Once her education began the story takes on a much clearer voice and image of the experiences of being deaf in race-segregated Louisiana. Fischer weaves her own narrative with the history of deaf residential schools and differing philosophies of deaf education that continue to plague us today. What is most remarkable about this account is Fischer's tenacity to continue her education through to a graduate degree despite barriers posed by gender and class. She was encouraged by teachers at the Louisiana School to take the test that would admit her to Gallaudet University, a test that she passed with flying colors. Her subsequent enrollment and attendance, however, was precariously marginalized by her feelings of filial duty and gender-influenced expectations of living and working at home. Because she was perceived as "different" she was not raised with the same demands and expectations that an Acadian-Cajun girl ordinarily would have

had. For example, she was not punished for physically abusing her siblings and friends primarily because it was thought that she was not capable of "normal" social behavior.

I would argue that the greatest barrier Fischer faced was the prevailing gender expectation that women in small-town Rayne did not go to college, rather than the barriers posed by deafness. In fact, I would suggest that Fischer's deafness aided her in overcoming gender barriers to her education by providing her with a route by which she did not have to conform to the traditional notions of the female gender.

I have to admit that as an oral, mainstreamed deaf adult, I am not wholly supportive of deaf residential schools for a number of reasons. But, after reading Fischer's story of success, I find myself reconsidering the value of Fischer's message: "When people ask me about educating deaf kids, I admit I am biased in favor of residential schools . . . but when they ask me what deaf kids really need, I don't talk about school at all. They need each other, I say, and enough `each others' to make a group of peers. They also need to know some deaf adults. Even the best hearing people can't help deaf people become successfully Deaf; only other deaf people can do that" (p. 253).

Frank, Gelya. *Venus on Wheels: Two Decades of Dialogue on Disability, Biography, and Being Female in America*. Berkeley, CA: University of California Press, 2000, 300 pages, \$50.00

hardcover, \$19.95 softcover.

Reviewed by Laura Hershey, Denver, CO.

*Venus on Wheels* is an odd, idiosyncratic book that purports to study the disability community almost as if we were an alien culture. And, perhaps, to many people, we are. Gelya Frank is an anthropologist who took a different track than many of her academic contemporaries. Rather than finding a tribe on a remote island to observe and chronicle, Frank found Diane DeVries, a California woman born without arms and legs.

The book chronicles Diane's life, her struggles and her accomplishments. It also describes her personality and her evolving values. But the real subject is the relationship between the two women. Frank probes the shifting emotions and power dynamics that define their decades of interaction - as researcher and research subject, as academic and student, as working professional and recipient of government benefits, as two women who have different kinds of disabilities and whose disabilities have very different meanings.

This book has received very mixed reviews in the disability press. Some reviewers take exception to the idea of a disabled woman's story being told by someone who - although she struggles with mental illness - is essentially outside the disability community. This "nothing about us without us" critique certainly has its merits. However, I found *Venus on Wheels* intriguing for that very reason: Disabled people are frequently written about; but rarely does the writer acknowledge the practical problems and ethical considerations. Frank openly confronts the "well founded" questions that arise in considering her career-long project of documenting Diane DeVries' life, including questions about her own role as the teller of DeVries' story: "There is . . . the matter of

my credibility: Did I understand the experiences of another, someone who is necessarily 'different'? Finally, there is the democratic questioning of expert authority: When and how should I be allowed to speak about Diane? Does my expertise involve appropriation and suppression of her autonomous voice and self-determination?" (p. 122).

Any disabled person who has been the subject of media coverage has experienced what Frank calls "objectification and appropriation" (p. 109). When a writer makes use of another person's life story, as Frank has done with DeVries', one possible outcome is clarity and insight. The other possible outcome, unfortunately more common, is mystification and disempowerment. Frank expresses appreciation for DeVries' patience and trust as the text developed over the decades. "It must have been nerve-racking," Frank writes, "for Diane to wait

and see what I would come up with next" (p. 109).

In documenting DeVries' life over two decades, the two women developed a collaborative relationship that was certainly dynamic, though not always easy. During one particularly troubling phase, Frank presents a paper at an international conference in which she examines several aspects of DeVries' experience. DeVries, however, rejects Frank's conclusions. Frank takes this criticism personally and later retaliates with a deeply insulting and highly disabiliphobic comment about DeVries' love life. At this point in the narrative I found myself resenting not only Frank's attitude, but also her position which gives her access to and the power to interpret or misinterpret DeVries' private feelings and experiences.

However, what ultimately emerges from this work is a portrait - not just of Diane DeVries, but of the culture and times in which she lives and the important historical trends that have empowered her and many other people with disabilities. "Diane's conviction that she can and should be able to make it in the community is a legacy from three sources in American culture," Frank writes. "First, her family maintained an adaptable, 'can-do' approach to Diane's early strivings with her disability. Second, institutions of rehabilitation had the unintended effect of sponsoring Diane's participation in a distinct peer culture of disability as she grew up in the 1950s and 1960s. Finally, since the early 1970s she has been empowered by the burgeoning independent living and disability rights movements" (p. 42).

Hardey, Michael. *The Social Context of Health*. Buckingham, England: Open University Press (Distributed by Taylor & Francis, Inc., 47 Runway Road, Suite G, Levittown, PA 19057-4700; 1-800-821-8312), 1998, 188 pages, \$27.95 softcover.

Reviewed by Stephen French Gilson, Ph.D., Associate Professor, School of Social Work, University of Maine, Orono, ME.

This book presents a thoughtful, reflective analysis of the human body as it is defined by health and sickness. Hardey attends to the social, economic, and political dimensions of health practice that "may be obscured by the faith invested in medical neutrality" (p. 9) encouraging the reader to consider if and how the medical professions

benefit, financially and ideologically, from determining the definition and meaning of health and illness. Hardey's discussion, in Chapter Two, of

multiple dimensions of health and the construction of "illness" should be of particular interest for people with disabilities. We are introduced to the absolutism of the sick role, which delimits illness exclusively to a biomedical definition, to a range of approaches to understanding illness including those championed by the "lay public." Hardey suggests that it is, in part, at this point that medical research begins to open up in terms of definitions of problems, demographics of participants, and general focus.

In Chapter 3 Hardey introduces the reader to a discussion of health, "persistent ill health and disability" (pp. 39-45) although he is unclear about whether these three categories of

health exist on a continuum or are mutually exclusive. Those who exhibit disability are expected to behave, perform, and function in particular ways. Yet, how disability is related to the categories of persistence and chronic disability raises issues that remain vague. For disabled people, Hardey does not specify how to interpret those health conditions or risks that do have associations with the experience of disability, but he indicates that there is a need to avoid defining disability as ill health.

