

Book, Video, and Film Reviews

Adamson, Madeleine. *Politics Unusual*. Berkeley, CA: Chardon Press, 1996, 56 pages, \$13.00 softcover.

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

Politics Unusual is a collection of eight short case studies of grassroots political efforts in the 1980s and 1990s. The cases involve campaigns for progressive political reforms and against conservative ballot initiatives on issues ranging from regulation of smoking to campaign finance reform to strip mining. Each case concludes with suggestions of its implications for grassroots organizing. In addition to the case descriptions, an introduction by Gary Delgado of the Applied Research Center summarizes the lessons learned from the cases. Contact information is provided for the organizations described in the cases, and several resources are listed related to foundation support for progressive political advocacy.

The major theme of the book is that long-term organizing efforts are far more important than short-term projects, and that the success of such efforts often depends on the existence of a progressive infrastructure that can educate the general public and mobilize their support. However, there is no theory of organizing or political action provided or referenced, and the case presentations are so brief that they provide far too little information to allow a reader to come to her or his own conclusions about their significance. The conclusions are presented in bullet form, and they are far too general to offer much guidance to aspiring activists.

Politics Unusual is more a pamphlet than a book. Its limited format and the polemic quality of the writing make it unsuitable for classroom use and not useful for research on social movements or social change. However, *Politics Unusual* does not appear to have been written with academics in mind, but rather for those who are interested in supporting grassroots organizing. For this audience, the book will provide some inspiration and a bit of useful advice. While none of the cases included has a disability focus, disability activists may find this work of interest, although they may find far more to consider in the classics on community organizing, such as Saul Alinsky's *Rules for Radicals*.

Reference

Alinsky, S. (1971). *Rules for radicals: A practical primer for realistic radicals*. New York: Random House.

Barker, Peter, Barrick, Jon, and Wilson, Rod. *Building Sight: A Handbook of Building and Interior Design Solutions to Include the Needs of Visually Impaired People*. London, England: HMSO and the Royal National Institute for the Blind (Distributed by Royal National Institute for the Blind, 224 Great Portland Street, London W1N 6AA, England), 1995, 184 pages, 25 pounds sterling, softcover.

Reviewed by Roberta L. Null, Ph.D., Common Place Design, Whittier, CA; author of *Universal Design: Creative Solutions to ADA Compliance* (Belmont, CA: Professional Publications, Inc., 1996).

Building Sight has gone far beyond the stated intentions of the authors from the Royal Institute for the Blind in London - to fill a gap in the range of literature available to the designers, developers, and managers of buildings and interiors concerning the needs of disabled people. In the forward, Sir Duncan Watson explains that the book set out to explore the particular problems facing visually impaired people in the built environment. More importantly, he notes, it also recommends the type of good design that is meant to include as many people as possible.

One of the definitions of universal design is that it is the best design for the most people over a period of time. Even though the term "universal design" is not mentioned specifically in the book, the authors have created a wonderful reference tool for design professionals that is focused on inclusive universal design. In their introductory remarks, the authors state, "Over the past 20 years there has emerged a growing awareness that good design - whether of buildings, interiors or products - should by nature be inclusive. Of course it would be impossible to design any environment to the

exact specifications of every minority group, each with its own individual demands. However, it is perfectly possible to create environments that embrace and invite the widest possible range of users" (p. 7).

In Section One - Design Principles - the stage is set for the inclusionary nature of the book. In Chapter 1 - Inclusive Design - the authors offer recommendations concerning the needs of the disabled population as a whole. More specifically, they address the needs of people with visual disabilities. In designing for special requirements, architects, designers, planners, and building managers will frequently improve the quality of the built environment for everyone. Chapter 2 - The Nature of Visual Loss - lists types of visual impairments and implications for building and interior design, and it includes a design checklist.

Section Two - Design Practicalities - takes a closer look at particular problems and gives step-by-step advice on design specifics. These include: Chapter 3 - Site, Street and Surroundings; Chapter 4 - Exterior Design; Chapter 5 - Interior Design; Chapter 6 - Lighting; Chapter 7 - Interior Decoration; Chapter 8 - Signs and Notices; Chapter 9 - Using Other Senses; Chapter 10 - Building Services; Chapter 11 - Building Management. Section Two chapters are illustrated with an outstanding collection of line drawings and photographs that show both good and bad examples of the design specifics described.

Appendices for the book include a well-illustrated section on how the eye works and a comprehensive bibliography. *Building Sight* is a MUST reference for any current or future design professional and, in addition, for all professionals concerned with disability or chronic illness. I would urge the authors and the Royal National Institute for the Blind to explore ways in which to make this valuable reference handbook more widely available. I have found the on-line book distributors, such as <Amazon.com>, to be very helpful for an international audience.

Bertling, Tom, ed. *American Sign Language: Shattering the Myth*. Wilsonville, OR: Kodiak Media Group (P.O. Box 1029-B3, Wilsonville, OR 97070), 1998, 112 pages, \$19.95 softcover (quantity discounts available).

Reviewed by Lois Bragg, English Department, Gallaudet University.

This latest offering from Tom Bertling and Kodiak Media Group is primarily a collection of memos and letters from members of the faculty of Gallaudet University in the early 1990s, written as contributions to internal policy discussions regarding the use of American Sign Language in the classroom. The contributors are vehemently opposed to ASL as a language of instruction, but few readers will be able to make any sense of the positions they stake out in these miscellaneous writings.

For one thing, the occasional nature of these memos and letters requires some context, specifically, the memos and letters detailing the policy changes to which these contributors object. Because Bertling's doctrinaire approach (exhibited in his previous books for Kodiak as well) disallows any representation of the opposing view, he unintentionally obfuscates his contributors' positions by depriving them of necessary context.

Second, while the contributors are indeed credentialed academics, and five of the six are deaf, their training and expertise lie in unrelated fields, and, on questions of language acquisition or bilingual education, they are merely lay people with uninformed opinions. While their writings have some sociological and historical value, they are worthless as contributions to linguistic discourse. Worse still, many of the memos eschew argument in favor of a religious sense of faith in the saving grace of English - and of the demonic nature and damning effects of ASL. Some, having been shot off in anger eight years ago, are so saturated with emotional appeals as to encourage pity rather than respect for the authors.

One contribution needs to be distinguished from the others to which the above remarks apply, and that is the review of Harlan Lane's *Mask of Benevolence* by Donald Moores. Moores very properly takes this icon of Deaf culture to task for both sloppy scholarship and stunning paternalism toward his Deaf subjects. I recommend it. But you can read it in the *American Annals of the Deaf*, Vol.

138 (1993), pp. 4-9, where it was originally published.

Burack, Jacob A., Hodapp, Robert M., and Zigler, Edward, eds. *Handbook of Mental Retardation and Development*. New York, NY: Cambridge University Press, 1998, 784 pages, \$80.00 hardcover, \$29.95 softcover.

Reviewed by Peggy Quinn, Associate Professor of Social Work, University of Texas at Arlington.

For scholars and researchers interested in the area of mental retardation, this is an excellent resource. Some of the premier authors in the field have contributed their knowledge and expertise.

The book opens with a discussion of the developmental approach, emphasizing that children with mental retardation experience basically the same progression as typically-developing children. The second and third sections describe communication, socialization, attention, and play, areas of development that are critical during infancy and childhood. There is considerably less information on issues of adolescence and adulthood. The final section focuses on the family and the environment. This is a highly technical book that will serve well for those searching for such information. In general, it presents studies, or reviews of studies, but it does not offer details on application and implementation.

One of the strongest attributes of the book is the fact that most of the chapters differentiate between various etiologies of mental retardation. There are separate discussions on children with Down syndrome, William's syndrome, fragile X, autism, and, in some cases, spina bifida. It is unusual, and very helpful, to find such explicit information.

Despite its numerous positive qualities, the book has at least two major deficits. For many readers of *Disability Studies Quarterly*, the lack of reference to a social model of disability may be disconcerting. The editors and authors rely on the traditional view of the individual as the source and center of disability. In addition, the book reflects the paucity of research in which a "family" is more than "mother." There is no reference to the developing body of work on fathers of children with disabilities. Perhaps future versions of this valuable work will be able to incorporate some of this information.

Buunk, Bram P., and Gibbons, Frederick X., eds. *Health, Coping, and Well-Being: Perspectives from Social Comparison Theory*. Mahwah, NJ: Lawrence Erlbaum Associates, Publishers, 1997, 460 pages, \$99.95 hardcover.

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

How to cope with issues related to health and well-being is a daily concern for many individuals with disabilities and chronic conditions. In this regard, the book under review provides a well-articulated, empirically-based perspective on many of these topics. The underlying theoretical foundation - social comparison theory - was stated 40 years ago and is now having an impact on the rapidly growing field of health psychology and, especially, on such research areas as health promotion, risk behaviors, decision-making of care, and other coping with respect to cancer, chronic pain disorders, coronary bypass surgery, depression, and occupational distress.

