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## Editor's Preface

On June 12, 1996, the Board of Directors of the Society for Disability Studies accepted the stewardship of the Disability Studies Quarterly. The offer was sent by Judy Norsigian on behalf of the DSQ Steering Committee. Along with the offer came the commitment by Dean John F. Brennan of the Sawyer School of Management at Suffolk University to publish DSQ for a twelve month period with an expectation of two further years of support. At the same meeting the Board elected me as editor for a three year term. There were four other tentative offers for publication support for which the DSQ Steering Committee and the SDS Board of Directors are gratified. As editor I will be seeking further financial support to guarantee the future existence of DSQ.

As part of his support for DSQ Dean Brennan made it possible for Nicole Medeiros, an MPA graduate student at Suffolk University, to join the DSQ staff as production assistant. Working with Monique Perrier, administrative assistant, she will improve the appearance of DSQ. Over the next year you will notice differences. Please tell us if there are any remarkably favorable or unfavorable changes in the appearance of DSQ. We are experimenting.

This issue on developmental disabilities is a first for DSQ. Phil Ferguson put together an exceptional issue which you will enjoy. Elaine Makas mentored another excellent collection of book reviews. There are also announcements and communications of note.

### **Focus on Developmental Disabilities**

Phil Ferguson

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The relationship of people with developmental disabilities to the rest of the disability community has not always been a comfortable one. Even the name itself reflects this uncertain status. As a label, "developmental disability" is a governmental creation. If you look at the official definition, you see a combination of age-related functional and categorical elements that seem to extend the application of the term beyond mental retardation. Yet, in most states, the term "developmental disabilities" has largely become a synonym for mental retardation. If a truly functional definition were applied, then many people with mild intellectual disabilities would probably not be eligible for the formal services that the DD label brings. On the other hand, many individuals with significant physical disabilities might become eligible for such programs. Of course, the reality is that what comes with such eligibility is often little more than the privilege of joining a wait list for vocational or residential support. Still, one wonders why more people with physical disabilities have not been banging on the doors of their local DD agencies demanding equal access to the official label and the services behind it. (It is equally true that in many states, individuals with multiple disabilities are excluded from eligibility for personal

assistance services if one of their labels is "developmental disability.")

This official ambiguity simply mirrors the continuing uncertainty within the disability rights movement itself. It is less common now, but I still remember how frequently many disability advocates would challenge some assault on their rights or dignity by loudly proclaiming: "I may be Deaf (blind, use a wheelchair, etc.), but I am not retarded." The implicit pecking order of disabilities usually found mental retardation somewhere near the bottom of acceptability, even within the disability community itself.

As this edition of Disability Studies Quarterly illustrates, the situation is changing. Increasingly, people with disabilities are cutting across some of the traditional barriers to scholarship and advocacy that have often perpetuated the separation that categorical programs encouraged. The contributions to this issue try to continue this process. Steve Taylor provides a brief but thorough review to some of the basic issues that surround the notion of disability culture and people with cognitive disabilities. The annotated bibliography that accompanies his piece makes an excellent starting place for anyone wanting to dive into the progressive research and analysis that has emerged within the field over the last 30 years. Susan Gabel tackles the thorny issue of inclusion in educational settings (and elsewhere) with a provocative application of Foucault's concepts of power/knowledge.

Finally, I try and review the recent historiography of mental retardation. Happy reading.

### Current Research

#### **Disability Studies and Mental Retardation**

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People tagged with the label of mental retardation -- or, if you prefer, cognitive, intellectual, or developmental disability -- have been major targets of social prejudice and discrimination in Western societies. Forced segregation, state sanctioned abuse and dehumanization, status degradation and public mortification, involuntary sterilization, denial of fundamental rights, and even euthanasia occupy prominent roles in the history of mental retardation. No one can deny that people labeled mentally retarded have endured many harms at the hands of the nondisabled majority.

Yet those interested in understanding the social phenomenon known as mental retardation and reversing the historical pattern have yet to find a comfortable intellectual and academic home. On the one hand, special education, vocational rehabilitation, and other helping professions are dedicated to treating or "fixing" what is presumably wrong with the mentally retarded. Even humanistic approaches in these fields are based on a belief in the objective existence of mental retardation. On the other hand, it has not always been clear whether people labeled mentally retarded can fit under the broad umbrella of the disability rights movement and Disability Studies as an area of inquiry.