Hardey lays out the journey from health to illness and disability. "While good health is valued, poor health and especially persistent and visible poor health may be feared and hidden" (p. 39). Hardey suggests that, in general, people of "good health" imagine their bodies as healthy and, at least, their immediate daily experiences to be ones in which sickness

would only be a betrayal of what they believe is their body's obligation to them. This obligation includes enabling one to perform daily activities without hesitation or intrusion, to make decisions based completely on self desire and economic capability, to be in sole or primary control of oneself, and to be independent to the degree that one wishes. Goffman (in Hardey) reminds us that "People expect . . . the cripple to be crippled; to be disabled and helpless; to be inferior to themselves, and they will become suspicious and insecure if the cripple falls short of these expectations . . . [the] cripple has to play the part of the cripple" (p. 40). Hardey posits that, as disabled people adopt strategies of full community living, work, and recreation, they must also adopt strategies to assure new social, economic, political, and healthcare identities. This will not be possible with a denial of one's health. It necessitates a changing disability identity that includes an accurate perception of one's health and diagnosis.

For the U.S. North American researcher, theoretician, and/or writer, the second half of the text, though analytically intriguing, may be of less direct relevance or value than Chapters 1 through 3. In Chapters 4, 5, 6, and 7, Hardey details microeconomics, politics, health practices, and policy creation within Britain. In addition to describing British health policies, Hardey provides an intriguing assessment and analysis. It is in this segment that Hardey examines and analyzes reports and studies written by British healthcare decision makers. Examples of the types of reports examined in this section are many issued by the Department of Health and Human Services; specific reports, such as

The Griffiths Report (DHSS, 1983); those by elected governments - Labor and Conservative Parties (Administrations/Governments); and major national surveys, such as the Labour Force Survey. Despite my reservations about the usefulness of data in terms of comparability and about being able to perform cross analysis between U.S. health data and British health data, Hardey's approach to and the nature of his analysis and argument may be quite instructive to U.S. North American Disability Studies scholars. Hardey's framework for the discussion and analysis of race and ethnicity, feminism, career force participation, and class within the context of health and illness may be a model that North American scholars may be interested in applying to a pluralistic approach to studying health, illness, and disability in the U.S.

Hathaway, Katherine Butler. *The Little Locksmith: A Memoir*. New York, NY: The Feminist Press at the City University of New York (The Graduate Center, 365 Fifth Ave., New York, NY 10016), 2000, 270 pages, \$35.00 hardcover, \$14.95 softcover.

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

I have sat here stumped for days trying to write this review. In part, I have been trying absorb the weight of this book - to comprehend both Hathaway's dense, yet luminous, insightful prose, and the political progressiveness of that prose for both disability and feminist scholars.

The other part of me has been trying to figure out a way to convey that progressiveness in a review, trying, as a good reviewer should, to find illustrative sentences, illuminating sections of text, that will give the reader a sense of the larger scope of the book. The second of these tasks, much to the chagrin of the composition instructor in me, has proved to be next to impossible. Not because, mind you, the book is bad; rather, it is that good. So, falling into the trap of friends who are constantly recommending books to me, let me make this imperative: "You have to read this book to see what I'm talking about."

The factual stuff is easy. The book, a memoir of a hunchbacked girl who comes of age and gains independence and marriage before her untimely death (she planned, according to Nancy Mairs's *Afterward*, to pen a companion volume), was published posthumously in 1943 to critical acclaim. Having long been "lost" and out-of-print, *Locksmith* is finally here, rescued and reprinted by the Feminist Press for what, one hopes, will be a long and successive run. Part Jane Austin, part Ibsen's *A Doll's House*, part Virginia Woolf's *A Room of One's Own*, *Locksmith*'s call for independence and selfhood, some thirty years before the rise of the 1970s Feminist Movement, shocks for its assertiveness, its clarity, its progressiveness, its continued relevance to the present.

From a Disability Studies standpoint much shocks here, too. Her insights and struggles around, for instance, the issue of parental guilt and around the issue of what, today, we might call abortion and genetics read as clear and insightful as anything else I have read. But, in order to sense the fullness and the complexity with which she grapples the issues, you need to read Chapter 7 in its entirety (pp. 31-38). To try to pick an illustrative sentence would be doing the book an injustice. You have to read it to see what

I mean. I do not know what I am shocked more by: that Hathaway was writing about these issues -issues those of us doing "the new disability studies" are just now unraveling - in the 1930s or that her insights are still relevant, painfully relevant.

Of course the book falters a bit in this progressiveness. Hathaway spends quite a bit of time throughout the text equating her disability to a lack of beauty and thus, consequently, her unworthiness as a female as both sexual object and subject. The measuring stick for this unworthiness is, of course, heterosexual marriage. Even though she does much to debunk both patriarchal notions of femininity and the stigma surrounding spinsterhood, critics today might bristle at this equation. But, one must remember, she is still someone raised and therefore bound to the conventions of her time even as she tries to free herself from them. Even her insights here, as feminist historiographer, prove enlightening and worthy of study.

Writer Alice Walker has said of finding the writings of one author, "I became aware of my need of Zora Neale Hurston's work some time before I knew her work existed" (Walker, Alice. *In Search of Our Mothers' Gardens*. San Diego, CA: Harcourt Brace Jovanovich, Publishers, 1983, p. 83). Walker found in Hurston both the political agenda of African American women and, in Hurston's prose her use of "Black English Vernacular," the freedom of artistic expression Walker needed as woman and artist. The Disability Community (and this scholar and writer in particular) have been waiting for the writings of Katharine Butler Hathaway. What a pleasure it is to welcome her home.

Lutkenhof, Marlene, ed. *Children with Spina Bifida: A Parent's Guide*. Bethesda, MD: Woodbine House Inc., 1999, 416 pages, \$16.95 softcover.

Reviewed by Patricia Sisco, M.Ed., Past Chair of Canadian Association of Independent Living Centres.

This book was written to be a guide for parents of children with spina bifida. The book actually proves to be an encyclopedia of knowledge that should be used not only by parents, but by any professional working with individuals with this particular debilitating condition. The book covers just about every conceivable topic including a definition of what spina bifida is, the medical problems associated with spina bifida, social implications, educational implications, employment issue, advocacy issues, issues of grieving, services available, and many other useful topics.

At the end of the book there are lists of definitions, a list of literature covering all the topics in the book, and an exhaustive list of organizations that anyone could contact to gain additional assistance or information.