According to Leon Festinger (1954), who developed social comparison theory, social comparison is one of the most important influences on a person's self-judgments. It is especially influential on one's judgments of his or her own abilities, opinions, emotions, motivations, risks, and opportunities for change under threatening circumstances, such as severe illness. Presented in the book are four theoretical traditions linking research with health, coping, and well-being. The early work on reference groups is reflected in chapters concerned with well-being, decision-making, and AIDS prevention. Affiliation under stress and emotional contagion are addressed in a chapter on surgical patients. Work on social cognition is discussed in chapters regarding unrealistic optimism about risk and how adolescents cope. Finally, most of the chapters contribute to downward- and upward-comparison

theory with a wealth of information about recent development.

Interestingly, several chapter authors present conflicting evidence regarding benefits and drawbacks of coping associated with different types of comparison. The influential factors appear to depend on different situations, goals, motives, and other individual differences. As such, more comprehensive views of conceptual frameworks have to be developed, such as Buunk and Ybema's (1995) identification-contrast model and Wills' (1987) structure of modes and families of coping.

While researchers will find the book very appealing, clinicians and practitioners in the field of disability may experience some disappointment. Limited by research largely rooted in the experimental tradition, conventional theory in social comparison may oversimplify coping in real world situations. Overcoming these problems demands methodological advancement of research, including multivariate studies with multiple-outcome measures, assessment of the effects of mediators and moderators in this process, and longitudinal studies with well-measured constructs. As previous authors have noted, much more work is needed in the future to elaborate aspects of the process of social comparison, especially in natural health settings.

References

- Buunk, B.P., & Ybema, J.F. (1995). Selective evaluation and downward comparison in coping with stress. *Journal of Applied Social Psychology*, 25(17), 1499-1517.
- Festinger, L. (1954). A theory of social comparison processes. *Human Relations*, 7, 117-140.
- Wills, T.A. (1987). Downward comparison as a coping mechanism. In C.R. Snyder & C.E. Ford (Eds.), *Coping with negative life events: Clinical and social psychological perspectives* (pp. 243-268). New York, NY: Plenum.

Daniels, Marilyn. *Benedictine Roots in the Development of Deaf Education: Listening with the Heart*. Westport, CT: Bergin & Garvey (Greenwood Publishing Group), 1997, 155 pages, \$55.00 hardcover.

Reviewed by Keith Mousley, National Technical Institute for the Deaf, Rochester Institute of Technology, Rochester, NY.

Today, educators of the deaf have many questions as to the best way to teach deaf children. Marilyn Daniel's book *Benedictine Roots in the Development of Deaf Education: Listening with the Heart* gives us a look at the history of deaf education, starting in ancient times and continuing to the present day. It is in those ancient times that we find the answers to these questions.

Chapter 1 briefly explains Jewish and Christian beliefs about deafness in antiquity. Chapter 2 starts with a Sixth Century document called The Rule of St. Benedict, which guided Benedictine communities for more than 1500 years.

The following is an excerpt from the Benedictine Rule (p. 8): "This, then is the good zeal which monks must foster with fervent love: they should each try to be the first to show respect to the other, supporting with great patience one another's weakness of body or behavior, and earnestly competing in obedience to one another. No one is to pursue what he judges better for himself, but instead, what he judges better for someone else. To their fellow monks they show the pure love of brothers."

Benedictine philosophies include preserving the dignity and equality of individuals, having respect for people and their differences, the importance of education for all people, and mutual teaching by which students teach each other.

It is in Chapter 2 that we meet Pedro Ponce de Leon, a Benedictine monk and the first teacher of the Deaf who used the Benedictine Rule as the basis for teaching deaf individuals. Ponce de Leon saw Deaf people as having equal intelligence. He showed respect for Deaf people and their differences, including their language and culture. He used the manual alphabet and sign language to communicate with them. In the following chapters we can see how his work had a huge impact on the future of deaf education.

In Chapters 3-6, we see the Benedictine-based teaching philosophies/methods that Ponce de Leon used being continued across the centuries through the works of Juan Pablo Bonet, Charles Michael de l'Epee, Thomas Hopkins Gallaudet, and Edward Miner Gallaudet. In Chapter 3, we learn about Juan Pablo Bonet's book *Simplification of the Letters of the Alphabet and Method of Teaching Deaf Mutes to Speak*. This book, in which the manual communication teaching method was used, was based on Ponce de Leon's work. We see in Chapter 4 that Bonet's book was used by Abbe de l'Epee, who founded the first school in the world for the deaf in France. Chapter 5 describes Thomas Hopkins Gallaudet's trip to France. He visited Abbe de l'Epee's school and learned their teaching methods. He helped to establish the first school for the deaf in America in Hartford, Connecticut (American School for the Deaf) and incorporated many of the methods learned in France. Chapter 6 focuses on Edward Miner Gallaudet, the son of Thomas Hopkins Gallaudet. Edward carried on his father's work and became the first superintendent of the Columbia Institute, now known as Gallaudet University.

It is in the 1800s that we see Edward Miner Gallaudet's struggle to improve educational opportunities for Deaf individuals. He embraced the combined method (sign language, speech, lip-reading) to teach the Deaf. This angered many oralists. It seems that it is here that the focus shifted from education to communication. For more than 100 years, this controversy has resulted in many children being pulled in different directions.

In Chapter 7, we see that, even though oralism was prevalent in the education of Deaf children in the early 1900s, Gallaudet University continued to use American Sign Language as a communication tool to teach Deaf individuals. This last chapter also looks at the recent chain of events at Gallaudet University since 1988, such as the Deaf President Now Movement, the acceptance of ASL as its own language, bi-lingual educational approaches, and hiring of deaf faculty in the program of education (35%). The book closes by showing that the methods and procedures used at Gallaudet University have Benedictine roots, roots that demonstrate that the preservation of dignity, equality, and respect for all people is of utmost importance.

This book is very interesting, informative, organized, and well thought out. There are so many facts and people to remember that you can get lost in history! Visual aids, such as a historical time-line, photographs, and excerpts from Bonet's book, would have been helpful. We see Gallaudet University's role in the history of deaf education. It would be interesting to see how Marilyn Daniels, the author, would tie in the history of deaf education with current methods used at NTID and other college Deaf programs. If you are Deaf or work in the field of deafness, this historical book would be an excellent addition to your personal/professional library. It has not only expanded my knowledge of the history of deaf education, it has helped me to appreciate its origins.

Davey, Basiro, Gray, Alastair, and Seale, Clive, eds. *Health and Disease: A Reader* (2nd Ed.). Buckingham, England: Open University Press (Distributed by Taylor & Francis, 1900 Frost Road, Suite 101, Bristol, PA 19007-1598), 1995, 436 pages, \$29.95 softcover.

Reviewed by Kristine Mulhorn, University of Michigan, Health Care Department, Flint, Michigan.

This book is a collection of well-written articles by writers such as Rosemary Stevens, Ivan Illich, Lester Breslow, and Vicente Navarro. The breadth of the text enhances its use in the classroom. The chapters cover a wide range of topics from conceptualizing health and disease, as in Susan Sontag's essay "Illness as Metaphor," to describing the social context of health care, as in a report on the traditional Indian health worker. The book also contains some writings covering difficult ethical questions. However, there are few, and only one is related to the complexities of disability. The book could add significantly to a sociology of health and illness, but some chapters could be supplemental readings in courses such as long-term care and global health.

Two reservations are holding back a strong recommendation for this book. First, the health care system of the U.K. is a significant contextual element for many of the readings. A noteworthy exception is Rosemary Stevens' contribution - "The Evolution of the Health Care Systems in the

United States and the United Kingdom: Similarities and Differences.” Here, without background knowledge of either system, the reader is immersed in a thoughtful discussion of why and how health care systems develop.

There is little discussion of disability in the book. One article, entitled “Pride against Prejudice: ‘Lives Not Worth Living,’” identifies key ethical concerns arising from the potential conflicts between the wishes of some persons to end their own lives and the role of the health care and social service industries. While the ethical issues come through, the article ignores the role of the disability rights movement in enhancing the lives of persons with disabilities. Given the significant role of society’s growing awareness of persons with disabilities as a political entity, the paucity of articles on the subject is a serious omission from the text that, otherwise, emphasizes social concerns.

DeBoskey, Dana S., ed. *Coming Home: A Discharge Manual for Families of Persons with a Brain Injury*. Houston, TX: HDI Publishers (1-800/321-7037), 1996, 73 pages, \$12.50 softcover (quantity discounts available).

Reviewed by Amy Horowitz, D.S.W., Senior Vice President for Research, and Director of the Arlene R. Gordon Research Institute, Lighthouse International, New York, NY.

