

## Book Reviews

Bruni, Maryanne. *Fine Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals*. Bethesda, MD: Woodbine House, Inc., 1998, 208 pages, \$16.95 softcover.

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

The author's goal is to provide ideas for fine motor development that are both motivating for children with Down syndrome and easy for parents to implement in everyday life. Drawing on her experience as an occupational therapist and as a mother of a child with Down syndrome, she largely succeeds.

In the medical model motor development is measured by the attainment of "milestones." Bruni acknowledges the meanings these hold for parents and therapists; however, rather than focusing on a timetable for achieving such milestones, she is concerned with providing children opportunities for ongoing development no matter how long a developmental stage may last for a particular child. This approach has the effect of normalizing the motor development of a child with Down syndrome, a welcome change from all too many guidebooks.

As a useful metaphor for hand skill development with which to frame the book, the author offers the construction of a house; stability, bilateral coordination, and sensation (terms she defines both abstractly and with concrete examples) are the foundations of the house. These support dexterity which in turn supports daily living skills and school-related skills. As in the construction of a house, the finishing touches may take the longest to complete; in Bruni's model, the process of fine motor skill development, beginning in infancy, continues into adolescence. Because the attainment of each skill is dependent on a series of preceding steps, "developmental assessments or checklists with an able/unable or pass/fail approach will not capture all those stages in between that our children may be in for so long" (p. 9). She advocates, instead, for assessments that are descriptive or that break skills down into levels of independence, a position many parents are likely to support.

I am unable to judge the occupational therapy value of the activities described in the book. However, each activity is designed to fit easily into family life. Activities are organized according to the house construction metaphor and their rationales are clearly explained; most activities are illustrated with photographs. Parents of children with Down syndrome will find the book a valuable and user-friendly resource.

Clark, Marsha, J., Kendrick, Martie, Chamberlain, Linda, Chelsey, Esther, Clement, Stacie, Cummings, Dawn, Henri-MacKenzie, Sue, Labbe, Tonya, MacDonald, Janice, McNally, Dianna, Niles, Nancy, Raymond, Roberta, and Russell, Candice. *Before You Decide: What Families Would Like Policy Makers to Know*. Orono, ME: The Center for Community Inclusion (University of Maine, 5717 Corbett Hall, Orono, ME 04469-5717), 1997, 36 pages, free, softcover.

Reviewed by Nancy Vitalone-Raccaro, Ph.D., Assistant Professor of Special Education at New York Medical College; and Barbara Gibbs Levitz, Parent, Director, The Family Resource Center at Westchester Institute for Human Development.

*Before You Decide* is a monograph that was compiled by a group of families who have children with disabilities and professionals in order to help policy makers understand how legislative decisions affect families. The aim of this project is noteworthy. The intent of the authors was to assist policy makers who may not have experience with disability issues to comprehend what the lives of families are like. Yet, we, as reviewers, have real concerns that the monograph may not have the desired impact. It is also a possibility that policy makers could misconstrue the intended message. There are some very concrete reasons why the booklet may fail to connect with the reader. The elucidation of weaknesses is not intended to discount this project as a whole;

components of the monograph are worthwhile. Furthermore, parents should continue to be supported and to be provided with various opportunities to express their individual perspectives. It is hoped that the comments of these reviewers will provide useful suggestions for future endeavors related to family involvement.

In general, the organization of the booklet is quite appealing. Topically, it is laid out very well. Each chapter - Community Awareness, Child Care, Education, Services, Accessibility, Medical Care, Work, Finances, Transportation, and A Vision for the Future - covers an important life area. The photographs are engaging and the idea of using direct quotes from families is a good one. Each page has a center section of text surrounded by parents' quotes. Unfortunately, the center section does not seem to be in the voice of families and, as such, separates the authors from the parents and sets up an "us and them" situation. For example, on page 8, the text reads, "Current laws support the rights of individuals with disabilities to be an integral part of their communities." The text continues with, "Parents often feel ostracized . . ." and "Many parents are told . . ." Likewise, on page 26, parents are referred to in the statement, "They dream of their children graduating. . . ." The content then becomes someone else telling legislators about families rather than families telling it from their own perspectives. The booklet loses the immediate connection between families and policy makers because someone else is interpreting for families. Policy makers are known to give less credence to professionals speaking on behalf of families, preferring families to speak for themselves. The current format does not present families' perspectives in their own words. The quotes are not enough. The voice of families without professional interpretation should have been maintained throughout the document for optimal impact.

While reading, these reviewers were acutely aware of a pervasive, negative undertone to the monograph. At times, it seemed nothing more than a complaint session. This comment is by no means meant to minimize the difficulties faced by some families. Clearly, life with a child with disabilities poses many challenges. However, this negativism is problematic.

First, it is a real turn off. Policy makers may not get the message because they have focused solely on the complaints. Second, because of the tone it appears that families have not recognized the many contributions that legislation has made in improving the lives of individuals with disabilities. Policy makers have played an important role in the past, although there are still many challenges families face. Third, solutions to the complaints were not offered. The content would have been more effective if both positive and negative quotes were used and if families first presented a situation then provided suggestions for what policy makers could do to help. Specifically outlining what is helpful and what is hurtful is a good way of getting the point across without minimizing a family's negative experiences.

This format was used on page 28 when the authors stipulated "What You Can Do" and "What We Can Do." It is exactly this kind of information that has the greatest potential for affecting positive change for children with disabilities and their families. It would have served well to duplicate this structure in each chapter for each of the life issues.

Doyal, Lesley, Naidoo, Jennie, and Wilton, Tamsin, eds. *AIDS: Setting a Feminist Agenda*. Bristol, PA: Taylor & Francis, 1994, 208 pages, \$24.95 softcover.

Reviewed by Kate Kaul, Social and Political Thought, York University, Toronto, Canada.

This collection apologizes in its introduction for its rather unfortunate moment of emergence during a flurry of publications on the subject of women and AIDS. It locates itself as an attempt to make links between feminism, both as a body of theory and as an activist politics, and the impact of the epidemic of HIV infection on women in Britain. The twelve individual essays describe areas for feminist intervention and activism in response to HIV/AIDS. The book includes contributions on - to name only a few - women and drugs, lesbians, women's mental health, and women's medical issues in the context of AIDS.

Michelle McCarthy's essay "Against All Odds: HIV and Safer Sex Education for Women

with Learning Difficulties” insists on a feminist framework for safer sex education that would include individual sessions with female counselors and would not be limited to HIV prevention. A disability rights framework might also prove useful. For example, McCarthy concludes that women in long-stay hospitals are unlikely to practice safer sex despite AIDS education programs. But the reasons she gives seem to have less to do with women with learning difficulties than with the structure of their institutions: a lack of privacy for sex, the prevalence of unwanted sex, and a lack of ongoing sex education. These conditions can be challenged from a disability rights perspective. McCarthy simply presents them as obstacles to the success of a feminist model.

Some interesting points emerge from the collection. Consistently, safe sex as protection against HIV is located within the larger historical and contemporary contexts of feminist concerns with issues of consent, power, and safety in sexual relationships. The scope of the book (from global issues to local specifics, practical research to occasional applications of theory) leaves it at times more suggestive than informative. This is, in part, because of gaps in available research on women and HIV/AIDS in Britain, gaps that the authors point out in their attempts to outline an agenda for feminist response to HIV/AIDS.

Fuhrer, Marcus J., ed. *Assessing Medical Rehabilitation Practices: The Promise of Outcomes Research*. Baltimore MD: Paul H. Brookes Publishing Co., 1997, 469 pages, \$67.00 hardcover.

Reviewed by Mitchell A. Kaplan, Ph.D., CSRS, CPSP, Program Evaluation Consultant, New York City, NY.

*Assessing Medical Rehabilitation Practices: The Promise of Outcomes Research* by Marcus J. Fuhrer is a thought-provoking, landmark book that makes a significant contribution to our understanding of the role that outcomes research plays in the evaluation of medical rehabilitation programs. The 19 contributors to the book are all well-respected clinical investigators and academicians from the fields of rehabilitation psychology, physical medicine, geriatrics, clinical epidemiology, and biostatistics who work at government and university affiliated rehabilitation research centers that conduct treatment assessment studies to determine the functional outcomes of individuals with disabilities who are participating in various types of medical rehabilitation programs. The book is organized into three main sections.

The first section, which is comprised of Chapters 1 through 8, provides readers with a descriptive overview of the historical underpinnings of outcomes research and its role in treatment evaluation in medical rehabilitation programs. The authors posit that the primary mission of outcomes research in medical rehabilitation is to link treatment outcomes to processes that can improve and evaluate their effectiveness. The authors also focus on some of the methodological concerns of investigators who conduct treatment intervention assessment studies in medical rehabilitation settings. Topics discussed include models of functional assessment, selection of assessment instruments, methodological issues associated with the measurement of individual functional status, and psychosocial and environmental factors that can influence treatment outcome. The authors also review some critical policy implications that have developed in the field of medical rehabilitation service delivery as a result of the application of findings of clinical treatment assessment studies.