The beauty of this book is that it is written with a brilliant balance expressing the views of consumers and professionals. There are chapters written by a parent who is a professional and one written by a parent who shares her experiences as a parent. The book concludes with a chapter written by a woman who is living with spina bifida. In this chapter she describes her schooling, her employment experiences, and the experience of moving from home. Each chapter ends with a series of quotations by parents. The whole book is written in language understood by all.

Although the book is very comprehensive, it does respond best to parents who have children who are higher functioning intellectually. Although the book does talk about the wide range of disability associated with spina bifida, it does not deal with the issue of institutional care, which, unfortunately, is the only answer for some individuals. The grief that parents feel when the child has such a debilitating condition could have been a chapter in itself. As well, the reader of this book might be left with the feeling that all services are automatically available just for the asking. The fact is that many parents often have to fight very hard for what they know is right for their child. This book would have been stronger if a chapter had been written to give parents some strategies to carry out this battle.

Palmer, Sara; Kriegsman, Kay Harris; and Palmer, Jeffrey B. *Spinal Cord Injury: A Guide for Living*. Baltimore, MD: The Johns Hopkins University Press, 2000, 306 pages, \$42.50 hardcover, \$15.95 softcover.

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

Few people would wish for the opportunity to give *Spinal Cord Injury: A Guide for Living* as a present. However, anyone who has a friend, colleague, or family member confronted by this trauma might find this a useful gift in difficult circumstances.

Is it the perfect guide for people faced with spinal cord injury? No. In the section on readjustment rather than urging people to report violations of the ADA to the Department of Justice or other appropriate agency, the book directs people to their Better Business Bureau! And it is a little discomfiting to see living in a nursing home presented as an option that some people with spinal cord injury may "choose" because attendant care and accessible housing are not available in their community. Suggestions that people explore the availability of Medicaid community-based services - and advocate for their adoption if they are not available - would have made this section somewhat more acceptable.

On the other hand, this book does a very good job of taking someone from the moment of injury, to hospital and rehabilitation, and into adjusting to life and relationships with a disability. It is easy to read and does not use a great deal of jargon in describing the physical and medical aspects of spinal cord injury. Furthermore, it illustrates that spinal cord injury and dysfunction manifest themselves across a wide spectrum of conditions by offering a variety of case histories from people with quadriplegia, to incomplete paraplegia, to those whose spinal cords have been damaged by disease rather than by accident. And, except for some small lapses (see above re the ADA), it offers practical advice on how people with disabilities can advocate for their rights to accessible housing, education, workplaces, and transportation.

Perkinson, Margaret A.; and Braun, Kathryn L., eds. *Teaching Students Geriatric Research*. New York, NY: Haworth Press, Inc., 2000, 103 pages, \$39.95 hardcover, \$24.95 softcover.

Reviewed by Debra Sheets, RN, Ph.D., Assistant Professor, Department of Health Sciences, California State University, Northridge.

This volume, co-published simultaneously in *Physical & Occupational Therapy in Geriatrics*, is an excellent collection of six papers describing two approaches for involving graduate students in the health and allied health disciplines in applied research. The volume is organized into two sections: the apprenticeship model and the partnership model. Each section is followed by articles providing a student perspective on the research process and examples of the completed projects.

The apprenticeship model places students in an established research project with a faculty mentor. Perkinson discusses the theoretical basis for the apprenticeship model and describes the training and research activities of the students. The next two articles examine the experiences of student researchers and describe the learning that occurs when they are engaged in the research process. The articles clearly articulate the wide range of relevant skills that students develop by being involved in research training apprenticeships.

The partnership model engages students in participatory research through a cooperative program involving the university and a community agency. The pedagogical details of this approach, which integrates active learning, problem-based learning, and community service learning to provide students with research training, are discussed. This program provides students with the opportunity to develop and complete a real life, applied research project to address an agency need. Practical and concrete suggestions for developing successful research partnerships are provided. The final two papers in this volume provide examples of student research projects completed under this program.

Applied research skills are increasingly critical for health care professionals who must be able to evaluate interventions and keep up with the growing body of knowledge. Faculty concerned with teaching applied research skills to future health care professionals will benefit from reading this volume. Students will also benefit from learning about the models, seeing the research process applied, and understanding how it relates to their success as clinicians.

Roulstone, Alan. *Enabling Technology: Disabled People, Work and New Technology*. Buckingham, England: Open University Press (Distributed by Taylor & Francis, Inc., 47 Runway Road, Suite G, Levittown, PA 19057-4700; 1-800/821-8312), 1998, 171 pages, \$28.95 softcover.

Reviewed by Lynn Gitlow, Ph.D., ATP, Occupational Therapy Department, Husson College, Bangor, ME.

This text explores how new technology can be used to open the employment environment to people with physical disabilities. The book is based on a research project completed in the United Kingdom in which the author investigated the extent to which new technology is used primarily by white-collar workers and how this new technology has affected the workers.

Part One of the book provides theoretical, historical, technological, and economic foundations for the study. First, various types of barriers, including deficit-based definitions of disability, lack of funding and information, and not listening to people with disabilities regarding new technology, are presented. Then, research already done in the field is critiqued for a one-dimensional deficit model approach. Finally, the author emphasizes the importance of placing new technology within a social context in order to fully understand the impact that it can have in promoting or impeding the inclusion of people with disabilities in the work environment.

Part Two of the book presents the research. The findings reveal valuable information that warrants reading. Some of the most interesting quantitative findings for me supported findings from other studies that most technological adaptations made for workers are neither high priced or high tech - most are mainstream products used by other workers. This is important information for those of us who are in the field of assistive technology and Disability Studies to have when we trying to break down attitudinal barriers to the workplace. The qualitative findings are similarly interesting and informative. The interviews reveal that, even though new technology can reduce the physical demands of a workplace so that an individual can reveal his/her abilities rather than disabilities, attitudes and other disabling barriers are equally as important, if not more so, as technology as it relates to including people with disabilities in work environments.

In the final part of the book the author makes policy and other recommendations based on the findings of his research. I am glad to see that one of Roulstone's recommendations focuses on increasing education for all regarding the potential of new technology given that "One key factor limiting the enabling use of new technology appeared to be the ignorance of the potential of new technology" (p. 141).

The overall concluding message of the book is that in order for people with disabilities to benefit from new technology, a deficit- or needs-based approach to policy and employment developments is not adequate. A social model or barriers approach in which people with disabilities are included must inform and guide practice. I recommend this book to anyone who is interested in understanding the complex factors that surround the potential for new technology to increase participation of people with disabilities in the workplace.

Scarce, Michael. *Smearing the Queer: Medical Bias in the Health Care of Gay Men*. New York, NY: Harrington Park Press, 1999, 219 pages, \$39.95 hardcover, \$17.95 softcover.