This easy-to-read manual is targeted toward family members of persons with a brain injury who have completed an inpatient rehabilitation program and are now coming home to live with their families. The manual was designed to be, and succeeds as, “a very practical addendum to any interdisciplinary rehabilitation effort” (p. iii).

Each section describes a specific issue (e.g., the “anniversary reaction”), gives specific examples of related problems, and suggests possible solutions. It is especially helpful in identifying issues that may arise both from the behaviors of the person with the brain injury and from common reactions of family members. Throughout the different sections of the manual, several common themes are stressed. These include maximizing independence of the person who is brain injured, the importance of seeking information and help from professionals whenever possible, and the potential benefits of support groups for both the family and the person with the brain injury.

The manual would have been more useful if it had included a list of resources (e.g., national organizations, websites, etc.) to which families could turn for further information; but, unfortunately, such a resource list is not included. However, given the material presented, the manual does represent a valuable and practical resource for family members. It would be especially appropriate to have this booklet available to families prior to the patient’s discharge to his/her home.

Dinero, Thomas E., ed. *Selected Practical Problems in Health and Social Research*. Binghamton, NY: The Haworth Press, Inc., 1996, 107 pages, \$29.95 hardcover, \$14.95 softcover.

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

This book contains a series of articles on measurement issues in social research. The articles were concurrently published in the journal *Health and Social Policy* (Volume 8, Number 1). The book contains many useful observations on measurement theory, research design, and common errors in measurement used in applied research. However, many of the articles combine quite elementary principles of measurement with fairly sophisticated technical issues in ways that would not satisfy either a beginner or an expert.

As someone with considerable experience in teaching social research methods, I suspect that much of the more interesting material in this collection would go over the heads of undergraduates or even beginning graduate students in the social science or health professions, while the more basic concepts included here are far less accessible in this volume than in many standard introductory texts in research methods. However, more advanced students of social research and research practitioners would find many of the chapters in the book quite valuable. For example, Dinero’s critique of the categorization of continuous data and Jones’ discussion of non-response and statistical inference raise significant questions about common research practices that often are taken for granted.

DSQ readers should know that this collection does not have any content specific to Disability Studies, nor does it directly address the thorny measurement issues that frequently come up in Disability Studies research, such as the definitional problems of identifying impairments and reaching people with disabilities, or the practical challenges of incorporating participatory action research designs.

This book would be a worthwhile supplemental text for a graduate social research methods course, and it would be of interest to practitioners and scholars interested in methodological issues in social research. Research methods instructors might also be interested in the opportunity offered by the publisher, Haworth Press, to order custom packets of articles from this book or any other Haworth publication.

Goss, David, and Adam-Smith, Derek. *Organizing AIDS: Workplace and Organizational Responses to the HIV/AIDS Epidemic*. Bristol, PA: Taylor & Francis, 1995, 176 pages, \$24.95 softcover. Reviewed by Betsy Johnsen, AIDS Legal Referral Panel, San Francisco, CA.

Perhaps even more than other people with disabilities, those with HIV/AIDS face intense social bias and discrimination. Since this impairment also affects most while at their peak of earning capacity, their role in the workplace is heavily influenced.

As part of a University of London series on the social aspects of AIDS, the book *Organizing AIDS* examines HIV/AIDS in the workplace, a subject ignored by most academic and popular researchers. Investigators have been more interested in issues surrounding HIV transmission, and, for many years, it was assumed that anyone discovering he or she had AIDS would quickly leave his/her job, making workplace issues irrelevant. Fortunately, some research on the topic was done, and this book was written.

The subject of AIDS in the workplace has increased in importance since the book's publication in 1995. New drug therapies to combat HIV have vastly reduced mortality and morbidity rates in developed countries. This, combined with HIV's continued high rates of infection (the United States alone originates 40,000 new cases per year), means there will be increasing numbers of workers with HIV/AIDS.

They will face a wide sweep of employment policies, ranging from "defensive" to "constructive." Authors Goss and Adam-Smith define these patterns of management response and examine the reasons behind their formation. They also provide useful explanations of how to change the policies, with some fascinating examples of where attempts at education have and have not succeeded.

The book also addresses legal protections for people with HIV/AIDS in the workplace, concentrating on British cases. The authors, both from England's University of Portsmouth Business School, are by no means exclusive, however, and compare Britain's laws to those of Europe and the U.S. It is particularly interesting to see how poorly the laws of Britain and Europe protect infected employees, despite their greater socialization of medical care and, thus presumably, lesser threat to business costs. The authors go on to provide an excellent summary of how the U.S.'s Americans with Disabilities Act offers far greater protection to people with HIV/AIDS. Although slightly dated now and, therefore, possibly untrustworthy, the book's discussion is still an interesting analysis of employment disability law.

Although much of *Organizing AIDS* is based on academic sources, the authors usually manage to explain any obscure phrases (e.g., "de-ontological stance"). The result is a book that provides both theory and practical advice for those who wish to expand legal rights and develop workplace policy related to HIV/AIDS.

Haseltine, Florence P., Cole, Sandra S., and Gray, David B., eds. *Reproductive Issues for Persons with Physical Disabilities*. Baltimore, MD: Paul H. Brookes Publishing Co., 1993, 400 pages, \$34.00 softcover.

Reviewed by Linda R. Mona, Research Associate, World Institute on Disability, Oakland, CA.

Although reproductive health issues for persons with disabilities have been explored more extensively in recent years, literature examining both the scientific and phenomenological experience of these issues has not been available until now. *Reproductive Issues for Persons with Physical Disabilities* is unique in that it approaches a variety of factors that are associated with reproduction both from personal perspectives of persons with disabilities and from scientific research. However, do not let the title of this book be misleading. Even though this piece does focus to a large degree on reproduction, it also addresses other topic areas related to the disability experience, such as intimate relationships, sexual health/functioning, parenting, and adoption. By covering this wide range of material, this book offers a blending of theoretical concepts and practical information useful for a variety of readers.

This book is divided into four areas: an overview of sexuality and reproduction, personal issues, clinical issues, and policy directions. In the first section, a thorough overview is provided that orients the reader to the material to follow. In addition, this initial portion of the book contains a narrative by Irving Zola that speaks to his personal journey dealing with sexuality, family relationships, and intimate relationships as a disabled person. Subsequently, the second section on personal issues also contains a variety of poems written by Zola that touch on the psychosocial issues related to reproduction, sexuality, and parenting. These writings, found interspersed among other articles written by people with disabilities, add a powerful message of realism to the reproductive and parenting issues faced by this community. Specific topic areas presented in the second portion of work include parenting with a disability, pregnancy and delivery, and the adoption process. The clinical section provides a scientific overview of research investigating reproductive disabilities, spousal relationships, genetic counseling, infertility, sexual function and dysfunction, and parenting. Written by many well-known authors in the disability community, this third section is interesting to both academics and consumers. Finally, future directions for research and training are provided in the last portion of this book. This section is helpful to those scholars who are looking for important research questions to investigate. In addition, it provides a brief overview of the previous chapters and the ways in which future policy changes can be made.

By presenting this information in an integrated context, readers are able to take away a comprehensive view of medically- and psychosocially-related issues that affect the reproductive health, sexuality, and parenting aspects of the lives of disabled people. The presence of the personal and anecdotal experiences of persons with disabilities adds an interesting perspective that maintains the interest of the reader throughout the entirety of the book. Readers should remain aware that this book was written five years ago, and, thus, some of the scientific and factual information provided is somewhat out of date. Specifically, it is recommended that individuals interested in the disability experience as it relates to sexually-transmitted diseases and spinal cord injury sexual functioning look to more current research to use as an adjunct to this work: Appropriate audiences for this book include persons with disabilities, health care professionals, and Disability Studies scholars.

Kurtz, Linda Farris. *Self-Help and Support Groups: A Handbook for Practitioners*. Thousand Oaks, CA: Sage Publications, 1997, 227 pages, \$46.00 hardcover, \$21.95 softcover.

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

This text would be ideal for any practical course for social workers, front-line workers, and advocates. Although it is intended for "practitioners" (i.e., not for people who attend the self-help groups), the content and concepts are useful to both self-advocates and professionals. The basic premise of the text is that self-help groups are primarily consumer run and non-directive, based on shared experiences and needs. The support groups are more typically facilitated by a leader, who may or may not share the experiences of the group members, and it tends to be goal-oriented towards new skills or information.

Some of the most useful information in the text is on recruitment and retention patterns. What organization has not struggled with maintaining membership and growth? The issues of illness, recovery, and stigma are dealt with clearly and thoroughly. Often the people in need of self-help are reluctant to seek it, or feel they are too sick, or not sick enough to attend regular groups. On top of this complication is the idea that once recovered or "helped" by the self-help, there may not be a need to continue attending. This is particularly true of cancer and bereavement support groups. However, it is not true of most of the twelve step programs, which encourage life-long commitment. Throughout the book, research conducted on the outcomes and processes of twelve step programs (National Alliance for the Mentally Ill and Alzheimer's Association, among others) is used to provide effective illustrations and case studies.