Chapter 3 by DeJong is one of the more interesting in the book because it examines the role of values in medical rehabilitation systems. DeJong contends that value perspectives of consumers, payers, and service providers are an integral part of the evaluation of outcome measures in medical rehabilitation because they reflect the myriad of interests of those who have a stake in the system. The author further contends that the value perspectives of different interest groups play a vital role in the way the results of treatment outcomes research are interpreted in the managed care health system of the mid-1990s.

The second section (Chapters 9 through 13) introduces readers to a discussion of some of

the major theoretical frameworks and conceptual models used by investigators to define the measurement parameters of treatment intervention outcome assessment in medical rehabilitation. Topics examined include the World Health Organization model of disability, handicap, and impairment and its role in the classification, conceptualization, and selection of functional assessment outcome measures in medical rehabilitation, functional independence measures, Rasch analysis models, program evaluation and performance index models, uniform data collection and monitoring systems, community integration measures, and quality of life and well-being scales.

The third section (Chapters 14 through 18) provides readers with some specific illustrative examples of how outcomes measurement techniques can be utilized to quantify the functional status of individuals with specific types of disabilities, such as those with central nervous system disorders, cardiovascular conditions, musculoskeletal disorders, developmental dysfunctions, and aging-related disorders.

Chapter 19, entitled "Postscript and Commentary," ties everything in the book together with a summation that reinforces the relevant and important role that outcomes research plays in determining the overall value and effectiveness of clinical intervention strategies in medical rehabilitation programs.

In the opinion of this reviewer, this book is a well-organized text that contains a wealth of technical information that will be of considerable interest to health care planners, policy makers, clinical rehabilitation specialists, and medical sociologists. The statistical information in the book is presented to audiences in a clear, concise, and understandable manner. I would strongly recommend that *Assessing Medical Rehabilitation Practices* be included on the required reading list of clinical rehabilitation educators and social scientists who are developing graduate level courses on health services research, health care planning, program evaluation, medical economics, and policy analysis. The book would also make an excellent resource for clinicians working in community-based medical rehabilitation settings who want to develop a greater understanding of the impact of their treatment intervention services on the lives of persons with disabilities and their families.

Geralis, Elaine, ed. *Children with Cerebral Palsy: A Parents' Guide* (2nd Ed.) Bethesda, MD: Woodbine House, 1998, 496 pages, \$16.95 softcover.

Reviewed by Dona Avery, English Composition Rhetoric Department, Arizona State University.

My yardstick for recalling whether or not a book on my shelves is a useful reference is the number of yellow Post-It notes I have added to pages to mark exceptional information. *Children with Cerebral Palsy: A Parents' Guide* now has so many sticky-tabs extending from its body that it could pass for a porcupine; it is the most important addition to my library in recent memory. Finally, here is a book that informs me of what I *should* have regarded as red flags as my unconventional son grew and developed in spite of my (and the doctors') ignorance. Geralis' book, first printed in 1991, should be purchased in multiples so that pediatricians, physical therapists, educational psychologists, and other service providers will be able to offer some tangible help to parents who have just learned that their child has cerebral palsy.

Thirty years ago, all that was available to us new CP parents was British author Nancy Finnie's volume, *Handling the Young Cerebral Palsied Child at Home*, which one of editor Elaine Geralis' contributing writers calls a classic (p. 102). But where Finnie's book (like many of its successors) seemed to address an audience of therapists, Geralis contributes a work meant for parents and carers of young children with CP. Because it is both basic enough to avoid terrifying bewildered parents and positive enough to encourage readers to want to know more, I concur with the publisher's assertion on the cover that *Children with Cerebral Palsy: A Parents' Guide* is "the first book that families should read." The foreword by Tom Ritter (brother to Jack, the sitcom actor, and son of Tex, the Western singer) gently invites readers on a journey that will change their lives -

and he pulls no punches about how arduous the trip will be. Families must face “a lot of hard work, perseverance, and patience” (p. viii), he writes, but today’s parents have more support than did his own (e.g., through the United Cerebral Palsy Association and equal rights legislation). Ritter admits, in all candor, that “many people still view [CP] in a patronizing way or avoid the disabled person entirely” (p. viii); but, in one move, he has addressed the disability, the family, the community, and mainstream ideology - all of which are central to parents’ concerns as they face the question marks of the future. Somehow, just knowing that someone has played this hand before prepares new parents to “play to win,” as Ritter remembers his father saying to him.

Ritter’s foreword is followed by a personal piece from editor Geralis, mother of a teenage son with cerebral palsy. After each chapter, there are two or three pages of direct quotes from other parents at various stages of their experience with cerebral palsy and their children. Far from being a collection of memoirs and eulogies of the tragedy genre that motivates telethons and TV dramas, however, this book will dry more tears than it evokes and it will stiffen one’s resolve to treat one’s children like persons, as Ritter advocates. It is, as the title claims, a guide, not a group-hug; a resource, not a redemption device. Cerebral palsy does not blame or victimize; it just *is*. And the informed parent can make all the difference in the child’s future.

Nine of the ten chapters are written by people with letters after their names representing professions with which the parents will likely come in contact: M.D.s, M.S.W.s, O.T.s, Ph.D.s, and Ed.D.s. But, unlike many of their local counterparts whom we meet face to face, these professionals seem to “look us in the eyes” and tell us crucial information without suggesting they have all the answers, without burdening us with their projected grief, without referring us to yet another expert on the “team.” Each writer takes time with us, explaining the basics without being condescending.

“What is cerebral palsy?” Dr. Elliot Gersh lays it out for us without expecting us to become medical experts ourselves. Sure, there are treatments and surgeries, possibly, in the future; but Gersh approaches these in a straightforward way clearing the fears of the unknown, preparing us for worst-case scenarios. Social worker Rita Burke is also a CP-mom so we are more receptive to her discussion of adjusting to our child’s condition. The P.T.s and O.T.s (people and tags that most parents never come across) introduce themselves in their chapters and explain what they do and why with a respectful stance towards the contributions and knowledge that the parents will provide as well. The professor, the counselor, and the lawyer offer advice in the areas of their expertise: the value of early intervention, guarding the family life and the parents’ own self-esteem, negotiating our legal rights and hurdles.

The final chapter, “Some Lessons Learned about Advocacy,” is by Fran Smith, a consultant on family support and empowerment, formerly with United Cerebral Palsy as Director of Volunteer Training and Quality Assurance. Smith has two children with CP and argues that parents must learn “how to be effective spokesperson[s] for their child[ren] when services are not readily forthcoming” (p. 378). “You have valuable information about your child,” she reminds us, “that no one else has. . . . You must be ready to participate as an equal partner whenever a decision about your child’s future is to be made” (p. 380). As a rhetorical move, placing this chapter last brings closure to the message with which Ritter began: treat your child as a person with the rights that other people have. Geralis could not have found a better final word for her *Guide*.

Buy the book for someone just beginning parenthood-with-difference. The glossary of medical terms, the reading list, the index to special equipment suppliers and the resource guide at the back of the book will become dog-eared (or Post-It-porcupined) in no time for they form a priceless reference work. But the care and thought that come across in the other 400 pages will nourish and sustain whole families in those early, chaotic years of unconventional parenthood.

Goldstein, Kurt. *The Organism: A Holistic Approach to Biology Derived from Pathological Data in Man*. New York, NY: Zone Books (Distributed by MIT Press, 55 Hayward Street,

Cambridge, MA 02142-1399), 1995, 422 pages, \$26.95 hardcover.

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

In 1934, German neurologist Kurt Goldstein (1878-1965) published *Aufbau des Organismus*. An English translation followed, which has gone in and out of print over the years. Its latest incarnation is courtesy of Zone, publishers of hip theory, and comes with a laudatory foreword by Oliver Sacks who recalls his excitement upon first reading Goldstein in a 1950s edition. All of this augers well for a Goldstein revival, but what does *The Organism* have to do with disability scholars?

Upon first entry into the text, not much. The initial chapters investigate theories of reflexes as Goldstein develops his argument that the organism (human or otherwise - Goldstein rarely departs from his use of this term to designate his subject) cannot be considered a collection of separately functioning parts. Reflex mechanisms are, in theory, the epitome of isolated functions, but in Goldstein's analysis they are revealed as part of a larger, more holistic response to stimuli, with the intensity - and sometimes the presence - of reflexes dependent on a number of factors including environmental ones. Goldstein pursues this argument through many dense pages that would defeat the casual reader (and almost the committed reviewer). However, in the second half of the book he comes to material more readily accessible to scholars in the humanities and social sciences.