Reviewed by Kate Kaul, York University, Toronto, Canada.

Readers interested in Disability Studies will find some of Michael Scarce's claims familiar. He suggests, for example, that "a great deal is at stake in viewing scientific knowledge as culturally constructed knowledge" (p. 11) and he draws on the work of Cindy Patton, Paula Treichler, and others in framing his inquiry into the sexual health care of gay men.

*Smearing the Queer* attempts to re-contextualize gay men's sexual health, suggesting new possibilities for health concerns shared by gay men and straight women, following the example of feminist health movements and treating AIDS and HIV as important concerns that are, nonetheless, only a part of gay men's health issues.

Scarce also puts AIDS discourse into a larger context of representations of gay men and disease. In his essay, "Harbinger of Plague," Scarce demonstrates that in the case of "gay bowel syndrome" gay identity itself (and, often, identification by researchers instead of subjects themselves), rather than any specific practice, was seen to be a cause of disease long before the AIDS crisis. Scarce's approach to gay men's sexual health values and gay male sexuality emphasizes improvements in technology (including the "female" condom and chemical barriers) rather than restrictions in sexual behaviour. Consistently, Scarce considers the opportunities offered by new technologies for sexual pleasure as well as for the prevention of disease.

Scarce himself describes *Smearing the Queer* as "a somewhat interdisciplinary assemblage" (p. 5) that juxtaposes pieces from various genres, including parody and poetry, with more traditional essays. This is not always successful. Scarce's poetry is less effective than his criticism and "Heterocopulative Syndrome," his parody of a homophobic journal article, is heavily referenced with academic footnotes some unnecessarily repeating the material of essays in the book.

Schalock, Robert L. *Outcome-Based Evaluation* (2nd Edition). New York, NY: Kluwer Academic/Plenum Publishers, 2001, 287 pages, \$49.50 hardcover.

Reviewed by Corinne Kirchner, American Foundation for the Blind.

Let us apply outcome-based evaluation (OBE) to Schalock's tome on that topic. A second edition appearing in just six years indicates a successful outcome from the publisher's stakeholder perspective. However, that outcome probably reflects the external environment of enormous interest in OBE rather than "internal validity," meaning the book's ability to achieve its stated objective. Schalock aimed to produce a "user friendly" tool for researchers and also for readers who are "neither program evaluators nor statisticians" (Preface to the 1st edition, on p. vi). From their perspective I doubt that outcome indicators would register positively, at least regarding writing style. The book leans to the pedantic, teeming with classification schemes represented in figures and tables, and each chapter ends with study questions. While graduate students and researchers may value the conceptual distinctions and tolerate the rather abstract nature of examples, that is unlikely for policymakers and other OBE users.

One wonders whether "input" resources were adequate. Poor editing is revealed by extensive repetition and small, but annoying, typos and errors. Notably, I tried several of the web addresses that promised to be a valuable contribution leading to data sources in education, health care, disability, and other social services. Disappointingly, some addresses were wrong and some led only very indirectly to what the text had suggested. (Website accessibility was apparently not Schalock's concern.)

Unfortunately, the heavy style overwhelms a welcome message calling for a non-formalistic approach. Schalock reminds us that programmatic reality is extremely complex and, therefore, OBE researchers and users need a laid-back attitude (my term, not the author's!). He points out that any one study is likely to yield incomplete results; that crucial knowledge of a program's context is gained as much from personal involvement as from formal measures; and that creativity/flexibility is needed, both in conducting research and in providing feedback to program or policy personnel. I recommend Schalock's thought-provoking final chapter, "Future Scenarios."

In summary, for academically-inclined researchers, this book offers a viable reference—an up-to-date structured summary of various strands evolving under the OBE banner. However, my suggested "benchmark" for a user-friendly manual to help researchers navigate an actual OBE venture and to communicate about the research with, say, Board members and program staff of a social service agency, is the United Way of America's *Measuring Program Outcomes: A Practical Approach* (Alexandria, VA: Author, 1996).

Scott, Ronald W. *Legal Aspects of Documenting Patient Care* (2nd Edition). Gaithersburg, MD: Aspen Publishers, Inc., 2000, 237 pages, \$49.00 hardcover.

Reviewed by Charles Goldman, Esq., Washington, DC, author of *The Disability Rights Guide*, and former General Counsel of the United States Architectural and Transportation Barriers Compliance Board.

This book is a book for providers of medical services. It is a "how to avoid malpractice" tome, not a disability rights book.

The author gives many practical examples and provides training materials that service providers, such as rehabilitation therapists, would do well to read and absorb. However, the book is clearly lacking when it comes to the patient side of the equation, particularly when it comes to the disabled person.

There are many scenarios for clinical documentation and patient records in legal proceedings. It is lamentable that nowhere is there any suggestion about making accommodations for a person with a disability. Informed consent for a person with a disability may well mean having the document state it was read to

the person who is vision impaired who was advised of and exercised to her/his satisfaction the opportunity to ask all questions and, then, having the person with the impairment sign the document. It may mean providing a qualified sign language interpreter for a hearing impaired person. However, these concepts are totally missing from the book.

There is no indication that the provider should be aware of laws such as the Americans with Disabilities Act, the Rehabilitation Act, or state/local human/civil rights laws that do have an impact on the provider-disabled patient treatment relationship.

On a most vital issue, DNR (Do Not Resuscitate) Orders, the author would be well advised to caution providers to get clear guidance from their regular attorney. The

issue is one indigenous to state laws which vary as to what is required. This section needs major amplification.

The author clearly knows his materials as the numerous examples attest. It would be nice if a second edition recognized that the patient with a disability has needs that may have an impact on the situation. This is a critical flaw.

Sherwin, Susan; Baylis, Françoise; Bell, Marilynne; DeKoninck, Maria; Downie, Jocelyn; Lippman, Abby; Lock, Margaret; Mitchinson, Wendy; Morgan, Kathryn Pauly; Mosher, Janet; and Parish, Barbara. *The Politics of Women's Health: Exploring Agency and Autonomy*. Philadelphia, PA: Temple University Press, 1998, 331 pages, \$59.95 hardcover, \$19.95 softcover.

Reviewed by Marsha Saxton, Ph.D., World Institute on Disability; Lecturer in Disability Studies, University of California, Berkeley.

Susan Sherwin has written another excellent book about women's health, this time together with a group of Canadian feminist health activists that includes physicians, lawyers, philosophers, social scientists, and genetics and community health experts.

Using the tools of feminist health ethics, the book explores the themes of agency (choice) and autonomy (self-direction) in health care and it addresses the problems arising out of the dominant structures of Western medicine which tends to ignore the role of social conditions and focuses, instead, on the individual as the locus for medical intervention.