Each chapter ends with discussion points, classroom assignments, and additional resources that would help teachers and learners to assimilate the information. Although the text does not exclusively focus on disability or illness, it does look at the differences between the "consumer" and family members. The issues of families seeking support because someone close to them has a problem are explored along with the concerns of people seeking help. There is also a focus on the role of the "practitioner," both in facilitating groups and in enabling clients to participate in groups and to take leadership roles.

Lastly, taking the concept of mutual aid into the next millennium, the author reviews the benefits and disadvantages of on-line and telephone support systems: "On-line self-help participation has several advantages beyond the obvious one of accessibility by people unable to travel to community groups. One can participate in most groups anonymously. Email can be sent and received at any time of the day or night, as and when one needs or wants to communicate" (p. 192).

The references and research studies cited in the book also make it a handy primer for dissertation writers to consider in designing research in the area of self-help groups.

Linton, Simi. *Claiming Disability: Knowledge and Identity*. New York, NY: New York University Press, 1998, 208 pages, \$45.00 hardcover, \$16.95 softcover.

Reviewed by Stephen French Gilson, School of Social Work, Virginia Commonwealth University, Richmond, VA.

Before I begin this review, in the spirit of being forthright, I must admit that, prior to having been asked to review Linton's *Claiming Disability: Knowledge and Identity*, I had read it and thoroughly enjoyed the text. My response to the request to review was one of unquestioning willingness, as I believe that it is a text that makes important contributions to Disability Studies. Linton has challenged us all to re-consider our views, beliefs, and perspectives on disability, the experience of disability, and Disability Studies. While there are many other fine texts available that make important contributions to this discussion and debate, *Claiming Disability* is presented in such a way that people new to this area of study and those in the related applied fields will be able to take away many valuable insights and new knowledge. An indicator of this was my use of Linton's work in a doctoral seminar that I taught in the Fall of 1998.

Among the foci of this course were the development of the ability to understand significant questions related to theory development, knowledge building and utilization, and enhancing the student's reasoning repertoire with respect to articulating a rationale for selecting a theoretical perspective for a social work purpose. The readings were selected to be compatible with each other and to identify parallels among populations. *Claiming Disability* fit well with Butler's (1990) *Gender Trouble*, Jencks' (1992) *Rethinking Social Policy*, Scott's (1997) *Contempt & Pity*, and Seidman's (1994) *Contested Knowledge*. As a professor, it was a delight to have had Linton's work fit so well within this context, and to have had it so well received by students whose area of interest was not Disability Studies. The students, however, did come away from their reading of *Claiming Disability* being able to identify the parallels and differences between the experience of disability and the experiences of gender, class, and race, and to better understand the intermix of those experiences. Dr. Linton is to be commended

for developing a text that helps to establish more firmly a discussion framework both within and outside of Disability Studies.

References

- Butler, J.P. (1990). *Gender trouble: Feminism and the subversion of identity*. New York, NY: Routledge.
- Jencks, C. (1992). *Rethinking social policy: Race, poverty, and the underclass*. Cambridge, MA: Harvard University Press.
- Scott, D.M. (1997). *Contempt and pity: Social policy and the image of the damaged Black psyche*. Chapel Hill, NC: University of North Carolina Press.
- Seidman, S. (1994). *Contested knowledge: Social theory in the postmodern era*. Cambridge, MA: Blackwell.

Lutkenhoff, Marlene, and Oppenheimer, Sonya G., eds. *Spinabilities: A Young Person's Guide to Spina Bifida*. Bethesda, MD: Woodbine House, 1997, 138 pages, \$16.95 softcover.

Reviewed by Marsha Saxton, Ph.D., World Institute on Disability.

Spinabilities is a collection of chapters written by nurses, occupational therapists, doctors, and one parent, with tips and resources on a wide range of pertinent issues for adolescents with spina bifida including bowel, bladder, and skin care, braces and wheelchairs, school and learning, friendships, dating, sexuality, nutrition, sports, and employment. The content seems aimed at kids ages 12 to 16 (though the format and reading level did not seem inclusive of kids with learning disabilities - about 70% of those with spina bifida). *Spinabilities* would certainly have been useful to me when I was an adolescent with spina bifida in the 1960s. In the era of the Americans with Disabilities Act, however, I think the youth of our movement should expect more disability consciousness from this book.

There were only a few quotes from young people with spina bifida, and these I found to be bleak, complaining of how hard coping is, rather than informative about living with a disability. Even with the cartoon illustrations, the book lacks a sense of humor. There are no role models of people with spina bifida actively addressing disability stigma and logistical challenges. Apparently, it did not occur to the editors to include a chapter or longer passage from an adult with spina bifida. I wonder if these professionals have interacted with disabled adults.

Much of the material is thoughtful and informative, but treatment of some key topics seems cursory, especially those topics for which disabled kids are the most eager: dating, sex, birth control, and pregnancy. There are only three sentences on attendant care and home health resources, an oblique reference to attitudinal barriers and discrimination, and little discussion of advocacy. The underlying message of the book is the Protestant work ethic, tinged with the medical model of disability: If you work hard to adapt, and if you follow your doctor's advice, you will fit in and cope okay. Not the most empowering message for disabled children.

Michalko, Rod. *The Two-in-One: Walking with Smokie, Walking with Blindness*. Philadelphia, PA: Temple University Press, 1999, 239 pages, \$44.95 hardcover, \$16.95 softcover.

Reviewed by J. Eric Pridmore, Ph.D. Candidate in the Sociology of Religion, Drew University, Madison, NJ.

Throughout this book, Rod Michalko offers the reader both personal and analytical insights concerning the reality of blindness and the significance of a guide. His sociological approach enables him to reconsider the traditional understanding of blindness as well as the relationship between humans and animals.

As the book begins, the author makes clear his distinction between sight and vision. This distinction is crucial. Michalko draws on the work of David Michael Levin to explain that "sight" in and of itself does not "see." Sight is incapable of really seeing anything, including itself. Michalko writes, "Sight is nature and *only* nature" (p. 16). What enables sight to see is not nature, but social

order. In brief, "sight is socially organized" (p. 16). Vision, in contrast, is a natural gift requiring human development and responsibility. Our response to this gift is determined by how we look at the world and what we see in it. Michalko concludes that the test of our self-development as humans is determined by what we make of our natural gifts in the context of our social life.

Society and nature come together for this author in the form of Smokie, an energetic black lab dog guide. In returning home with Smokie, Michalko returns with a new and different identity. Those who previously were unaware of his vision loss would, on seeing Smokie, identify Michalko as "blind." Moreover, Michalko and Smokie are identified as distinct, but inseparable, beings. He describes this in Simmel's (1950) terms as a "dyadic identity" or, in other words, "the two-in-one." The fact that people would often confuse Rod's and Smokie's names exemplifies this new dyadic identity.

It is in the formation of this two-in-one relationship that Michalko is able to take on his identity as a person who is blind. However, in taking on this identity in the form of Smokie, "a clear and distinct symbol of blindness" (p. 94), he loses focus on his blindness. He writes, "... while I was working with Smokie, I was not thinking about my blindness. . . . I had never before had such a constant and consistent mark of my blindness, but for the first time I did not feel the negative social impact of such a mark" (p. 94).

While his analysis is strong, I must admit that at times his account of Smokie seems somewhat embellished. This takes away somewhat from his overall argument, particularly since he states that so many of the previous writings on dog guides are exaggerated and embellished accounts. It was also bothered by Michalko's account of his sighted partner's use of a guide dog. Although not blind, his partner, Tanya, would often use her companion dog, which she had trained as a guide dog. For one thing, I did not understand how Tanya's activity pertained to the larger schema of the book. Secondly, her passing as a dog-user, when she is actually not, may serve to make the legitimate use of dog guides more difficult. In my opinion, the use of dog guides in such places as restaurants and hotels is difficult enough at present.

Despite these minor criticisms, Michalko does a good job of framing both visual impairment and the use of a guide dog in sociological terms. It is a good treatment, and his use of such social theorists as Marx, Durkheim, Goffman, and Berger (to name a few) makes his argument clear and coherent.

Reference

Simmel, G. (1950). *The sociology of Georg Simmel*. (K. Wolff, Trans.). New York, NY: Free Press.

O'Leary, Kathlene. *Crohn's, Colitis, Hemorrhoids, and Me: A Patient's Story of Hope, Humor, and Living with Inflammatory Bowel Disease*. Laguna Niguel, CA: Anderson Press, 1995, 121 pages, \$12.95 softcover.

Reviewed by Julie E. Amberg, MSW, Oakland, CA.