Goldstein writes from a place within the medical community of the 1930s, but he is clearly at odds with what we have come to regard as the hegemonic medical model of disability. Instead, locating himself in the tradition of 19th Century British neurologist Hughlings Jackson, he provides a foundation for a critique of the pathologizing of disability and, in so doing, also demonstrates the contingency of this medical model. *The Organism* is, thus, an important document of the history of medical models of disability and it further demonstrates that the medical need not be completely dissociated from the social model even if, in practice, it usually is.

Goldstein's work becomes most explicitly relevant to the disability theorist in Chapter X, "On Norm, Health, and Disease. On Anomaly, Heredity, and Breeding." Here, he argues against attempts to establish a physiological norm based on social statistics or notions of the ideal. Instead, he contends that the individual norm alone is relevant for a biological and holistic understanding of an organism, thus insisting on a clear distinction between disease and anomaly. Disease is something that happens to an individual; anomaly requires reference to "a larger social unit" (p. 343), not only because this provides a social model to define anomaly, but also because, as he insists throughout the book, the milieu of an organism is critical to its ability to thrive. Goldstein's critique anticipates the contemporary distinction between impairment and disability. This position also allows him to attack the eugenics movement of his own day arguing that "we can neither determine nor predict when and where abnormality becomes harmful or, perhaps, extremely valuable for the individual and the community as well" (p. 350).

This work is a difficult read, especially in the early chapters, but it is important for disability scholars as a historical document and because it articulates an alternative, non-pathologizing medical model of disability. Read Chapter X, if nothing else.

Greene, Roberta R., and Watkins, Marie, eds. *Serving Diverse Constituencies: Applying the Ecological Perspective*. Hawthorne, NY: Aldine de Gruyter, 1998, 388 pages, \$53.95 hardcover, \$27.95 softcover.

Reviewed by Patrick J. Devlieger, University of Illinois at Chicago, Department of Disability and Human Development, Chicago, IL.

Intended primarily for social workers, this edited book is written to develop both a diversity approach and an ecological perspective to human service. In fourteen chapters the authors bring these viewpoints to a large variety of social challenges in diverse populations. While the book is theoretically sustained by the ecological perspective, its benefit seems to be that it provides

its reader with a theoretical framework that should facilitate practical applications. Whereas the book provides a positive outlook to many social challenges, its objectives are not to provide a critical analysis or a critique of social ills.

The authors explain that the book is to apply an ecological perspective that “allows for several theories to be brought together to better explain the person-environment connection” (p. 9). Whether the book is successful in going much beyond systems thinking and some of its most early incarnations in functionalist thinking is doubtful. While systems thinking has effectively pointed to the complexity of multi-level impact on behavior, and the ecological incarnation points to the person-in-context, the interconnections of systems and their mutual impact and the role of constituents and stakeholders in planning, decision making, and development, these ideas are not new. More importantly, the criticisms of systems theory, especially its low potential for addressing change, seems to have remained in the ecological approach. Nevertheless, the applications to multiple areas does provide the professional with a broad framework that considers the impact of multiple constituencies.

Disability Studies scholars and advocates may benefit from such a framework. However, because this book is primarily written for professionals, it limits the potential benefits for Disability Studies as an academic field that is currently fully immersed in developing its theoretical and political bases and, to a lesser extent, in translating knowledge for professional practice.

Hareven, Tamara K., ed. *Aging and Generational Relations: Life-Course and Cross-Cultural Perspectives*. Hawthorne, NY: Aldine de Gruyter, 1996, 300 pages, \$29.95 softcover.

Reviewed by Diane Weiner, Staff Research Associate, UCLA American Indian Studies Center.

This volume offers a collection of articles about the changing nature of kinship and its impact on aging. Employing a cross-cultural perspective, the authors analyze intergenerational relations in the United States, Europe as a whole, Italy, Taiwan, Thailand, Sri Lanka, and Japan. The majority of these chapters use quantitative methods to assess the ways changing roles and status influence the distribution and reception of social support. Special attention is given to kin networks, household composition, and the interactions within and between households and residents. Personal and collective (familial, regional, state, and nation) histories provide the framework for these comparative studies.

A main objective of all the authors is to dispel and disrupt national myths about aging and kinship networks. For example, in “Generation in the Middle: Cohort Comparisons in Assistance to Aging Parents in an American Community” by Tamara K. Hareven and Kathleen Adams, the authors examine caretaking patterns during life courses of several generations in Manchester, New Hampshire. This qualitative study reveals that, although values associated with family support were passed between generations, historical, economic, and social factors encouraged diversity in the ability to perform idealized caretaking goals. In “Fathers and Sons in Rural America: Occupational Choice and Intergenerational Ties across the Life Course,” Glen Elder, Jr., Elizabeth B. Robertson, and Rand Conger qualitatively and quantitatively investigate the notion that occupational differences are a reflection of familial ties - continuation of farming among sons represents strong cooperative affective links. We learn that this employment choice is influenced by several factors: economic, educational, psychological, and social issues. And, when older farming fathers become ill and/or disabled, social support offered by sons is shaped by geographic factors and frequency of interactions - not by feelings of intimacy, as might be supposed. Peter Uhlenberg’s study of “Intergenerational Support in Sri Lanka: The Elderly and Their Children” investigates aspects of disability and dependency among a growing population: older people in a country with a relatively young age distribution. The comparison of qualitative and quantitative data as well as information about older and younger people allow the author to undo stereotypes about the religiosity, affect, residence preferences, and interdependence of older Sri Lankans. Such

information and that described by other volume contributors illuminates ways to address similar questions among other populations.

This book is particularly suited to sociologists, anthropologists, gerontologists, health planners, economists, and their upper level graduate students. Many politicians, especially those who espouse to be concerned with Social Security and disability issues, would benefit from this book. However, I am not sure that the overwhelming amount of statistical data and tables would be understandable to all. One should be quite familiar with both qualitative and quantitative analytic methods. For those people who do feel comfortable with such techniques, this book, in whole or in part, provides useful insights about 20th Century situations as a foundation for developing approaches and plans for the 21st Century.

Hollingsworth, J. Rogers, and Hollingsworth, Ellen Jane, eds. *Care of the Chronically and Severely Ill: Comparative Social Policies*. Hawthorne, NY: Aldine de Gruyter, 1994, 240 pages, \$42.95 hardcover, \$21.95 softcover.

Reviewed by Kristine A. Mulhorn, Ph.D., MHSA, University of Michigan-Flint.

*Care of the Chronically and Severely Ill* addresses a significant policy challenge facing the industrialized world. The book describes the development of policies in the U.S. and the U.K. to address care of people who are chronically and severely ill. The three populations included in this group are frail elderly individuals, those who are under 65 and home-bound, and people with serious mental illnesses. As these populations continue to grow, due to demographic and technological changes, both societies have developed policies within two separate social service and health care systems.

The authors present the various types of care available and the problems of coordination and comprehensiveness of care as the need for a more and more diverse array of services increases. For example, Hollingsworth and Hollingsworth highlight the emergence of networks, an alternative form of delivery for disabled people. In this arrangement, coordination of services is made possible through flexibility, innovation, and customization as service organizations integrate the management of resources and develop system-wide standards and budgeting. Hospitals, nursing homes, vocational services, and other social service agencies work closely together to coordinate care often with a central authority monitoring the coordination.

The discussion includes other mechanisms for coordination and comprehensiveness. The editors accomplish their goals of policy earning and policy understanding by addressing the issues of coordination and comprehensiveness in depth. In a series of essays, the authors discuss these challenges to society in the context of several different care options - high technology home care (HTHC), nursing home care, and various services needed for those who are mentally ill.

The depth and specificity of the discussion contribute to the successful analysis of the policy differences in the U.S. and the U.K. The authors consider financing designed to encourage better, lower-cost alternatives to institutionalized care, such as HTHC. Programs such as Medicaid waivers continue to be important mechanisms for trying out such strategies, indicating the currency of the discussion.

The book is a complete, far-reaching coverage of policies through the early 1990s. The volume is highly recommended for students of social policy and public issues related to the care of individuals who are chronically and severely ill.

Lavin, Claire, and Doka, Kenneth J. *Older Adults with Developmental Disabilities*. Amityville, NY: Baywood Publishing Company, Inc., 1999, 160 pages, \$32.00 hardcover.

Reviewed by Dr. Maryam Rahimi, Assistant Professor, Department of Rehabilitation, University of Maryland, Eastern Shore.

Less than three decades ago most older persons with developmental disabilities did not survive into later life. With better treatment, care, and understanding, the numbers of persons with

developmental disabilities are increasing and should continue to do so. In their book, *Older Adults with Developmental Disabilities*, Lavin and Doka aim to concentrate on the unique issues these individuals face.

The book covers a spectrum of topics important to older developmentally disabled people - from how the population is changing, to the social and psychological transitions that accompany the aging process, to the services and policies available to aid them. There is also a guide for families to help them recognize and prepare for the changes in care that will inevitably occur for the individual as the primary caretakers also age. The authors have included extensive information on the resources available for assistance from the government and other sources. Additionally, each chapter contains a section on conclusions and implications to aid the reader and to provide a quick reference point.