The book addresses a range of issues of importance to Disability Studies researchers including medicalization, diversity, genetic screening, and aging. In the spirit of feminist inquiry, the authors include their own personal perspectives sharing insights from their roles as patients in relationship to medical providers.

The chapter that most captured my interest was "The Politics of Health: Geneticization Versus Health Promotion" in which Abby Lippman explores the innovations of the new genetic technologies that are being applied to diagnose, treat, and categorize health conditions previously identified in other ways. The term "geneticization," coined by Lippman, describes the new paradigm of "seeing humans, their strengths, and their frailties, through what has been called a 'genetic prism'" (p. 68). With the recent completion of the human genome map, the pressure is on healthcare systems and practitioners to utilize and validate the new screening technologies.

The new genetics is exemplary of the medicalization that Disability Studies often criticizes as one of the current bases of disability stigmatization: our flawed genes define and explain our difficulties. Locating the problem within our molecular structures exonerates society from responsibility for

justice. Lippman cautions us: "Offering prenatal testing to a woman does more than limit her choices about childbearing (can she refuse it?): It can diminish her well-being, a necessary component of health, during pregnancy. On the collective level, too, it speaks

loudly about the kinds of children we will welcome in society while more subtly transforming procreation from a process of giving life to one of giving genes" (p. 69).

Interestingly, genetic testing and labeling have expanded the populations of people who are discriminated against (in employment and in the private medical insurance system) and, subsequently, protected by disability civil rights legislation in the United States further blurring the distinctions between those who are disabled and those who are nondisabled.

Stenager, Elsebeth; and Stenager, Egon. *Disease, Pain, and Suicidal Behavior*. Binghamton, NY: The Haworth Press, Inc., 1998, 143 pages, \$39.95 hardcover, \$19.95 softcover.

Reviewed by Ravi A. Malhotra, LL.B., M.A., Ottawa, Canada.

In this very brief volume the authors, both physicians at hospitals in Denmark, provide a discussion of methodological problems in past studies of suicide and its relationship to physical and mental disabilities. There are separate chapters on mental disorders, neurological disorders, cancer, other somatic disorders, suicide attempts, and pain. There are also a number of annotated tables summarizing previous studies, often from Scandinavia, and the authors' assessment of their accuracy.

From the perspective of a Disability Studies proponent, this book presents several serious difficulties. First, it clearly is presented entirely within the medical model. Unlike some books that attack the disability rights/empowerment model, such as books arguing against full inclusion of students with intellectual disabilities in educational settings, this text, unfortunately, fails to demonstrate an even dim awareness of the basic principles of the social-political model of disablement. Hence, we are treated to ignorant statements such as the assertion that people with spinal cord injuries are "primarily dependent on the help of other people and have reduced possibilities of education and raising families" (p. 41). Essentially, this book seems completely unaware of a vibrant disability rights movement to secure wheelchair access, better support to permit people with disabilities to become parents, and even the notion that there may be a social and political economy dimension to the problem.

More surprisingly, the text does not seem to succeed even on its own very narrow medical model terms. It has very little direct analysis and it confines itself, mostly, to evaluating previous studies of suicide. While one hardly expects physicians to analyze at length the implications of, say, Durkheim's theories of suicide for Twenty-First Century suicide prevention mechanisms, the almost complete lack of any kind of serious reflection is somewhat disconcerting. Given their medical model paradigm, they do broach the issue as to whether some suicides should be prevented at all. Yet, even here, they fail to take any kind of cogent position. Had they even argued that those with severe somatic conditions would be better off committing suicide, at least one could say that the authors took a stand no matter how much disability rights advocates passionately disagreed with them. Paragraph after paragraph repeating mortality rates from other scholars' studies simply will not do.

Unfortunately, we are left with an excessively brief and poorly conceived work that does little to contribute to the literature on this crucially important question. While the authors correctly draw attention to the increased risk of suicide faced by people with a variety of disabilities, it will have to be left to others to write a more comprehensive, analytical account that addresses the complex issues at stake.

Stiker, Henri-Jacques. *A History of Disability* (Translated by William Sayers). Ann Arbor, MI: The University of Michigan Press, 1999, 261 pages, \$52.50 hardcover, \$19.95 softcover.

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

*A History of Disability* is a translation of the 1997 *Corps infirmes et sociétés* with an excellent foreword by David Mitchell and a helpful translator's note. This edition also includes Stiker's preface to the 1997 edition which is an expanded (but not revised) version of the original publication in 1982. Six chapters, an epilogue, and a short appendix discuss concepts of disability from antiquity through the present.

The title of the book is misleading. The original French title captures the content perfectly. If "History" had to be part of the English title, it should have been "The History of Thought About Disability." This is not a narrative history, but an account of the concept of disability in various societies at various times. Stiker himself, though trained as a historian, made a decision, outlined in his introduction, not to write a traditional history. In fact, in the strongest and most ahistorical chapter, "The Birth of Rehabilitation," Stiker writes: "Readers will have seen that my objective has been to theorize" (p. 183).

Readers should remember that, while foundational, this work is nearly twenty years old. Decisions had to be made in revising the 1982 work for 1997 publication and in making that edition available for a wider, English-speaking audience in 2000. Stiker explains, in the preface to the 1997 edition, that he left the 1982 text unchanged because if he had revised the 1982 edition in light of all of the scholarly literature that had since become available, the book would be unwieldy. (He did, however, update the footnotes to reflect some of the scholarship.)

It is a pity that it took nearly twenty years for an English translation of this key scholarship to become available. Now that we have it, and at a reasonable price in paperback, *A History of Disability* should be read by everyone interested in any aspect of Disability Studies and every library should own a copy. The brilliant conceptualization of disability makes this an indispensable tool in Disability Studies.

Stringer, Ernest T. *Action Research: A Handbook for Practitioners*. Thousand Oaks, CA: Sage Publications, 1996, 170 pages, \$42.00 hardcover, \$18.95 softcover.

Reviewed by Liz DePoy, University of Maine, Orono.

While not the first book to address action research, Stringer has written one of the most important books in this emerging approach to inquiry about humans in their

communities. Stringer goes beyond the notion of participation to elevate research to a social, democratic process driven by a strong ideology.

Stringer introduces action research as a purposive, interpretive process of inquiry, positioned in a community context, which is founded on five principles: empowerment, democracy, equity, liberty, and life enhancement. He then goes on to set a framework for conducting research that is comprised of three elements: looking, thinking, and acting, all of which are conducted interactively in a spiraling fashion, in which all parts of the research process inform all of the other parts. Embedded within this multidimensional ideology Stringer paints action research as a process in which community problems are identified, examined, and systematically addressed.