While Kathlene O'Leary's short journal offers a sketch of her adjustment to life with Crohn's disease, readers hoping for insight into the psychosocial complexities of living with this hidden disability will be disappointed. In eleven brief chapters, O'Leary attempts to chronicle her "medical and emotional 'experiences' relative to Crohn's disease and Colitis [sic]" during the first two years of her illness and resulting disability. She fails to provide enough detail, however, about her physical, psychological, or social world to gain any genuine understanding of her experience, and she makes no mention of broader, more political issues of disability identity. Indeed, O'Leary seems to understand her experience only through the dominant medical model, consistently referring to herself and others with Crohn's disease or colitis as "patients" and focusing what little descriptive detail she offers on her physical symptoms and associated medical interventions.

The reader does get some sense of how physically painful the disease can be and of the important role of hope and social support in coping with such pain. Unfortunately, O'Leary's self-conscious, stiff, and disjointed prose (and the apparent lack of editing) distract and confuse the reader,

and they leave one wondering if her journal is not really a promotion for the many physicians and pharmaceuticals she touts throughout the book or, perhaps, a lengthy thank-you letter to her family and friends.

This last point raises the question of how self-published journals such as O'Leary's function, both for the individual author and for the public. It is in the raising of this question, along with that of when, how, and why a personal disability identity develops or fails to develop, that *Crohn's, Colitis, Hemorrhoids, and Me* may prove valuable to the Disability Studies community.

Parasnis, Ed. *Cultural and Language Diversity and the Deaf Experience*. New York, NY: Cambridge University Press, 1996, 306 pages, \$49.95 hardback.

Reviewed by Sharon Barnartt, Professor, Gallaudet University.

This book explores the premise, held by some members of the deaf community, that deafness is solely a linguistic issue, and, therefore, deaf people are a cultural and linguistic minority group. That is, this perspective explicitly denies that deaf people have a physical impairment or a disabling condition or are members of the disability community. Called by some the "bilingual-bicultural perspective" (or bi-bi for short), this perspective focuses not so much on audiology or even on sign language per se as on the ways in which deaf people's experiences are analogous to the experiences of members of ethnic, racial, and linguistic minority groups. The book explicitly does not address issues of relevance to "deaf people who do not know ASL, deaf people who are members of an ethnic minority group in America and use that group's language, deaf people who are new immigrants to the United States, and those deaf people who only use speech and speech reading" (p. xiii).

The book is a collection of articles, many written specifically for this book, and most written by researchers and faculty members at the National Technical Institute for the Deaf (NTID) at the Rochester Institute of Technology. Articles in the first two sections, which are titled "Bilingualism-Biculturalism and the Deaf Experience: An Overview" and "Psychosocial, Cognitive and Language Experiences of Deaf People," are of an academic nature. Most of the articles in the first section provide a historical and theoretical foundation for notions of bilingualism without specific reference - or with only slight reference - to deafness. These include "Living with Two Languages and Two Cultures" by Grosjean, "Perspectives from the History and the Politics of Bilingualism and Bilingual Education in the United States" by Hakuta and Mostafapour, and "Cognitive and Language Development of Bilingual Children" by Hamers. The second section, which includes articles by Carol Padden, Susan Foster, Greg Emerton, Gerald Bateman, and Tom Holcomb, among others, addresses more specifically the question of whether, or to what extent, it makes sense to view deaf people as a linguistic minority group. Articles in this section consider aspects of bilingual development, education, marginality, minority status, and political activism as they apply to the deaf community. (The latter is the first-ever article on mainstream political activism - or lack thereof - by deaf people.)

The third section of this book, which is less academic in tone, gives this book some of its uniqueness. In this section, well-educated deaf people discuss their own experiences from the perspective that is presented more academically in the first two sections. The articles include several in which authors who have been deaf from birth discuss their experiences growing up, several which focus on the experiences of deaf people with their own children or their own parents, one by a woman who became deaf post-lingually, and two by hearing women who are married to deaf spouses. Of the latter, one grew up with deaf parents, and one did not.

This book presents an important advance in the ways deafness is viewed. Moving away from medical models and deficit models, it presents a more comprehensive picture than has been presented in other books of a view of deafness that is coming to the fore in some sectors of the deaf community. It should be read by all people who know or work with deaf people.

However, this perspective also suggests an ideological separation between deaf people and people with other types of impairments, which could in the future lead to political splits between the two communities. If the perspective suggested in this book affects policy decisions, it could also lead

to policy distinctions between deaf people and people with other types of impairments. Thus, it is an important book for people who are interested in any facet of impairment, disability, or handicap to read.

None of this is to say that this book will be acceptable to all readers. The perspective being presented is radical, to say the least, and it may be shocking to people who are not familiar with the deaf community. Not only will not all deaf people agree with it, neither will all people with other types of impairments. However, it should be read by anyone who wants to become familiar with the main currents of political thought in the deaf community at this time.

Russell, Marta. *Beyond Ramps: Disability at the End of the Social Contract*. Monroe, ME: Common Courage Press (P.O. Box 702, Monroe, ME 04951), 1998, 256 pages, \$18.95 softcover.

Reviewed by Rosemarie Garland Thomson, Department of English, Howard University, Washington, DC.

With this accessible, ardent, and fact-packed book, Marta Russell lays out an activist manifesto for a disability politics. Russell extends the radical genre exemplified by Angela Davis' criticism of the prison-industrial complex, Jonathan Kozol's castigation of poverty, and Adrienne Rich's denunciation of compulsory heterosexuality to expose America's shameful treatment of disabled people. *Beyond Ramps* is a call to activism that offers America's betrayal of disabled people as emblematic of how the politics and policies of late capitalism have ravaged the democratic project. While carefully explicating one-by-one the major particular sociopolitical issues that involve disability, Russell always returns to her larger economic critique. The virtue of this strategy is that the book emphatically advocates for the disabled community without seeming narrow or partisan. She relentlessly documents the economy of scarcity that capitalist excesses have established, but she admirably refuses to erect a hierarchy of oppression that would exclude other subordinated groups from her circle of advocacy.

Russell's radical premise (in the sense that she is left of liberal reformist solutions) is that there is a fundamental American social contract in which "the first and only legitimate object of good government," to quote Thomas Jefferson, is "the care of human life and happiness" (p. 8). She argues persuasively that the failure - indeed the refusal - of the government to honor this social contract with regard to disabled people indicates the failure of the democratic ideal upon which this country was founded. The book leads the reader through both the theoretical presentation of disability as a social construction and the history of disability oppression, challenging ableist cultural assumptions about normalcy, language, the right to die, health, eugenics, overcoming disability, perfect babies, abortion, charity, genetic testing, work, and entitlements. Perhaps her most fundamental critique is against an ethos of economic efficiency used to strip disabled people of access to the "care of human life and happiness" that constitutes the social contract and promotes the general welfare. Succinctly put, her main point is, "The Republican/Democrat equation is clear: The rich get unimaginable wealth and power, and we get Mother Theresa" (p. 199).

Beyond Ramps should be taught in every Disability Studies course offered, as well as in any course about minority issues or politics. Although this book does not cover new theoretical or historical ground for the Disability Studies scholar, it is bursting with specific information from the perspectives of scholarship, policy, and activism. Its ideal audience is readers who want to understand or who need to understand the dynamics of oppression in American society, especially those who support racial, gender, ethnic, or sexual equality, but have not made connections between those systems and disability.

Sweeney, Wilma, K. *The Special-Needs Reading List: An Annotated Guide to the Best Publications for Parents and Professionals*. Bethesda, MD: Woodbine House, Inc., 1998, 332 pages, \$18.95 softcover.

Reviewed by Laurie R. Lehman, Associate Professor, Long Island University, Brooklyn, New York.

The Special-Needs Reading List provides a plethora of resources on disability subjects. Ms. Sweeney does a fine job of organizing each of the forty sections, divided into general topics and specific disabilities, enabling readers to find books of interest easily. She addresses important topics such as future planning, advocacy, and sexuality. Such sections as Attention Deficit Disorders and Autism include many different references showing the author's extensive research. Most impressive are the listings of fiction and nonfiction appropriate for children of various ages, specific sources for siblings, and websites supporting people with disabilities.

One comes away highly impressed with the vast number of books and organizations available to families and children with disabilities. Since many parents are not aware of this material and could benefit from a network of assistance and support, this book is invaluable. Ms. Sweeney is to be commended for selecting books from varied perspectives, with particular acknowledgment of the voices and experiences of individuals with disabilities.

Though a needed reference for general information about disability as well as the insider's view, certain aspects of the book raise questions. Given the number of citations, the guide gives the misleading impression of being a comprehensive compilation for professionals as well as parents. Yet, the vast majority of resources are specifically written for parents of children with disabilities. Ms. Sweeney chooses practical, how-to books geared to the novice, and she presents a simplistic view of the subject that, at times, is exacerbated by overly positive and flowery language. Many book descriptions lack scholarly depth, with exceptions referred to as "technical," possibly reflecting the author's awkwardness with more complex material.