Most importantly, the book contains interviews with older adults with developmental disabilities providing a powerful glimpse into their lives and needs as they face old age. Few professionals have had the opportunity to work extensively with these individuals and may not have a full appreciation of the complex combination of social, medical, psychological, and emotional needs. Particular attention is paid to how these needs can be addressed and how they can vary from person to person.

Lavin and Doka contribute valuable insight into the world of the older developmentally disabled person. The broad scope of information in the book is a good resource, both for families and for professionals counseling these individuals. The great need for additional research into this area is obvious after reading this book. For a thorough introduction to the needs of older adults with developmental disabilities, Lavin and Doka's book is an informative and thought-provoking read.

Lorber, Judith. *Gender and the Social Construction of Illness*. Thousand Oaks, CA: Sage Publications, 1997, 148 pages, \$45.00 hardcover, \$17.95 softcover.

Reviewed by June Halper, MSN, RN, CS, ANP, Gimbel MS Center, Consortium of MS Centers.

*Gender and the Social Construction of Illness* is a book that focuses on contemporary health care from a medical sociology perspective. The author provides an overview of illness and its impact on individuals and society and an evaluation of the health care system and its reaction to gender-related issues.

The author begins with an overview of gender and the meaning of illness in the social context. She demonstrates how, once one is ill, treatment might vary based on gender. Her chapter on "Women Get Sicker, but Men Die Quicker" explains the differences in treatment between genders and the resultant social implications. Ms. Lorber then discusses specifics such as gender and the medical encounter, PMS and menopause, and gender and AIDS. She addresses models of care for women versus men, reproductive issues and hormonally-mediated events such as fertility problems and menopause, and the impact of AIDS on men and women. Discrepancies in care and reactions to individuals by gender are described with examples from the literature and from research. The author notes that the doctor-patient relationship is based on medical norms as well as affected by gender, symptoms, and diagnosis - an eye-opening experience for this reviewer. While the chapter on PMS and menopause is very interesting, the final chapter on AIDS is extremely enlightening, both from the patient perspective and from the viewpoint of the health care professional, particularly the nurse.

*Gender and the Social Construction of Illness* is extremely well-written and very interesting cover to cover. It contains an excellent blend of good writing, appropriate resources, relevant models, and sensitive interpretations of human responses to illness and gender. I will find it very relevant in my practice, since two-thirds of my patients who have multiple sclerosis are women and they have had experiences like those contained in this book. This book is recom-

mended to health care professionals.

Michalko, Rod. *The Mystery of the Eye and the Shadow of Blindness*. Toronto, Ontario, and Buffalo, NY: University of Toronto Press, 1998, 189 pages, \$45.00 (U.S./Canada) hardcover, \$17.95 (U.S./Canada) softcover.

Reviewed by Emilie Schmeidler, American Foundation for the Blind, New York, NY.

In this intriguing book, *The Mystery of the Eye and the Shadow of Blindness*, Rod Michalko draws on his own experience as an increasingly blind person and on biography, sociology, and philosophy to address the question: What is blindness and what is its place in the world? He confronts what he sees as the taken-for-granted view of blindness as tragedy and he proclaims the alternative of blindness as teacher.

For sighted people and for many who become blind, seeing is the normal state of affairs. Blindness represents loss: loss of ability, loss of the knowledge brought by seeing, loss of life as they know it. The everyday way of thinking about - and dealing with - blindness has three stages. First is the discovery that something is wrong with normal seeing. This is followed by a diagnosis that the condition cannot be cured. The third and final stage is training in the ways to carry out ordinary activities so that the blind person will be able to fit into the (sighted) world. "The successful blind person is understood as the one who comes to know that the only reality is the one experienced through sight and is the one who acts 'as if' she or he knows this reality intimately" (p. 92).

What is wrong with this picture? For one thing, it judges blindness to be a tragedy - a loss that offers nothing positive - a mere shadow of sight. For another, it trains blind people in techniques for doing ordinary things so that they can be as much like sighted people as possible. The alternative Michalko urges is recognizing that blindness, like sight, has much to teach everyone and that blind people need to live decisively, seeing their lives as narratives and committing themselves to examining and reflecting on life.

After a brief introduction, Chapter 2 poses the question, What is blindness? According to Michalko, sighted people think they are superior *because* they can see and that blindness is defined by lack of sight. To the contrary, he asserts: The meaning of blindness is socially constructed as people, both sighted and blind, act on the basis of what they believe blindness to be. In Chapters 3 and 4 he examines the process of discovery, diagnosis, and rehabilitation and he critiques it.

In Chapters 5 and 6, Michalko explicates blindness as a social fact, created by the ways people think about it and the ways they interact with each other. To do so, he uses "passing" (blind people acting as though they are sighted). Some passing involves deception: As adolescents hide their differences from their peers in order to appear normal, blind people sometimes act as though they are sighted to have others see them as normal. In contrast, passing that does not involve deception displays that the blind person is able to fit into the social world and acknowledges the role of sight. Passing by trying to hide one's blindness leads to self-alienation. Passing that displays social awareness affirms blindness as a life worth living; this is an entree into the examined life.

Both forms of passing require that the blind person be aware of ways that "being sighted" is displayed. They require the blind person to be much more aware of actions and what they convey than a sighted person needs to be. For instance, in public places such as streets people are seen but not noticed and Michalko describes the lengths he had to go through not to attract attention when he needed several cycles of traffic signals to gauge when he could cross a street safely.

Blindness teaches that there is much more than visual images. The eye merely sees. The unthoughtful life, Michalko says, is satisfied with that: Seeing is believing. The "I," however, directs the eye to notice; actions and interactions create meanings. "There are stares and cold stares, glances and penetrating glances, eyes that reveal and eyes that tell nothing, looks that are friendly and warm and looks that kill, and all of these emanate from the side of eyes that goes beyond the

realm of physiological function into the realm of the mysterious" (pp. 90-91).

The examined life understands the importance of meanings rather than mere seeing. Thus, Homer, though blind, was able to make vivid, compelling depictions of scenes he had never seen. What then is blindness? It is not the tragedy it is often seen as being. Rather, it is a teacher of the good life - the value of an examined life - and the meaning of blindness is created and recreated by the way it is lived.

*The Mystery of the Eye and the Shadow of Blindness* is an ambitious effort. Rod Michalko weaves together stories, philosophy, and sociology in a rich, complex argument. The book is stimulating and thought-provoking. At times, however, because he is bringing such diverse strands together, and because parts are so abstract, it is hard to feel solidly grounded.

Mika, Kristine L. *Program Outcome Evaluation: A Step-by-Step Handbook*. Milwaukee, WI: Families International, Inc., 1996, 112 pages, \$13.95 softcover.

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

For several decades, most federally-funded health and human service programs in the United States have been expected to conduct program evaluations that measure the outcomes of their programs. More recently, other funders and stakeholders in health and human service agencies, including state and local government agencies, federated funders of community services such as the United Way, and many private foundations, increasingly have required local agencies to assess the outcomes of the programs they fund. Conducting rigorous outcome evaluations is typically challenging and often threatening for service providers, yet assessing program outcomes is a necessity in the current environment for human services.

This handbook by Kristine L. Mika contains much valuable information on program outcome evaluation and was written for the nonprofessional evaluator who would like to complete an outcome evaluation. It is organized into chapters corresponding to the various stages of the evaluation process and each chapter contains several examples and references for further reading. The book has no particular Disability Studies component, but rather addresses human service programs generically.

Mika, who has extensive experience both in conducting program evaluations in human services and education and in college-level teaching, writes in a clear and thorough manner that would be accessible to agency staff and volunteers without a background in social research. As someone who has provided technical assistance on outcome evaluation, I found the book to be very sensible in balancing the principles of research design with practical considerations.

The major limitation of the book is that, in about a hundred pages, it cannot be comprehensive enough to stand on its own as a guide to aspiring evaluators. There are comparable books on program evaluation that provide far more extensive information on research design. (One classic and recently revised text is Rossi, Freeman, and Lipsey's *Evaluation: A Systematic Approach* published by Sage Publications.) One potential, but omitted, topic of particular interest to *DSQ* readers is the failure to address issues in participatory action research where consumers of service help to shape the research process.

However, as any program evaluator would tell you, an effort should be assessed in terms of what its objectives are. Kristine Mika has succeeded in writing a thoughtful, readable, and useful book. *Program Outcome Evaluation* should be a potentially valuable resource to service providers and to consumers concerned with evaluating the impact of social programs. The book would also be suitable for classroom use in social research or program evaluation courses as a supplemental text.