In concert with emerging "human inquiry" approaches all participants in the research process are equally valued for their roles with the researcher as facilitator. Much time is spent on describing the role of facilitation and how it purportedly differs from the traditional role that the researcher has taken in positivist approaches to systematic inquiry. Moreover, it is critical in community action research to identify the stakeholders in the problem identified and to engage all stakeholders, even in the presence of dissent, in the research process and outcome. Thus, although Stringer notes that this book is an instructional text for practitioners, this reviewer suggests that its strength lies in its detailed and in-depth treatment of the social-political process of research.

The text begins with the advancement of the philosophical, moral, and purposive set of assumptions and principles on which action research is anchored. Stringer then asserts that the reader will find this text to be a "how to" guide for conducting community action research. Looking, Thinking, and Acting provide the sequential framework for the next set of chapters which are intended to walk the reader through the skills necessary to conduct community action research.

Looking, according to Stringer, is the translation of observations of a problem into systematically obtained information. Throughout the looking process thinking occurs in which all of the research participants have an interpretive function. Thinking is, thus, a process in which interpretation of what is derived from "looking" creates joint constructions of what is known. Acting involves the "use" of research to produce social change. Several chapters are devoted to action as a planning and change mechanism that is capable of producing change on micro and macro levels of concern.

Although it might seem that the research process stops with acting, Stringer posits two more steps. First, the research team must evaluate the extent to which and for whom the inquiry produced a desired benefit. Implicit in this step is the critical role of reflection and evaluation in structuring community action research agenda. The second step is celebration which puts closure to discreet parts of community action research.

This small book is not only important in the growing literature on action research, but is classic in its discussion of research as a process of human communication. It does leave the reader with some questions, however. First, although it is described as a skills book, the treatment of skills is insufficient in and of itself to guide practitioners through the research process. It is suggested that any researcher or set of participants seek

additional detail in order to conduct research. Second, research is described in terms of a set of communicative processes, but the substantive products and the distinction between research and other interpretive processes are not clear.

Similar to its lack of specificity in other areas, the book does not make an adequate distinction between action research and evaluation research nor does it convince the reader that the "facilitator" who owns skills will not become the traditional leader in the research process. Thus, the value of this book lies in its ideology, not in its "step by step" approach to conducting and using action research. All who are concerned with social justice and change through the use of democratic systematic inquiry will benefit from reading Stringer's book. The dilemma for the reader, as for Stringer, seems to be in how such a laudable ideology of knowledge generation and use can actually be implemented. We look to Stringer in his next text and to others in the field to transform ideology into action.

Taymans, Juliana M.; West, Lynda L.; and Sullivan, Madeline, eds. *Unlocking Potential: College and Other Choices for People with LD and AD/HD*. Bethesda, MD: Woodbine House, 2000, 400 pages, \$18.95 softcover.

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

*Unlocking Potential: College and Other Choices for People with LD and AD/HD* is based on a 1985 book with the same title, written by Barbara Scheiber and Jeanne Talpers. The contents of this new book are vastly different given the significant developments in our understanding of learning disabilities (LD) and attention deficit/hyperactivity disorder (AD/HD) as well as the legislative changes and organizational developments in colleges, universities, schools, support services, and other options for people with LD and AD/HD.

The transition from high school to postsecondary education and employment is filled with apprehension for everyone. This book guides the reader through that transition with information, suggestions, and strategies to ease the passage for people with LD or AD/HD. It was written to address the informational needs of certain populations: adolescents and young adults who have been diagnosed early and have received special services in school, people not diagnosed until they became adults, and people interested in traditional postsecondary education or in the employment market. I found the emphasis of this book leaning toward the first category of people although there is a wealth of information for all.

There are many answers in this book. Much of the information needed to "unlock the potential" in order to gain a successful, satisfying adult experience is found between these covers. The topics addressed include definitions and theories/causes of LD and AD/HD, relevant legislation (written in understandable terms), the diagnosis process, assessment, making educational choices, and practical strategies for success in school or the workplace (alternatives for learning, time management, organizational skills), to name a few. Some topics are dealt with more heavily than others, but this is not a problem. Each chapter contains a solid reference section for further research. These

sections include lists of books, fact sheets, websites, listservs, and organizations that can offer much more information for the reader.

*Unlocking Potential: College and Other Choices for People with LD and AD/HD* is an easy-to-read book that takes the guesswork and some of the anxiety out of looking into the future. It should be on the shelf of every counselor or coordinator, anyone who works with people with LD or AD/HD.

Unwin, Nigel; Carr, Susan; Leeson, Joyce; and Pless-Mulloli, Tanja. *An Introductory Study Guide to Public Health and Epidemiology*. Buckingham, England: Open University Press (Distributed by Taylor & Francis, Inc., 47 Runway Rd., Suite G, Levittown, PA 19057-4700; 1-800/821-8312), 1997, 160 pages, \$25.95 softcover.

Reviewed by Gerry Hendershot, University Park, Maryland.

Before his death in 2000, Boston University epidemiologist Allan Meyers advocated including Disability Studies in the public health curriculum. Meyers believed that public health workers need to understand central ideas of Disability Studies: that disability is not a health condition, but a social condition; that the best disability policy is universal design, not medical intervention. The dangers of misinformed public health workers are illustrated by the World Health Organization's *World Health 2000* which proposes a system for evaluating health care that assumes the lives of persons with disabilities are less valuable than those of other people.

Readers of this journal will applaud Meyers efforts, but let me challenge them to a reciprocal effort. If public health needs to know about Disability Studies, Disability Studies needs - just as much - to know about public health. To understand and rebut works like *World Health 2000*, the disability community needs disability scholars with training in the basics of public health and epidemiology. This book may be a good place to start. It is suitable for use in courses in Disability Studies either as the text for a course or as the source of readings for a module. As a career health statistician, I can vouch for the soundness of its treatments of epidemiology and public health.

A feature of this textbook is its commitment to participatory learning. Each chapter is organized around: (1) questions the chapter will answer, (2) outcomes the student will be able to do after completing the chapter, (3) exercises students are challenged to work, (4) a summary of issues, and (5) suggested reading.

I found myself participating as I read, a process that often questioned my assumptions (good!). This style puts responsibility on the student and the teacher. Will teacher and student think through the problems in the exercises when they know that the text will soon suggest answers?

Readers beware: the authors are Brits and address a British audience. Because the U.K. has universal health care, parts of the text will be difficult for students in countries with other systems to comprehend. That is not necessarily bad because it presents opportunities to learn about another kind of health care system.