In addition, the selections represent limited models of disability. Citations with descriptors such as "coping" and "challenge" are common, highlighting the child-as-problem syndrome of the medical model. Little attention is given to alternative approaches to disability, such as the minority group approach (and there is no mention of the Society for Disability Studies or the *Disability Studies Quarterly*).

Even with these shortcomings, *The Special-Needs Reading List* provides a very useful and much-needed service to families by bringing together in one volume many disability resources and ways to access them.

Thompson, Robert J., Jr., and Gustafson, Kathryn E. *Adaptation to Chronic Childhood Illness*. Washington, DC: American Psychological Association (750 First Street, NE, Washington, DC 20002), 1996, 394 pages, \$49.95 hardcover.

Reviewed by Heather Holloway, State University of New York at Buffalo.

Adaptation to Chronic Childhood Illness is a comprehensive text dealing with a growing issue in the field of Disability Studies. Throughout the United States, ten million children and their families deal with chronic illness, and the number continues to rise. How children and their families adapt to spina bifida, sickle-cell disease, diabetes, cystic fibrosis, cancer, and asthma are examined from a biopsychosocial standpoint.

By dividing the book into four distinct sections, Thompson and Gustafson effectively deal with the impact of chronic childhood illness, the developmental changes that accompany illness, the enhancement of adaptation, and goals for public policy. To give the reader a clear picture of the cases presented, each disability/illness is examined in terms of etiology and description, manifestations and course, and treatments that are currently being used. The remainder of the first section deals with the social and psychological adjustment of the child, her/his family, and peers. Several tables are included in this section detailing previous studies on this subject.

The second section addresses developmental changes in the concept of illness, stress, and coping. Coping methods and strategies are examined from both the child's and the parents' viewpoints. There is a very interesting discussion on how a child's psychological adjustment affects the parents' adjustment.

Adherence to medical regimes and pain management are dealt with in the third section. In many cases of chronic childhood illness/disability, adhering to a strict medical regimen is often difficult. The reasons for this problem, and different models of dealing with it are presented here in a very effective manner. Thompson and Gustafson also discuss different psychological approaches to dealing with the pain from medical procedures.

The last section is one of extreme interest for researchers of public policy. Both current and future policies and research issues are examined, as is the importance of parental input in issues concerning disabled children. This text is a wonderful guide for those interested in chronic childhood illness/disability. It examines the subject from a practical combination of biomedical, socio-economic, and psychological viewpoints.

Turner, Bryan S. *The Body and Society: Explorations in Social Theory* (2nd Ed.). Thousand Oaks, CA: Sage Publications, 254 pages, \$69.95 hardcover, \$26.95 softcover.

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

I am unfamiliar with Turner's first edition of *Body and Society*, and I approached his second edition with enthusiasm. The cover features a still life by Francisco Goya - the skinned head and bloody ribs of a sheep. This is a change from the first edition, which was graced by Picasso's "Les Femmes d'Alger (O. J.)" According to Turner, Picasso's illustration was "too literal as an expression of the problem of the body and embodiment" (p. xi). I was intrigued by this evidence of Turner's careful attention to detail; however, I closed the book with disappointment.

My dissatisfaction springs from three interrelated causes. (1) The works from which Turner draws for his new edition are sadly out of date. One glance through the list of references is enough to establish that the most recent piece was dated 1984 (a book written by Turner himself on economic development in the Middle East). The twelve-year gap between references and publication date is a significant oversight for a topic such as the body - a field that has undergone revolutionary changes in the last two decades. The bulk of the works cited in the reference list hail from the 1960s and the 1970s. Since *Body and Society* is not a historical piece about these decades, I am forced to conclude that the second edition is not much different than the first.

(2) Some of Turner's information is incorrect or out of date. For instance, in discussing the AIDS epidemic, he states that "medical research institutes will be funded to discover an antibiotic treatment of modern venereal diseases" (p. 210). As most people know, AIDS is viral in nature, and looking for an antibiotic treatment would be a criminal waste of resources. Furthermore, because of his lack of current information, Turner perpetrates unhelpful stereotypes. He accuses general practitioners of being "poorly equipped to understand the social dynamics of illness" (p. 212). This may be true of general practitioners, but they are a dying breed. The curriculum followed by family practitioners (a specialty that is replacing general practice) includes careful study of a systems approach to medical care, taking into consideration not only the patient, but his/her family.

(3) Some of Turner's statements are dangerously seductive, since they are based on accurate observations about the relationship between women and their bodies. At the same time, the subtext sends an unhealthy message. For instance, he comments that "although women have a phenomenological possession of their bodies, they have rarely exercised full ownership" (p. 220). Unfortunately, this statement is preceded by a description that fully (though probably unconsciously) reflects the premise that there is a split between the body and the mind. Having written about the body as both a social and a natural phenomenon, Turner concludes by saying, "I possess my body, but there is a sense also in which it possesses me" (p. 220). This statement, among others, leaves me with the uneasy impression that Turner is uncomfortable with the "body" or at least with his body.

The consequences of Turner's outdated references, his occasionally incorrect information, and his unease (should I say dis-ease?) with the body make reading his book an exhausting activity. Trying to sort out well-reasoned statements from those that are contaminated by outmoded information or unconscious personal perspectives might be worth the trouble if there were thirty hours in

every day. As it stands, I would rather recommend readers to turn to works by Garland, Linton, or Hahn if they wish to find well-informed, healthy, well-reasoned, and up-to-date observations about the body and society.

Wendell, Susan. *The Rejected Body: Feminist Philosophical Reflections on Disability*. New York, NY: Routledge, 1996, 206 pages, \$16.95 softcover.

Reviewed by Rosemarie Garland Thomson, Department of English, Howard University, Washington, DC.

Like many significant academic studies, this book grows out of the author's own experience. In keeping with feminist academic practice, Wendell makes explicit how her personal experience has informed her analysis of disability. This situating of the critic (as we call it in critical theory) sharpens her important contribution to the philosophy of disability by reminding the reader that the particulars of impairment influence the definition of disability.

Wendell's first task is to use philosophical inquiry to query "whether 'people with disabilities' is a meaningful category" (p. 8). She examines next the social factors that interact with impairment to create disability. Here she focuses on the politics of appearance, normative expectations, and cultural representation. Her following move is to shrewdly infuse Goffman's stigma theory with feminist theory. In doing so, she speculates suggestively on the notion of interpreting difference as neutral, or perhaps as a valuable source of knowledge, laying out an implicit rationale for positive identity politics. Next, she critiques two cultural discourses that define disability: first, the fantasy of the perfect body that is driven by commercial interests and the media; and second, the authoritative medical discourse that frames disability as illness and lack, rather than difference.

After these clarifying critiques, Wendell turns more toward feminist issues, such as the controversial ethic of care, which she insists more fully consider the perspectives of people with disabilities. Finally, using feminist insights about the body, she offers a philosophy of transcendence for living with pain. At this point, the particularity of her account is essential so that readers recognize that suffering is only one manifestation of some impairments, not the universal mark of disability.

This book enriches the growing field of Disability Studies by using a humanities perspective to blend social, philosophical, and personal analyses of disability. Wendell shows very usefully how feminist theorizations of the body, care, standpoint, and appearance can expand disability theory.

Wilkinson, Sue, and Celia Kitzinger, eds. *Representing the Other: A Feminism & Psychology Reader*. Thousand Oaks, CA: Sage Publications, 1996, 204 pages, \$65.00 hardcover, \$19.95 softcover.

Reviewed by Adele Gorelick, Washington, DC.

"Nothing About Me Without Me" reads the button distributed by the Oregon Developmental Disabilities Council, and the idea is echoed by disability activists throughout the U.S. Participatory action research is part of an attempt to address this long-standing issue: How do you represent Otherness when you are not yourself a member of the population you are studying?

Because the female has been the archetypal Other, this collection of short articles by an impressive array of writers contributing to the third of Sage's series of *Feminism & Psychology Readers* reflects ample credentials for a discussion of the Other.

We read about infertility, being overweight, HIV/AIDS, the white woman researcher and the black woman subject, lesbian/bisexual politics, young and old, prostitutes. For those interested in disability concerns, there is the dilemma of being able-bodied and teaching Disability Studies.

If women have been universally "othered" by the male establishment, people with disabilities, male and female, are the ultimate Other. We are either invisible ("Does she want milk in her coffee?") or incapable of choice ("Let's keep them safe in a separate building.").

To be sure, the I-you, we-they dichotomy is present for everyone. Negotiating the problems of Othering, say the editors, has taken several paths: speaking only for ourselves (when you rewrite

Others' stories you are, according to bell hooks [as quoted from *Yearning*], "author, authority . . . colonizer" [p. 11]); celebrating Otherness (with the attendant "temptation to exaggerate the exotic" [p. 13, as quoted from Olson and Shopes in "Crossing Boundaries, Building Bridges"]); destabilizing Otherness (with its risk of thinking simply in terms of duality, "keeping the binary structure intact" [p. 15]); and interrupting Othering ("how to speak without our words serving to disempower Others" [p. 16]).