Mohr, Lawrence B. *Impact Analysis for Program Evaluation* (2nd Ed.). Thousand Oaks, CA: Sage Publications, 1995, 311 pages, \$49.95 hardcover, \$23.95 softcover.

Reviewed by Thomas E. Stripling, Paralyzed Veterans of America, Washington, DC.

Dr. Mohr offers in this second edition a continuing scholarly presentation in all aspects. Not a general review, nor a "how to" guide by any stretch, this is a detailed, mostly academic presentation of theory, pros and cons, for design, execution, and validity of impact analysis within program evaluation. Seemingly, Dr. Mohr does not think casually about the field of impact analysis. His primary tenet is that impact analysis is an illuminating, yet excruciating, effort, often short-handed by analysts and decision-makers misunderstanding the essential problem and outcome for which they are attempting to develop an answer. As presented, this text is not for the novice investigator, the mathematically weak, or the average policy maker. This is a clear, albeit labor intensive, technical presentation of what properly should be called the "scientifically rigorous research pursuit" of impact analysis for program evaluation. The audience should be warned that this presentation is no simple read!

By his own early admission, the field of impact analysis is dynamic and greatly in need of a tested organization as a framework for evaluators to reduce inferences and to arrive more quantitatively at causation. Essentially, the issue is what has happened as a result of a particular program, process, and/or policy. Dr. Mohr contends that quantitative answers do take into consideration deliberate organization, relationships, safeguards, and consistency of effort. This suggestion is heartfelt throughout the text regardless of the absence of any specific actual pronouncement. Dr. Mohr recognizes that the questions facing program evaluation are harder and more complex with each passing public resource debate. Dr. Mohr knows that emerging demands from public and private decision-makers for sophisticated program evaluations that could affect millions of expenditures have cast the field into the unenviable task of being more responsive to stimuli and circumstances than any simplistic  $A+B=C$ .

Dr. Mohr offers a gallery of study designs and discusses each with respect to his theory and experimental models and with numerous references and examples. There is little doubt at the conclusion of the presentation that Dr. Mohr has made an advancing contribution to the field of impact analysis.

The first three chapters introduce the reader to the framework of impact analysis which leads the theory of impact analysis in Chapter 4. The remaining chapters discuss the regression framework, albeit a controversial one, regression-discontinuity design, comparative change design, criterion population design, time series design, and ex post facto design. And, finally, the remaining chapters discuss sub-objectives, qualitative method, and multiple outcomes. Collectively, Dr. Mohr has wrestled with all the central issues of design and has provided evidence regarding strengths, weaknesses, and differences. The careful reader will gain large insights for his/her own impact analysis challenges. This text, however, is not truly a stand-alone reference. The degree of technical detail and the web of underlying science would place this text best in a continuum with an instructor and student dynamics.

This reviewer simply found the text overwhelming on more than one occasion. It is not a text that can be visited periodically to obtain an appreciation of the complete picture. It is a way of testing one's seminal logic in order to process some parts of the discussion. Yet, this reviewer found an elevated respect for the quantitative need that should underlie any evaluative effort as those numbers relate to the process of showing causation. This reviewer recommends Dr. Mohr's presentation as a mentoring text for anyone engaged in program evaluation in general, but impact analysis in particular.

Rumrill, Phillip D., Jr., ed. *Employment Issues and Multiple Sclerosis*. New York, NY: Demos Vermande, 1996, 192 pages, \$29.95 softcover (U.S.), \$38.00 softcover (international).

Reviewed by Nancy R. Mudrick, School of Social Work, Syracuse University.

In the past, many books about employment and chronic conditions, such as MS, would start by discussing how to assess whether someone with that condition should work. *Employment Issues and Multiple Sclerosis* refreshingly assumes that persons with MS desire to work, may need

to work, and are able to work. From the very start, the focus is on how to support and sustain work effort. The types of information and advice offered reflect, as well, an understanding that the factors that affect employment extend beyond the fit between job tasks and physical limitations. Chapters in this book address employment rights and the ADA, the development of job accommodations, the tax code and its relation to work expenses (for employees) and accommodations (for employers), and assessment tools to assist people with MS and human service providers in the development of appropriate employment situations.

While the perspective throughout is one of empowerment and consumer choice, not all chapters appear to be targeted to the same audience. The first chapter presents a clear overview of multiple sclerosis, helpful to someone first encountering MS, but the third-person text of this chapter suggests an audience of new professionals or family members. Chapters 2-4 seem to be aimed at human service professionals. These chapters are focused on job assessment, acquisition, placement, and retention. They offer practical suggestions to providers working with someone with MS. However, they undercut the consumer and empowerment focus by implying a distance between the professional and the client.

Chapters 5 and 6 are clearly aimed at persons with MS. Chapter 5 provides an overview of the Americans with Disabilities Act, with a focus on knowing your rights and how to negotiate accommodation in the workplace. Chapter 6 offers invaluable information on how to use the tax code to facilitate the financing of employment and work accommodations. The final chapter of this slim book nicely summarizes the issues raised in the various chapters and offers ten policy/program/research recommendations. The rationale for each is presented and opposing views to these recommendations noted. Appendices list the names and addresses of a number of resources for employment and accommodation assistance.

This book offers practical assistance in a number of areas - from assessment instruments to the explication of the tax code. However, I found the chapters aimed at consumers more engaging than those aimed at professionals. Although a minor point, the author incorrectly uses the term "unemployed" in the chapter on "Correlates of Unemployment," equating being out of the labor force with being unemployed. This detracts from the overall aim of the chapter. Chapter 3 ends abruptly with a partial hyphenated word, so there is never real closure to this contribution. In general, I found myself struggling to stay focused throughout Chapter 3 where much of the content might be more appropriate in a training manual. Perhaps, because of the shifting perspectives taken in the various chapters, there is something in this book for everyone - people with MS, their family members, their employers, and rehabilitation and human service professionals. This is clearly a post-ADA volume with a focus on work abilities and employment rights. The specific application of these perspectives to the lives of people with MS may facilitate their implementation.

Rupp, Kalman, and Stapleton, David, eds. *Growth in Disability Benefits: Explanations and Policy Implications*. Kalamazoo, MI: W.E. Upjohn Institute for Employment Research, 1998, 451 pages, \$33.00 hardcover, \$23.00 softcover.

Reviewed by Corinne Kirchner, American Foundation for the Blind.

About halfway through this hefty, well-edited compilation of papers and commentary from a 1995 conference sponsored by the Social Security Administration, there is an attention-getting set of quotes; they stem from a survey of local Social Security office managers about the topic at hand - growth in disability benefits. Their views strike either a very refreshing or a very disconcerting note depending on whether you lean toward the quantitative, painstaking econometric analyses that dominate the first half of this book or toward the more qualitative views "from the trenches," as the second half is billed. A sample of the quotes conveys almost audible exasperation:

We were asked to do SSI outreach for many years. When we are asked to do something, we do it, and we do it quite successfully. Why do you now want to

know why there was an increase in applications? [And another...] The increase in disability claims is not a great mystery to those of us in the field offices. Rather, it is a logical outcome of this agency's initiative and goals over the past several years.

If the answer is so self-evidently an intended outcome of a programmatic push, was it really necessary to undertake the diverse body of research over several years that examined factors such as demographic shifts nationally and by state, state economic environments, patterns of applications, awards, continuing disability reviews, and other potential explanatory variables? Certainly, the two approaches came up with different explanations and policy implications.

And, as a researcher, I would defend the research effort precisely because it can uncover what is not self-evident. (But, then again, not everything uncovered is worth the cost!)

Furthermore, this research effort was outrun by events - the dramatic growth in benefits, which in 1992 provoked the research program, had already peaked by the 1995 conference; and other program concerns had emerged when the book's preface was written in 1998. These are, of course, general hazards of policy research and the editors address them convincingly, I believe. The studies reported here achieve, to a greater or lesser extent, longer-run value both by furthering analytic designs, especially the mix of qualitative and quantitative insights, and by raising substantive concerns that will remain relevant to the nation's disability income benefits policy for the foreseeable future. Notably, findings about the younger age and greater extent of mental impairments among new beneficiaries have long-range implications.

For non-economists (such as me), the first half is reasonably easy to follow, and, when the going gets rough, there remains the incentive to read on in order to find the periodic points when we can wag a finger at the economists overlooking some rather obvious non-economic factors. And then, as hinted above, plowing ahead brings many rewards in hearing voices not conventionally brought together within a research orientation. Included in the interesting company, besides the front-line administrators, are people with disabilities who also have become leading voices on the federal policy front. The challenge of the social model of disability to the underlying rationale and aims of the Social Security benefits programs is addressed, although in a rather muted and piecemeal way.

As a final set of merits, the research effort is contextualized in several ways, though each is not developed in depth - historically, internationally, and with reference to separate but indirectly-related policy efforts, notably welfare reform. In sum, this book is still timely and should have staying power as a useful reference enhanced by diverse bibliographic references in most chapters and a reasonably detailed index.