Volkmar, Fred R., ed. *Autism and Pervasive Developmental Disorders*. New York, NY: Cambridge University Press, 1998, 294 pages, \$74.95 hardcover.

Reviewed by Sandra McClennen, Professor Emeritus, Department of Special Education, Eastern Michigan University.

Dr. Volkmar's goal was to provide a summary of current knowledge in the disciplines relevant to autism spectrum disorders from an international perspective (the U.K., Canada, Germany, Australia, and the U.S.A.). Because of publishing schedules, the most recent references are dated 1995. In the fields most familiar to this reviewer, education and psychology, research since then has affected some of the conclusions.

The first chapter addresses diagnosis and definition. A history traces the development of understanding that autism is not "childhood schizophrenia" and is unrelated to schizophrenia in a causal sense. The incidence of schizophrenia among people with autism is about the same as it is in the general population. Changing definitions and relationships of disorders currently considered to be on the autism spectrum are differentiated. There is mention of differentiating psychiatric from neurological conditions, but, unfortunately, there is no detailed discussion of this important topic.

There have been claims recently that the incidence of autism is increasing. The second chapter summarizes epidemiological surveys and concludes that there is no evidence of increase. To the best of my knowledge this conclusion continues to hold, although there is still controversy.

A chapter on psychological factors summarizes research in areas of sensorimotor and perceptual development, motor development, the role of attention, motivation, general intellectual function, academic functioning, "splinter" abilities, memory, social development and behaviour, emotion perception, language, "theory of mind," and executive function.

Authors of the chapter on genetic epidemiology provide evidence that autism is certainly a genetic disorder. Although there is not yet consensus on the mode of transmission, the authors expect it to be determined eventually. The neurobiology chapter presents research supporting genetic transmission and discussing possible paths ending with an explanation of the two major theories. A chapter on psychopharmacology summarizes research on classes of drugs. Many are useful to some, all have deleterious effects on a few. There is no way to predict individual reaction to a given drug nor, even, to a given dose of a given drug. It is a reminder that every use of a psychotropic drug is an experiment on that individual.

A chapter on behavioural and educational approaches recognizes the importance of intensive early intervention coupled with the support of the entire family. This is followed by a very interesting chapter on adult outcomes.

The good news is that admissions to institutions/hospital care have fallen greatly and that, with family and other support systems, those with good communication skills and appropriate education may, with hard work, realize dreams of work, relative

independence, and, most importantly, friends. Others, however, remain in need of support, often 24-hour support, and quality of life is dependent on family or community service systems.

This chapter also discusses the relationship of autism to other disorders and to violence. These authors support the finding that the incidence of schizophrenia among people with an autism spectrum disorder is about the same as it is for the general population. The likelihood of anxiety and depression as secondary disorders, however, is high. About one-third of those with an autism spectrum disorder have epilepsy. And, the incidence of violence is less among people with an autism spectrum disorder than among the general population.

The final chapter, "Autism and the Evolution of Human Social Skills," attempts an "integrated model of the biological basis of human social behaviour" (p. 255). I found it a very interesting chapter, but I will leave it to other readers to decide whether the authors succeeded.

It was disheartening to find that, once again, most of the authors fell into the trap of circular thinking: stating common characteristics of autism, then failing to analyze their impact on the individual with autism and how those characteristics may affect the individual's behavior. They examined the possible causes of those characteristics, but with one exception ignored descriptions by people with autism of what it is like to live with these characteristics.

Weber, Jayne Dixon, ed. *Children with Fragile X Syndrome: A Parents' Guide*. Bethesda MD: Woodbine House, 2000, 472 pages, \$17.95 softcover.

Reviewed by Timothy Lillie Ph.D., Assistant Professor, The University of Akron, Akron, OH.

If I were the parent of a child identified with Fragile X syndrome, I would be in the bookstores at once looking for a book like this. Unfortunately, it is difficult for me to estimate the degree of confidence that one can have in its perspectives on the genetically-determined condition. I am not an expert on the syndrome, which can cause mental retardation, so I cannot comment on the accuracy or value of the information presented.

The tone (friendly, easy to read) of the book recommends it to parents though (since this is an edited book) there may be some unevenness. There are chapters on the Family, Legal Rights and Hurdles, and Advocacy. Information about these topics is always good to see in books directed to parents of children with disabling conditions. There are also walk-throughs of the Individualized Education Plan (and Individualized Family Service Plan) that, while not detailed, will serve to introduce parents to what - to them - is essentially a foreign language and an often poorly understood area of service provision.

The usefulness of this book in the field of Disability Studies is due to a large number of quotations from parents who have the most information about and connection to their children. Listening to people with disabling conditions is a common, even essential aspect of the field. Listening to parents should also be part of the discussion and

training in the field, if only because so many children will grow up in the "special education" system in which parents can, if they like, be very involved. At some point in the process, parents must be encouraged to let go to the extent that their children can make their own decisions. They will not, in this writer's opinion, do so unless they have been convinced, since diagnosis, that professionals and others with disabilities will be as caring for their children as they are. Parents are not interested in the medical model versus the social model unless they are convinced that the social model will not only explain their child's situation, but will lead to better, effective, and reliable service provision.

Whitbeck, Lee B.; and Hoyt, Dan R. *Nowhere To Grow: Homeless and Runaway Adolescents and Their Families*. New York, NY: Aldine De Gruyter, 1999, 228 pages, \$47.95 hardcover, \$23.95 softcover.

Reviewed by Mitchell A. Kaplan, Ph.D., CPSP, Research Project Manager, Project on Pain Management and Chemical Dependency, Institute for Education and Research in Pain and Palliative Care, Beth Israel Medical Center, New York City.

Whitbeck and Hoyt have written a landmark book that provides social service professionals with insight into the many serious psychosocial problems that beset homeless and runaway adolescents and their families. Through in-depth one-on-one interviews with various groups of adolescents, the authors provide readers with a window into the often misunderstood world of young people living in public shelters and on the streets of large urban cities.

The book is divided into three sections containing thirteen chapters. Chapter One gives readers a brief overview of national estimates of homelessness among adolescent populations nationwide from the mid 1970s to the early 1990s. The authors contend that statistical evidence cited in numerous federally-funded studies clearly indicates that the problem of homelessness among troubled youth in this country has reached overwhelming epidemic proportions over the last two decades. Findings clearly show that increasing numbers of adolescents are leaving home to escape family situations that they feel seriously threaten their health and well being. Whitbeck and Hoyt end Chapter One with a discussion of the three developmental stages of what they call "precocious independence" (p. 66) which causes troubled adolescents to break the bonds of parental authority and seek independent control of their lives in the social world.