I like Michelle Fine's approach (as quoted from "Working the Hyphens" in *Handbook of Qualitative Research*): "By working the hyphen, I mean to suggest that researchers probe how we are in relation with the contexts we study and with our informants' understanding that we are multiple in all those relations" (p. 16).

Erica Burman asks that we work to "recognize ourselves in Others" (p. 26). Anita Harris suggests "fruitful and respectful representation" (p. 152), a strategy of advocacy that "establishes with the powerful the responsibility of dealing with the power imbalance" (p. 154). Gabrielle Griffen says, "It is only through the acknowledgement of difference and the impetus to use that difference in favour of other women, that representing Others can become a tool for change" (p. 174).

The notion of social change "works the hyphen." Partnership models involving both Maori and non-Maori researchers, described by Kate Paulin (pp. 113-117), could be a model. Another model is Deborah Marks' pragmatic approach "to identify and challenge any exclusionary practices which might be operating in my institution" (p. 66). "I hope," she says, "that a pragmatic approach avoids the arrogant enterprise of representing the experience of the disabled 'Other'" (p. 66). (As Brown puts it, "Whoever the Others might be, they are not solely located in their bodies" [p. 129].)

And then there is the purple and yellow button worn by the self-advocates in Oregon: "Nothing About Me Without Me." That says it all.

Video Clips

Gralen, Paul, and Wendt, Adam (Producers). *Abandoned to Their Fate: A History of Social Policy toward People Labeled Severely Disabled* [video]. Eugene, OR: Northwest Media Inc. School Projects/STP (1235 University of Oregon, Eugene, OR 97403; 541/346-2488), 1997, 27 minutes, captioned and uncaptioned, \$45.00 purchase.

Reviewed by Phyllis Rubinfeld, Ed.D., Professor, Hunter College of the City University of New York.

Paul Gralen and Adam Wendt have succeeded in creating a video, which is both dignified and informative, that is based on the work of Philip Ferguson about attitudes toward people with significant disabilities. This brief piece takes on the demanding task of documenting the history of people with mental retardation, mental illness, and physical disabilities from the Middle Ages through today. The visual presentation chiefly features sketches and current photos, all of them tastefully done. The visual aspect of the medium is used to illustrate the well-known fact that, historically, people with disabilities have tended to be both abandoned and invisible within the larger society; the text is taken from Ferguson's research and lectures.

Ferguson's thesis is that society's perception of disabled people is the result of its own aesthetic, moral, and economic failures. He addresses the fact that diagnoses of mental illness and/or mental retardation are often based solely on physical appearance, thereby reflecting a traditional cultural bias in favor of physical beauty. He connects the fact that physical appearances perceived as "scary" were frequently correlated with negative sexual overtones, pointing out that people so identified were the focus of such extreme measures as the Eugenics Movement, which promoted forced sterilization of the "unfit" and the notorious 19th Century "idiot asylums." The visual impact of a photograph of a gravestone labeled simply "220" graphically and dramatically points out that people with disabilities continued to be isolated and abandoned even after death, when they were denied the dignity of having their names carved on their tombstones.

The 19th Century rise of the poorhouse and rehabilitation through physical regimen and

control are discussed in an informative and dramatic manner, while respecting the dignity of the people labeled severely disabled. Attention is given to the 1960s' reliance on institutions, which declined, although community programs still remain segregated. Disability rights advocates challenge these segregated programs, and there is a move from abandonment to inclusion.

The only criticism I have of this video is the photo of Charles Lawton, which is dated; and, thus, a very important point is lost. In addition, I would suggest that this video be expanded into a longer, more in-depth history. It is an excellent and tasteful history of social policy toward people labeled severely disabled.

Philip Ferguson's research and lectures have resulted in a video from a cultural sociopolitical perspective based on the principles and philosophy of Disability Studies. This video can join the few videos about disabled people that come out of a scholarship called Disability Studies.

Gralen, Paul, and Wendt, Adam. *Abandoned to Their Fate: A History of Social Policy toward People Labeled Severely Disabled* [video]. Eugene, OR: Northwest Media Inc. School Projects/STP (1235 University of Oregon, Eugene, OR 97403; 541/346-2488), 1997, 27 minutes, captioned and uncaptioned, \$45.00 purchase.

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

This video focuses on societal response, primarily in the first half of the 20th Century, toward those with disabilities. The presentation is singularly narrated and supported visually by a well-researched photo collection. The argument is made that society historically has rendered persons with disabilities invisible, based on the perception of such individuals as human "failures" - in aesthetic, moral, and economic terms.

The concept of aesthetic failure is sharply illustrated through the example of an IQ test from the mid-20th Century that required a child to select the "pretty" face from among a row of faces with physical disfigurements. The legacy of such "failed appearance" used as a source of entertainment is shown in the "Zippy the Pinhead" comic strip character, based on actual carnival sideshows featuring persons with microcephaly.

Another video segment addresses the societal notion of persons with disabilities as representing economic failures. An example is given of an institutionalized group of young men with mental illness being given the task of moving a pile of large rocks, only then to be told to turn around and return them to their original location. This exercise in futility is echoed toward the end of the presentation, as a brief discussion of more recent advancements refers to the replacement of simulated tasks with meaningful occupation. The video ends by challenging the viewer to cultivate an awareness of media images of disabilities, and to encourage the replacement of historically-based stereotypes with images of dignity and competence.

I would recommend the use of this video in any higher education setting to broaden student awareness of historical treatment of people with disabilities.

Michalczyk, John J. (Producer/Director). *In the Shadow of the Reich: Nazi Medicine* [video]. Cicero, NY: Program Development Associates (5620 Business Avenue, Suite B, Cicero, NY 13039; 1-800/543-2119), 1997, 54 minutes, \$99.00 purchase.

Reviewed by Carol Poore, Department of German Studies, Brown University.

This short documentary video provides a clear factual introduction to some of the ways in which Nazi physicians participated in sterilization and "euthanasia," selections at the death camps, and unethical human experimentation. Drawing on both historical material and interviews with contemporary experts (including Michael Kater, Benno Muller-Hill, Michael Grodin, and Susanne Hahn), the film stresses the enthusiasm with which large numbers of German doctors supported the Nazis' goal of creating a biological superstate by eliminating the "unfit." Although only twenty-three physicians were eventually charged with crimes at the Nuremberg Physicians' Trial in 1946-1947, the film

correctly shows that this small group had been buttressed by much wider agreement with Nazi policies from the ranks of their colleagues.

First, the film highlights the international nature of the eugenics movement (known as "racial hygiene" in Germany) as it developed around the turn of the century. It briefly mentions the popularity of eugenic thought in the United States and a few of the connections between German and U.S. eugenicists. In fact, when the Nazis first came to power, they looked approvingly to U.S. sterilization laws as models for their own such law.

Second, the film enumerates the ways in which doctors, nurses, and other members of the medical profession with the mindset of genetic perfectibility played leading roles in the campaigns to eliminate people with specific disabilities and in genocide. Under the Nazis' racial programs, between 300,000 and 500,000 people were sterilized involuntarily, and about 120,000 people (many of them children) were killed by doctors at six "euthanasia" centers in Germany. Doctors, including the notorious Josef Mengele, selected who would live and who would die in the concentration camps and carried out military and genetic experiments on the inmates there. The film concludes that the lesson to be learned from the Nuremberg Physicians' Trial is that of the inviolability of human research subjects.

This film provides a helpful historical introduction to some pressing issues in bioethics today that are of utmost relevance to people with disabilities. The Nazis sterilized, starved, killed by injection, or gassed many of those with disabilities whom they wanted to eliminate. Their methods reflected the level of their scientific knowledge. Yet, through more "advanced" techniques, such as prenatal testing for genetic abnormalities, and through the growing acceptance of euthanasia in the form of physician-assisted suicide, perhaps the Nazis' goals are being carried out with more refined means today. This film presses such questions onto the viewer. Its only drawback, in my opinion, is its shortness. It remains very cursory, and I think it would require quite a lot of supplementary knowledge in order to be used effectively in a classroom or discussion setting.

Michalczyk, John J. (Producer/Director). *In the Shadow of the Reich: Nazi Medicine* [video]. Cicero, NY: Program Development Associates (5620 Business Avenue, Suite B, Cicero, NY 13039; 1-800/543-2119), 1997, 54 minutes, \$99.00 purchase.

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

Seeing a movie like *Schindler's List* can leave a sinking feeling of reality in your stomach. Then, along comes a documentary on the reasons for the events in Nazi Germany and the origins of the beliefs that led to these events to not only turn your stomach, but leave everlasting visions of horror in your mind. *In the Shadow of the Reich: Nazi Medicine* takes an all-too-real look into the origin and development of Nazi eugenics (a form of biological "cleansing" through sterilization) and how that belief escalated to a full-blown extermination.