Scherer, Marcia J. *Living in the State of Stuck: How Technology Impacts the Lives of People with Disabilities* (2nd Ed.). Cambridge, MA: Brookline Books, 1996, 181 pages, \$17.95 softcover.

Mary Anne Moisan, MS, OTR/L, PT, Assistant Professor of Occupational Therapy, Lewiston-Auburn College of the University of Southern Maine.

*Living in the State of Stuck: How Technology Impacts the Lives of People with Disabilities* should be read by anyone who is seeking to gain understanding and the perspective of people living with disabilities. In spite of the subtitle, this book goes well beyond a discussion of technology. This second edition, based on research by the author Marcia Scherer, provides insightful narratives of people with disabilities allowing the reader to be part of the context of these people's lives and to understand the wide ramifications of sometimes simple technology. Scherer is true to a major theme evident throughout the book: One must consider the issues of technology within the context of people's lives - individual people with unique life experiences and contexts. In this spirit, Scherer strongly imbeds the discussion of technology in broader social, cultural, and

political contexts, allowing the reader to understand the issues in greater layers of complexity.

There is a thoroughness of the information provided in this book that makes it suitable for consumers, professionals, and even students who are just beginning to explore the impact of technology. In the beginning chapters the reader is introduced to individual people with disabilities. In addition to these personal narratives, basic information about their disabilities is presented complete with figures and summary tables. Scherer chose just two disabilities on which to focus: spinal cord injury and cerebral palsy. In doing so, she is able to compare and contrast the different issues of individuals who acquire their disabilities as adults versus those who are born with their disabilities.

Basic information continues with chapters discussing definitions and examples of technology (both low tech and high tech) as well as a brief history of societal and political forces that have shaped our current views and legislation regarding technology.

Following this, a more in-depth look at the individuals presented in the early chapters is provided, outlining their stories of the impact technology had on their lives. Scherer carefully identifies and integrates contextual issues surrounding the individual stories: rehabilitation success and issues of coping, quality of life, life experiences as a person with a disability (PWD Experience), and independent living programs and associated values, to name a few. Toward the end of the book, more specific information is provided regarding factors to consider when matching persons with assistive technology. The book concludes by presenting the ongoing issues for the individuals in the book.

This book is a must-read for all professionals who work with individuals with disabilities especially those who are in positions to recommend and/or prescribe technology. Scherer's comprehensive perspective is particularly important for individuals who work with the physical aspects of people's disabilities within a medical model of service delivery. Scherer helps us to understand that what may seem best for an individual from a rehabilitation perspective may not be the best from a more holistic life perspective.

Van Dijk, Teun A., ed. *Discourse as Structure and Process*. Thousand Oaks, CA: Sage Publications, 1997, 356 pages, \$75.00 hardcover, \$28.95 softcover.

Reviewed by James F. Gilsinan, Saint Louis University.

This book will not appeal to the disability rights activist because it is highly theoretical. It will not appeal to academic researchers interested in disability issues, particularly those trained in the medical and natural sciences, because the subject matter is anchored more in the humanities than in traditional, quantitative science. It may not even appeal to certain scholars in history or the social sciences because of the unfamiliar terms used in the text. Terms like "semiotics," "ethnomethodology," and "illocutinary act" may deter even those wanting to move beyond their narrow field of interest. Even the most adventuresome will be hesitant to pick up this volume when they realize that this is simply the first in a two-volume set detailing the sometimes esoteric debates within the field of discourse analysis. Nevertheless, this collection of articles describing the field of discourse analysis and its many variations can be an essential tool for those interested in both the theoretical and the practical potential of Disability Studies.

Disability Studies, like many cross disciplinary endeavors, lacks a clear, coherent intellectual character. Rather its theory, methods, and problems are those of whatever discipline the researcher happens to espouse. The tent is so big that people who hold totally opposite views of disabilities can lay claim to its cover. The tensions between the medical model and the empowerment model when approaching the subject matter illustrate the point. While this state of affairs is not unusual in a fledgling discipline, it may be time to begin the serious work of constructing a common paradigm for the enterprise. This book, which describes the study of discourse, provides one map toward this goal.

Since the editor and the various contributors need two volumes to answer the question,

“What is discourse,” this short review will have to oversimplify an extremely complex phenomenon in order to illustrate both the theory and the practice of discourse studies. Discourse is how people talk, write, and convey meaning through a variety of linguistic, physical, and symbolic representations. It includes not only how sounds, words, and sentences are structured, but the rules used in conversation for exchanging meaning. It includes the study of signs in the sense of understanding how certain physical representations convey meaning. In short, the many ways people communicate through spoken language, writing, or physical representations (pictures, films, built structures) are encompassed by the study of discourse. These can all be seen as texts, phenomenon to be read in order to discover how people structure their reality and the values they wish to convey or uphold.

The relevance of discourse analysis for Disability Studies should be apparent. Members of the disability community have often been victims of the use and control of language and symbols by others. Understanding how language is constructed and used can liberate an individual from definitions of self that are debilitating rather than uplifting. And, as many activists have known, the built environment is often a text that conveys the message of exclusion. Thus, exposure to at least some of the techniques of discourse studies can have practical application as seemingly benign or neutral symbols are shown to be sources of unexamined and, therefore, unchallenged discriminatory practices. Finally, discourse analysis provides a way for the many disparate disciplines that contribute to Disability Studies to draw from a common research frame. This can include the physical and biological sciences around questions of the physical production of sound and language, the social sciences which link linguistic and symbolic meaning to the structural and value dimensions of society, and the humanities which can articulate how grammatical and literary conventions convey both intended and unintended meaning.

Van Dyck, Jose. *Manufacturing Babies and Public Consent: Debating the New Reproductive Technologies*. New York, NY: New York University Press, 1995, 248 pages, \$18.50 softcover.

Reviewed by Ravi A. Malhotra, LL.B.; and M.A. Candidate, Norman Paterson School of International Affairs, Carleton University, Ottawa, Canada.

Few health topics in the last decade have been as controversial as the cluster of issues commonly discussed under the label of new reproductive technologies. Hence, Jose Van Dyck's recent contribution is a welcome and articulate introduction that intelligently outlines the various perspectives in this often complex field. The issues examined in the book range from general concern over the implications of in vitro fertilization (IVF) to feminist assessments of new reproductive technologies to more specific problems such as the ethics of postmenopausal pregnancies and transracial impregnation. Van Dyck competently engages these difficult subjects in a clear, interesting, and non-technical manner throughout the text taking examples from both the United States and Britain. Moreover, the work transcends rigid disciplinary boundaries by including analysis of the portrayal of new reproductive technologies in contemporary science fiction. Indeed, Van Dyck makes a convincing argument regarding the importance of the interaction between science and culture.

Throughout the book, Van Dyck utilizes a discursive analysis to examine how various media, including mainstream newspapers, technical scientific publications, and feminist journals, portrayed and framed the issues relating to new reproductive technologies. This is especially effective in her discussion of the case of Anna Johnson, an African American vocational nurse who agreed to carry the fetus created in vitro from the egg and the sperm of her white friends. During the pregnancy, however, Johnson changed her mind and filed a lawsuit to gain custody of the child. Van Dyck brilliantly outlines the racial and gender implications of the case and how the media was biased against Johnson. Her account of the complex disagreements among feminists is also valuable.

Nevertheless, Van Dyck's work leaves a lot to be desired. First, the complete absence of discussion of the implications of IVF for people with disabilities is glaring. While this book was clearly never intended as a Disability Studies project, the potential impact that new reproductive technologies may have on people with disabilities, from possibly discriminatory practices with respect to access to fertility treatment to the expanded use of eugenic abortion, is so significant that the absence of any commentary whatsoever undermines the work. This is particularly frustrating because Van Dyck herself is so conscientious in examining racial and gender bias in new reproductive technologies. Moreover, it might have been insightful for Van Dyck's own project to consider whether infertility itself is a disability and, if so, what the social-political model of disability might suggest about problems faced by women and men with infertility.

More fundamentally, however, the theoretical framework of the book, using discourse analysis of a number of media, often gets in the way of the analysis that Van Dyck is trying to make. While a certain amount of postmodern jargon is par for the course in much of contemporary social science, the Foucauldian framework in Van Dyck's work sometimes appears to be an unnecessary diversion that distracts from her substantive points. Although the emphasis on discourse analysis is hardly surprising, given Van Dyck's own background as a journalism professor it seems at times as if analysis is forced to fit a pre-conceived model that must always return to discourse and postmodern concepts of cultural studies. For a solid and well-written commentary of media and fictional discourses of new reproductive technologies, Van Dyck's book is worthwhile. Disability Studies scholars and activists, however, must await another book on new reproductive technologies that incorporates their voices, issues, and struggles.