Chapters Two, Three, and Four describe the development of the Midwest Homeless and Runaway Adolescent Research Project which was sponsored by a three-state consortium of youth outreach social service agencies in the Midwestern United States. In Chapter Two the authors describe the characteristics of the research sample as well as the social scientific methodology the investigators used to collect the data.

In Chapters Three and Four the investigators use case study analysis to examine the disorganized family histories and other destructive life course events that cause troubled adolescents to run away from home. The investigators argue that multiple family transitions, coupled with intergenerational factors such as drug and alcohol abuse, criminal encounters with the law, and parental sexual abuse, serve to break down the

structural bonds of mutual trust and support between troubled adolescents and their parents or other primary caretakers. They further believe that the breakdown of these parental/caretaker bonds at this critically important stage of development represents one of the primary reasons the majority of troubled adolescents wind up homeless on the streets.

Chapter Five takes the discussion a step further through a more in-depth examination of the parent/caretaker relationship from both the adolescent and adult perspective. The investigators found that the groups gave amazingly similar descriptions of their family lives during the course of the study interviews. The oral histories generally included detailed descriptions of high levels of family conflict, disorganization, violence, and substance abuse which were major contributors to the erosion and ultimate breakdown of cohesive ties within the family structure leading to the development of "precocious independence" at which time adolescents develop early dependence on themselves, as opposed to dependence on their parents or other adult caretakers, prior to running away from home. The investigators examined and compared parenting behaviors of runaway and non-runaway adolescents. They also compared the self reports of these two groups of adolescents on measures of parental warmth, support, rejection, and monitoring. Based on these comparisons they concluded that homelessness for adolescent youth is not something that happens overnight; rather, it develops out of the process of family marginalization that occurs when adolescents are forced to take on the responsibilities of adult independence before they are ready.

Chapters Six and Seven examine the social support networks and survival strategies that runaway adolescents utilize once they leave home. The authors posit that, for the majority of runaway and homeless adolescents, peer groups represent the primary source of social support to whom they turn when things get rough after leaving home. The discussion in these two chapters also analyzes the various strategies that runaway adolescents utilize to gain some level of day-to-day subsistence in the social world outside their home environments. These strategies include contacts with public shelters, social service agencies, and health care providers who can help runaway adolescents to get the basic necessities to maintain themselves once they are out in the world on their own.

In Chapters Eight and Nine the authors describe the sexual histories of the runaways and the risky sexual behaviors they use to survive on the streets. Topics discussed include condom use, sexual risk behaviors, HIV, and other sexually transmitted diseases, pregnancy histories, pregnancy outcomes, and various forms of what the authors call "survival sex" (p. 100). The investigators also explore social factors that they believe are predictors of these behaviors among homeless and runaway adolescents living on the street. These include early involvement with peers who abuse drugs and alcohol, close ties with friends involved in sexual activity for money, early sexual victimization by caretakers, concerns about HIV/AIDS risk behaviors associated with early sexual relations with adults, and various forms of criminal, physical, and sexual assault. The investigators strongly believe that each of these factors played a significant role in contributing to life on the streets for the troubled adolescents in the study.

Chapters Ten and Eleven examine developmental consequences of running away from home faced by troubled adolescents. The discussion focuses on the psychosocial factors that play a key role in the internalization and externalization of problems associated with adolescent development. Topics discussed include predictive factors associated with symptoms of clinical depression, posttraumatic stress disorder, delinquent behaviors, and drug and alcohol abuse.

Chapter Twelve brings the discussion of homeless and runaway adolescents full circle by examining the negative developmental effects that originate in dysfunctional families of adolescents who leave home, using a theoretical model of risk amplification developed by the investigators. The theoretical risk amplification model used in the investigation assesses the combined indirect and direct negative effects of early family history and later street experiences on the adolescent's perception of victimization and well being.

Chapter Thirteen rounds out the book with an examination of the future options of runaway and homeless adolescents in the study. In this chapter the investigators seek to identify resiliency factors that will enable some of the troubled adolescents in the study to beat the odds and lead productive lives off the streets in spite of their prior social histories of being runaways. Using both open- and close-ended one-to-one interview techniques, the investigators identified a number of resiliency characteristics and talked candidly with the adolescents about their future plans and the interventions they felt should be used to assist other troubled young people their age who are having similar problems.

In sum, *Nowhere to Grow* by Whitbeck and Hoyt is a landmark book that provides professionals with an excellent understanding of the social world of troubled youth. Research findings are presented to audiences by the investigators in a very clear, concise, and objective manner. I would strongly recommend that this book should be included on the reading lists of professors

who teach graduate level courses that train graduate students for entry into the field of human services. The book would also make an excellent resource for human service professionals who work in community based agencies that provide social services to troubled adolescents and their families.

#### Books for Kids

Rickert, Jane Elizabeth; and McGahan, Pete. *Russ and the Firehouse*. Bethesda, MD: Woodbine House, 2000, 29 pages, \$14.95 hardcover.

Reviewed by Peggy Quinn, University of Texas at Arlington, with assistance from Emma and Clair Daly.

With the story of Russ and his visit to the firehouse, Woodbine House continues its history of offering a variety of books for both adults and children. *Russ and the Firehouse* is a delightful story written for first or second grade readers. The photographs are colorful and clear.

This book is part of a series by Ms. Rickert as she follows her son's developmental progress. In these books her emphasis is on Russ' activities, not on the fact that he happens to have Down syndrome.

In this story, Russ' mom takes him to the Chicago firehouse where his Uncle Jerry works. Throughout the day, Russ follows his uncle and learns about a firefighter's job. Alongside his uncle, Russ helps with tasks such as washing the firehouse dog and, then, the fire engine. Helping to test the fire hydrant and the giant hose seems to be the most fun. At the end of the day his mother picks him up and he says farewell to his friends.

As we, as disability researchers, continue our efforts to assist the general public in recognizing that people with disabilities are People First, this book serves as a delightful mechanism for accomplishing our task. Parents, grandparents, and teachers will enjoy the story and young children will have a great time demonstrating their reading skills. Readers of *Russ and the Firehouse* see a child who has Down syndrome and his participation in activities typical for children his age.

A field test of *Russ and the Firehouse* with Emma, 8 (who has Down syndrome), and Clair, 6, indicated that they enjoyed the book. Clair found it easy to read. Emma thought the colorful pictures were OK, but was not in a reading mood that evening.

This is not a scholarly book. It is a storybook for children and their adults. It is a great demonstration of the social model of disability in terms and concepts that can be understood by people of all ages. Buy it. Share it. Enjoy it.

[< Back to the Table of Contents >](#)