This documentary highlights the conceptualization of eugenics in the United States and shows how this belief was incorporated into German medicine in the early 1900s. At this time it was believed in the U.S. that there were "good" genes, and there were "bad" genes. The so-called "bad" genes were the cause of such disabilities as blindness, mental retardation, and schizophrenia, as well as other impairments and deformities that were considered "not normal." It was decided that people should not be able to bear offspring if they had any history of this in their family. These beliefs led to sterilization laws throughout the U.S.

German medicine, revered for its advances in the world of medicine at the time, mirrored what the United States had conceived. But what was to come would change the world forever. In 1933 the National Socialists took over Germany, and the racial theories of the time began to give way to practice. In a span of over seven years, it was estimated that 300,000-500,000 people were sterilized to prevent genetically "inferior" offspring. This gave way to euthanasia, which allowed those who would not live "normal" lives to die a "pleasant" death. The costs alone makes you wonder how a

government could promote such a program. The German government did recognize the cost and, so, began the more extremely unethical elimination process of anyone who did not fit the Aryan definition of a "normal" person. Doctors, the only ones to make these diagnoses, the people we trust with our lives every day, became leaders of the extermination squads picking and choosing sons, daughters, wives, husbands, brothers, mothers, all to be killed for not fitting the Aryan ideal. Mentally retarded children were starved to death, families were placed in designated ghettos to die, human pharmaceutical studies were carried out, and tortuous twin studies were conducted to further German medicine.

After all was said and done, the Nazi doctors were finally brought to trial in 1946 for their crimes. Their defense, based on a justification of the need for information, did not carry much weight. As a result of the trial, a ten-point Code of Ethics evolved for doctors that helped open our eyes to life and to not taking stock in the biases against those who may be different than we are.

The documentary's use of detail and graphic visuals sets the tone for a deluge of thoughts and emotions to mull over. As a student about to enter a health profession, it is hard to fathom the doctors' thinking at that time. The advancement of medicine is always a great thing. But at the expense of human life? If people choose to subject themselves to medical research to help find a cure, then I see no harm. For example, AIDS patients today sometimes willingly subject themselves to new medical experimental studies that may or may not work. They are guinea pigs in the doctors' hands. As more diseases develop with no known cures, will we again turn to human trials in the hope that they will help the human race continue on? It is said that history repeats itself, but, in the case of Nazi Germany, let us hope that it does not.

Sutherland, David (Producer/Director), Sutherland, Nancy, and Ticchi, David (Producers). *Out of Sight* [video]. New York, NY: The Cinema Guild, Inc. (1697 Broadway, Suite 506, New York, NY 10019-5904), 1994, 85 minutes, closed captioned and video description encoded, \$395.00 purchase, \$125.00 rental.

Reviewed by Paul. K. Longmore, Professor, Department of History, and Director, Institute on Disability, San Francisco State University.

This video documentary profiles Diane Starin, whose eyes were surgically removed due to cancer of the optic nerve when she was 18-months old. Living in a small northern California town, the 34-year-old woman is an expert horsewoman. Several brief scenes also show her as a leader in the local blind community. She instructs a blind teenager both in cooking and in orientation and mobility. She moderates an advocacy group that discusses how to support a blind boy's right to educational accommodations and critically considers a newspaper's publication of a stereotyping joke. But Starin's activism is a minor theme in this documentary. The video focuses mainly on her troubled relationship with her lover, Herb Martin, a 60-year-old alcoholic cowboy with whom she lives and raises horses. Herb is typically emotionally distant and, at times, emotionally abusive. Diane, in retaliation against Herb and out of longing for tenderness and true intimacy, sleeps with a great many men she meets at country-music clubs. In the end, she falls in love with a 24-year-old man who wants to marry her. Her mother, Harriet, and her best friend, Gillian, openly ponder with her whether she should move out to join her new lover or stay with Herb, who has been diagnosed with terminal cancer, in hopes of inheriting his house. Then there is Ziggy, Diane's stepfather, who frankly despises her, but is unable - or unwilling - to explain just why.

Starin comes across as capable, articulate, assertive, and attractive. Yet, by scanting or avoiding a number of issues, this video leaves viewers with an incomplete understanding of this woman. Why is she on SSI? She mentions employment difficulties in passing. What sorts of work has she done? Has she encountered job discrimination? How has disability prejudice affected her relationships, especially with men, and with Herb and Ziggy in particular? What does she see as her role in the blind community and the importance of blind people in her life? (Gillian has a visual impairment, too.) Attention to these sorts of questions would have yielded a more revealing, more complex, and

less puzzling portrait of this interesting blind woman.

Vasey, Sian (Producer/Director). *Disability and Motherhood* [video]. Cicero, NY: Program Development Associates (5620 Business Avenue, Suite B, Cicero, NY 13039), 1995, 25 minutes, \$99.00 purchase.

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

The consensus of a number of staff at Through the Looking Glass is that this is a good introductory videotape about mothers with physical and vision disabilities. It touches on significant issues and could be a catalyst for discussion, while its brevity would be advantageous for use in a support group, an in-service, or a class. Diverse audiences could benefit from viewing the tape, e.g., prospective parents or parents with disabilities, or professionals and students unfamiliar with disability. The videotape has a respectful orientation and uses first-person accounts of three mothers: Lydia Thomas, a wheelchair user with paraplegia; Cathy Rafferty, who has cerebral palsy; and Ellen Blackman, who is blind. Michele Wates, a mother with a disability and the author of *Disabled Parents: Dispelling the Myths*, provides an informed commentary.

The joys and resourcefulness of each mother are presented, without avoiding the dilemmas or sources of pain in the women's experiences. For all three mothers, one has a sense of the gradual gaining of confidence in mothering, despite obstacles. Ellen describes her postpartum anxiety and her need for privacy in order to explore baby care solutions without feeling judged. She conveys the initial pressure to be Supermom, associated with reluctance to seek support, and how she eventually chose some assistance. These early struggles contrast with images of independence and of flourishing with her children, e.g., cuddling with them while she reads Brailled stories.

Wates mentions the variability of professional and social responses to mothers with disabilities, through time as well as depending on their disabilities. Varying attitudinal obstacles are illustrated by contrasting the experiences of two of the women. Lydia, a wheelchair-user, has concluded from responses to her that attitudes have changed, and "it's a bit of a myth" that people make negative comments about disabled mothers. Cathy, who has cerebral palsy and speech involvement, describes numerous insensitive public and professional responses to her role as a mother, including staring at her, as captured on videotape. Her resourcefulness in helping her older children deal with stigmatization among their peers is illustrated through their proactive development of a class project on disability.

The videotape ends with Cathy, the mother who has described the most obstacles to mothering: "I think the reason I seem to be a success is that I'm happy with who I am, and disability is a part of that. If you take my disability away - who knows - I might have made a lousy mother."

Vasey, Sian (Producer/Director). *Disability and Motherhood* [video]. Cicero, NY: Program Development Associates (5620 Business Avenue, Suite B, Cicero, NY 13039), 1995, 25 minutes, \$99.00 purchase.

Sandra Laplante, Student, Masters in Occupational Therapy Program, Lewiston-Auburn College of the University of Southern Maine.

Most women with disabilities are able to conceive and to carry and give birth to children. The challenge comes after the birth. Because of their experiences in a fairly inaccessible world, the mothers in this video feel quite prepared to cope with the challenges of raising a child. The three fascinating women in this video present their unique lives, relationships, and child-raising stories, each with a very different experience.

Lydia, who uses a wheelchair, describes the smell of a baby as "simply delicious." She expresses complete happiness with her experience as a pregnant woman and, currently, as a mother. While her physical condition after the cesarean birth reminded her of her limitations when she was first injured, she feels that the awareness of the public has improved greatly in recent years, and she

notes that she felt very much supported through her pregnancy and birthing process.

Ellen, who is blind, experienced childbirth several times and indicates that she always encounters others who ask "how are you going to manage?" before they congratulate her on her new baby. She expresses a desire to have privacy to experiment with her new challenges on her own, as opposed to having so many people around her trying to solve problems for her. She feels that there may be some disadvantages to her children because of her condition, but she perceives that there are some advantages as well.

Cathy, who has cerebral palsy, makes great efforts to ensure that her children are not "made to wear her disability at such an early age." She does this by being proactive and encouraging open communication with others. Her experiences with the general public have been mainly stares, but she feels strongly that motherhood is her right, and she has never felt that she should have to ask anyone if she should have children.

One piece that could have been addressed more was the relationship with the male partner and his role in child care. What is each woman's experience with her significant other since the birth of their child?

Lastly, the title *Disability and Motherhood* places the emphasis on the disability. Perhaps *Motherhood and Disability* would have been more appropriate.