Vaz, Kim Marie, ed. *Oral Narrative Research with Black Women*. Thousand Oaks, CA: Sage Publications, 1997, 272 pages, \$19.95 softcover.

Reviewed by Christine A. Loveland, Ph.D., Professor of Anthropology, Shippensburg University, Shippensburg, PA.

Although very little in this edited volume directly addresses issues related to disability or chronic illness, its detailed and varied presentation of the value and mechanics of oral narrative research makes it potentially useful to researchers in the field of Disability Studies. In addition, its comparative focus on Africana (African and African American) women is unusual and often enlightening.

The book is organized into four major sections. Part I is titled "Ancestor Mothers" and contains two chapters that are part autobiography and part literature review. Part II has material of interest to almost anyone who uses qualitative research methods. For example, Chapter 6 includes a guide to the collection of oral histories, suggested methods for teaching students how to obtain oral histories, and even sample interview questions. Christine Obbo, the author of Chapter 4, makes an excellent point about the difficulty of participant observation research when she notes that "deep immersion in a different African society can produce culture shock in an African, as it does in a foreigner. An educated African, by virtue of missionary education and exposure to foreign theories, and often lifestyles that are different from those of the ordinary people, may not find it so easy to do participant observation" (pp. 47-48). Her discussion adds another dimension to a book that stresses the positive value of membership in the study group (in this case, African women).

Part III, "Health and Well-Being," is of the most obvious interest to researchers in Disability Studies. It includes chapters on sexual behavior and HIV infection, obesity, and health problems of older African American women. The last section of the book, Part IV, "Research Processes: Negotiating Institutions," has detailed material on the mechanics of qualitative research. Chapter 13, "Social Conformity and Social Resistance" by Kim Marie Vaz, includes a thought-provoking discussion of the reflectivity that is basic to oral narrative research.

This book would be useful in courses on qualitative research, Women's Studies, Ethnic Studies, and/or African(a) Studies. It would not be as obviously appropriate for courses in medical

anthropology or Disability Studies.

I am a cultural anthropologist, and I would like to add one other observation. Currently, there is considerable debate within anthropology about the utility of the concept of "race." The American Anthropological Association has adopted a "no-biological-race" premise; that is, there is no scientific validity or basis to the categorization of people into racial groups. This book is a reminder that the concept of race is a crucially important one for many researchers; inclusion in this volume was dependent on each contributor's gender and race. This demonstrates the power of race as a socio-cultural construct in the formulation and execution of research projects and it is one of the ways in which I found this to be a thought-provoking book.

## Books for Kids

Kent, Deborah, and Quinlan, Kathryn A. *Extraordinary People with Disabilities*. New York, NY: Children's Press, a Division of Grolier Publishing, 1996, 288 pages, \$16.95 (U.S.) softcover, \$22.95 (Canada) softcover.

Reviewed by Adele Gorelick, Washington, DC.

Vi ar en resurs i samhället! reads the poster from Sweden hanging in the offices of the Administration on Developmental Disabilities where I work. . . . "We are a resource in society!"

This might well be the subtitle for *Extraordinary People with Disabilities*, a book in a series published by Children's Press, a division of Grolier Publishing. Other books are *Extraordinary American Indians*, *Extraordinary Asian Pacific Americans*, *Extraordinary Hispanic Americans*, *Extraordinary Women Scientists*, and *Extraordinary Young People*.

The 60-80 stories in each book of "struggle, achievement, victory, and, sometimes, loss" (back cover), interspersed with short background articles, might be considered corny - too much courage and good news - but these are reference books for the middle school or high school library and they represent a repository of information on both well-known stars - Helen Keller, FDR, Harold Russell, Frida Kahlo, Stephen Hawking, Itzhak Perlman, and Stevie Wonder, to name a few - and the not so world famous - Horace Pippin, Alicia Alonso, Beverly Butler, Wilma Mankiller, Temple Grandin, Harilyn Rousso, and Jim Abbott. As Judy Heumann, Assistant Secretary of Education, says in the introduction, "It's time for us to celebrate the leaders among us, the people who have made an incredible difference in the world" (p. 10).

Readers need to know these people. We need to try to ignore wording like "Frida's right leg was withered and very weak" (p. 68) or "He [Hawking] began to realize he needed a healthy mind to be a scientist, but not necessarily a healthy body" (p. 147). (People with disabilities can have healthy bodies!) And ideas like "Most of them [people with disabilities] spend their lives trying to break down society's stereotypes about who they are" (p. 9) (really!) or "By the early 1970s, disabled people were busy changing the laws in California, New York, and other states" (p. 86). (I see a speeded-up movie of little ants on little yellow Amigos.)

Cartoonist-activist John Callahan is described as "a quadriplegic" (p. 197) - we label jars, not people - but, truly, there are some wonderful things about this book, too. There are some excellent quotes, such as the following. John Hockenberry, journalist [to the people who stared]: "I was getting by in dealing with my predicament. To them, I was standing on a ledge and not jumping off. To me, I was climbing up to get a better view" (p. 212). Jean Driscoll, athlete: "It used to be that stories about disabled athletes only turned up in the human interest pages. Now we're getting onto the sports pages where we belong" (p. 241). Ed Roberts, disability rights activist: "Get political or die, or go to a nursing home. If you're not part of the political process, people will be talking for you" (p. 130). Temple Grandin, livestock-handling equipment designer: "If the genes that cause . . . [autism] were eliminated, there might be a terrible price to pay. . . . It is possible that persons with bits of these traits are more creative, or possibly even geniuses" (p. 185).

Someone did an excellent job of finding photographs and people to whom to introduce

us - Susan Nussbaum, actor-playwright; Wilma Mankiller, principal chief of the Cherokee Nation; Henry Hisor, journalist; John Langston Gwaltney, anthropologist; and Jacobus tenBroek, educator-activist - as well as telling us more about baseball's Bill Veeck; photographer Dorothea Lange; Harriet Tubman, rescuer of slaves; and poet Audre Lorde.

But the very best thing, despite the weaknesses mentioned above, is that authors Deborah Kent and Kathryn A. Quinlan have dealt head on with some tough issues: shame, low expectations, low self-esteem, denial, deception, mental illness.

Kent, a social worker and writer who draws on her experiences as a blind student, and Quinlan, who works in marketing and communications and who was once a personal-care attendant, have not avoided some controversial subjects - Jerry's Kids, Baby Doe, assisted suicide, ADAPT, mainstreaming, cochlear implants, the economics of "community burdens." They have done a good job of explaining all points of view. My only wish is that they had made more explicit the idea that "We are a resource in society!"

Stuve-Bodeen, Stephanie. *We'll Paint the Octopus Red*. Bethesda, MD: Woodbine House, 1998, 28 pages, \$14.95 hardcover.

Reviewed by Peggy Quinn, BSW Program Director, University of Texas, Arlington, TX.

This delightful book is designed to assist parents and other family members in answering the questions and concerns of children who are 3 to 6 years old and have a sibling who has Down syndrome. Given the designated audience, the book accomplishes its goals gently and accurately.

The story describes a child's adjustment to the notion of a sibling and then the further adjustment when she learns the baby has Down syndrome. It is not clear whether the author and illustrator know about the social model of disability, but they definitely demonstrate it in the book. As the older sibling assesses what her new brother can do, she decides that he will be able to do everything she had planned. He just may be a bit slower.

This is one in a series of very helpful books published by Woodbine House and directed toward parents and families of children with Down syndrome. Other titles I have found helpful are *Communication Skills in Children with Down Syndrome: A Guide for Parents*, and *Babies with Down Syndrome: A New Parents' Guide*. In each book, information is provided in a readable, usable form. It is accurate and positive.

For professionals working with families of children with Down syndrome, *We'll Paint the Octopus Red* and the other Woodbine Books can serve as an excellent resource base.

## Video Clips

Grable, Gillian (Executive Producer), and Reedus, Narcel G. (Writer/Director/Producer). *Waddie Welcome: A Man Who Cannot Be Denied* [video]. Athens, GA: Program Development Associates (5620 Business Ave., Suite B, Cicero, NY 13039; 1-800-543-2119), 1997, 26 minutes, open-captioned, \$89.00 purchase.

Reviewed by Rosalind Kopfstein, DSW, Rhode Island College School of Social Work, Providence, RI.

*Waddie Welcome* tells the story of an 83-year old man with cerebral palsy who lived in a nursing home due simply to the fact that he requires a lot of personal care. Waddie had lived at home until all of his caretakers died. At the opening of the video we first hear about Waddie from others - good people who care about him - but Waddie is not seen or heard. As the video unfolds, the viewer understands more about what is presented and why person-centered planning and the Circle of Friends concept is so valuable.

This video describes the processes of guardianship, advocacy, person-centered planning, and personal choices of an individual unable to advocate for himself without the assistance of others. Waddie's legal guardian describes him as a person who cannot verbally communicate.

However, Waddie is very capable of communicating once the advocates learn how to listen effectively. We learn about the virtues of the advocates, the guardians, family friends, a Georgia State Representative, and the church-based Circle of Friends.

In the middle of the video we hear about Waddie's dream of living with a Black family with children in his native Savannah. We learn that Waddie can reach his dream only through the efforts of many others to secure Medicaid waiver funding essential to support his move from the nursing home into a family home. The painstaking process of advocacy and choice highlights both the personal commitment of the people around him and the formal systems required to move Waddie from an institutional setting to a community-based one. The video also explains how the guardians worked with Waddie during one of his hospital stays. The advocates ensured that Waddie's preferences regarding his medical care were communicated clearly.

This video provides testimonials about each of the advocates and does over extol the virtues of the members of the Circle of Friends. "Blessed are the Peacemakers" is the tag-line. However, the one advocate who uses a wheelchair does sound the most authentic because she could relate to Waddie's fate. This advocate almost ended up in a nursing home herself simply because of her chair.

Providing a brief introduction to this video would help focus the viewer's understanding of what is happening to Waddie as we travel down his path to a regular life in the community. This video is fine for a limited audience of potential Circle of Friends volunteers, for recruiting community advocates, or for students unfamiliar with deinstitutionalization processes. However, the church-based orientation may be inappropriate for some audiences. Its limited depth makes it less valuable for professional trainings.

The video closes with this quote (source unknown): "Never doubt that a small group of thoughtful committed persons can change the world. Indeed it is the only thing that can." *Waddie Welcome* shows us that disability advocates who clearly focus on individual choices can help many reach their dreams.

Grable, Gillian (Executive Producer), and Reedus, Narcel G. (Writer/Director/Producer). *Waddie Welcome: A Man Who Cannot Be Denied* [video]. Cicero, NY: Program Development Associates (5620 Business Ave., Suite B, Cicero, NY 13039; 1-800-543-2119), 1997, 26 minutes, \$89.00 purchase.

Reviewed by Crae Akerson, Student, Masters in Occupational Therapy Program, Lewiston-Auburn College of the University of Southern Maine.

This is a rather dry, but good, documentary about a man named Waddie Welcome and a Citizen Advocacy Group from Savannah, Georgia, who helped Waddie obtain his freedom. Waddie was born with cerebral palsy on July 14th in 1914. He lived with the love and security of his family and friends for over 60 years. Then, after the death of his last brother, Waddie was put in a nursing home 30 miles away from his home, church, and friends. He was miserable and begged everyone who came to see him to take him home. Through the use of still pictures, a narrator, and some moving footage, we learn about how a circle of friends fought to get Waddie out of an institution and into a loving home.

"To institutionalize people who have a disability is like locking them up in jail, and they have committed no crime" (Debbie Selman, disability rights activist, who is in Waddie's circle of friends). Waddie was beaten, molested, and robbed at the nursing home and he was not able to defend himself because of his inability to communicate. Over a period of two years a circle of friends (some long time, but some who had just met Waddie) remained persistent, made unending phone calls, found financial support, and helped Waddie to realize his dream.

This film makes the viewer very aware of the atrocities that can occur in institutions. This kind of an existence is dehumanizing and yet many who are developmentally disabled do not have a choice. There are almost 5,000 people with developmental disabilities living in nursing

homes and other institutions in Georgia alone. All human beings deserve the right to live in a home with love and friends.

Grundmann, Mike. *Face First* [video]. Boston, MA: Fanlight Productions (4196 Washington Street, Suite 2, Boston, MA 02131; 1-800/937-4113), 1998, 29 minutes, \$195.00 purchase, \$50.00 rental/day.

Reviewed by William Sayers, Willard, NY.

This is a then-and-now short documentary about people with facial anomalies that routinely qualify as disfigurement among their regularly-featured fellows. It has no cinematic merit, consisting simply of talking heads (parents and children) and photographs from the childhood and surgical history of three of the four subjects. The objective of the film maker, who was born with a cleft palate and attendant impairments, seems to have been to lay to rest the devils of his past and thereby to validate himself in his own eyes as having adapted to the world as we have it.

The film's content is, therefore, predictable and scarcely enlightening. More serious than *Face First's* stylistic naivete is its insistent promotion of the adaptation of the aberrant to the norm rather than the accommodation of the latter to the former (although the video does find room for one dissenting voice on this count). The four subjects are people who have taken control of their lives. Apparently, by force of personality, intelligence, openness, and, most importantly, articulateness, they have claimed their place in the world - but not greatly changed it. It is also striking that Grundmann did not explore the dimensions of impaired vision and hearing of one of the women interviewed as if only those problems to which he himself could directly relate warranted commentary. This attitude carries over to production details: the film is without captions and thus is inaccessible to deaf and hard-of-hearing people.

But the sense of being alive, even when hurting, of the people met in the film make it worth the viewer's half hour: the uncontrolled laughter of a young woman at Grundmann's description of his childhood face looking as if it had been caught in a blender; another's humorous recollection of her parents' shock that her asymmetrical face could attract a boyfriend; the bearer of the least run-of-the-mill features, if one should dare a scale in such matters, turning out to be a stand-up comedian and stage-front purveyor of information on disability (although it is not quite clear to which audiences). What little of the film that stays with this reviewer, aside from the vibrant normalcy of the subjects' comments, are the smiles of the children in the faded photographs still not fully convinced that pain is the human lot.

Kahn, Richard (Producer/Photographer/Editor), Little, George A., and Green, Ronald M. (Executive Producers). *Dreams and Dilemmas: Parents and the Practice of Prenatal Care* [video]. Boston, MA: Fanlight Productions (4196 Washington Street, Suite 2, Boston, MA 02131; 1-800/937-4113), 1998, 58 minutes, \$245.00 purchase, \$50.00 rental/day.

Reviewed by Heather Holloway, M.A., Edinboro University of Pennsylvania.

*Dreams and Dilemmas* offers some very emotional looks at the decisions that must be made by the doctors and parents of critically ill infants. Unfortunately, a great deal of information to support these emotions is missing.

The film revolves around twin boys who were delivered early. Although the film does mention the early delivery, it does not explain the surrounding circumstances. The viewer is left wondering if the early delivery had other ramifications on the parent decisions and emotions that are not being explained. The directors took great pains to film the video without narration or interruption. However, there are times when captions or narration is needed.

There are many scenes where several people are making important medical decisions about the twins and influencing the parents. At no time is it explained who these people are. The parents are severely affected by the information and advice given to them by these individuals yet

the viewer does not know why the parents are so intent on listening to them. Are they doctors, nurses, surgeons, social workers, disability advocates, family members? The viewer is left pondering who they are and why they influence the parents.

There are a few scenes where printed information is placed on the screen to explain the medical progress of the twins. These screens need to have audio narration for visually impaired viewers.

The video progresses through the early diagnosis of the twins, the parents struggle to accept this, the medical decisions that they must face, the strain on their marriage, and eventually the homecoming. During all of this the viewer is caught up in the overwhelming emotional pain the parents must be feeling, yet there is also a feeling that not all of the information about the people involved is being presented.

This film is an excellent emotional look at medical ethics and decisions. However, it leaves the viewer wanting more data to truly understand what is being presented to them.

Kahn, Richard (Producer/Photographer/Editor), Little, George A., and Green, Ronald M. (Executive Producers). *Dreams and Dilemmas: Parents and the Practice of Prenatal Care* [video]. Boston, MA: Fanlight Productions(4196 Washington Street, Suite 2, Boston, MA 02131; 1-800/937-4113), 1998, 58 minutes, \$245.00 purchase, \$50.00 rental/day.

Reviewed by Mary Anne Moisan, MS, OTR/L, Assistant Professor of Occupational Therapy, Lewiston-Auburn College of the University of Southern Maine.

The video *Dreams and Dilemmas* is a stark and intimate documentary about a couple dealing, over the course of six months, with the premature birth of twins. The entire film is without narration and consists of segments of actual events in the lives of the couple and the twins. The events are followed closely over the first week, then monthly thereafter. We see real interactions between the couple and the healthcare team (including physicians, nurses, social workers, and a chaplain), healthcare team members consulting with each other and the couple themselves struggling over very personal issues and decisions regarding the care of these fragile infants.

It is clear from the film that, besides the intense medical interventions and issues, the experience of premature birth extends well beyond the hospital and the babies themselves. As we see the babies struggle for life, we also see the strain this situation has on the couple's marriage and family relationships. We see the personal and emotional impact these dilemmas have on hospital professionals. We get a glimpse of the necessary resources to support a fragile infant in the community.

In terms of helping an outsider to begin to understand the implications of premature birth and neonatal intensive care from a family perspective, this film hits the mark. However, the intensity and emotional nature of this real-life portrayal may be overwhelming for some viewers. The important information contained in this film is delivered in such a powerful manner that the timing of viewing is critical when using this as a learning/teaching tool.