In this brief article, I argue that the study of mental retardation, as a social and cultural construct, belongs in Disability Studies and demonstrate how many of the principles associated with Disability Studies can be applied to the study of mental retardation. At the conclusion of this article, there is an annotated bibliography of selected books and articles that can serve as a foundation for inquiries in this area.

The perspectives and experiences of people labeled mentally retarded must provide a starting point for all research and inquiries in the study of mental retardation. Consistent with a Disability Studies perspective, studies must focus on how people tagged as mentally retarded view and experience their worlds. In contrast to people with disabilities such as deafness, blindness, or mobility impairments, many of those labeled mentally retarded cannot easily communicate their views. From a Disability Studies perspective, this becomes a problem to be solved -- how can we understand their subjective experience? -- rather than grounds for dismissing their points of view.

Mental retardation is a social construct and cultural artifact. This is not the place to provide a critical review of efforts to measure the illusive concept we call intelligence or to explain how mental retardation has been reified. Selections in the following annotated bibliography address these issues in depth. Suffice to say: of course, there are differences among people in intellectual ability, but this does not prove the objective existence of the construct of mental retardation or the utility of dividing humanity into two groups -- the retarded and non-retarded. Who is or is not considered mentally retarded hinges on arbitrary and professionally controlled definitions and classification procedures. The construct of mental retardation exists in the minds of those who label other persons, and

not those so labeled.

People labeled mentally retarded represent a minority group. The category of people labeled mentally retarded represent an historically powerless and discriminated-against minority group. The minority group model associated with Disability Studies generally (Hahn, 1987; Linton, 1994) applies equally well to people with this label.

That said, the concepts of a disability culture and a disabled identity are foreign to people labeled mentally retarded. If the starting point for inquiries into the disability experience is the point of view of disabled persons themselves, then we must take seriously the perspectives of people defined as mentally retarded. For people labeled as mentally retarded, the concept of culture carries negative meanings. One meaning associated with culture is the professional construct of cultural-familial retardation, a construct rooted in the Eugenics movement and used to justify sterilization and other policies designed to prevent the spread of feeble-mindedness.

Another meaning of culture is Goffman's (1961) notion of the subterranean life of inmates of total institutions. In this latter sense, people labeled retarded may be said to share a distinctive culture to the extent that they have been forcibly removed from their families and communities and subjected to the routines of various forms of total institutions and human service settings.

Whereas many leaders of the disability rights movement claim pride in an identity as a disabled person, representatives of the growing "self-advocacy" movement reject the mentally retarded tag and insist on being defined as "people first." What draws people labeled mentally retarded together is a recognition of their oppression and determination to oppose how they have been defined and treated in society. Coming

together represents an affirmation and celebration of common humanity.

The important role that family members play in the lives of people labeled mentally retarded must be recognized. For various reasons, some legitimate and some not, parents and other family members are influential in the lives of children and adults labeled mentally retarded. Scholarship in this area includes inquiries into the views and experiences of families of people with the mental retardation label. It should go without saying that the voices of family members cannot be regarded as a substitute for the voices of labeled people themselves.

Inquiries into the social, cultural, political, and economic situation of people labeled mentally retarded must be grounded in concepts and philosophies associated with Disability Studies generally. The classics and the heroes guiding Disability Studies can also guide those wishing to understand and change the situation of people labeled mentally retarded. The point of studies in this area is not to establish a separate field of inquiry, but to explore how people labeled mentally retarded can be included in broader discussions of such issues as disability, gender, race, culture, and class.

This raises the interesting and challenging question of who should speak for people labeled mentally retarded in academic and scholarly circles. Should the voices of members of other groups who have faced societal prejudice and discrimination be privileged? Or should we listen to parents and family members of people labeled mentally retarded and especially those defined as severely disabled? Should long-term allies and advocates of people defined as mentally retarded lead the way? Each of these groups can play an important role in studies in this area.

Consistent with a Disability Studies

perspective, however, people labeled mentally retarded must be permitted to speak for themselves. The culture of academe, with its emphasis on literacy and intellectual skills, poses obstacles to the participation of people so labeled in research and training in this area. A culture that evaluates students by their SAT or GRE scores hardly presents a welcoming environment for those with a substandard IQ. Herein lies the challenge for those of us concerned with understanding this social cultural phenomenon. We must find creative ways of involving people labeled mentally retarded in our work, whether through oral histories and autobiographies, jointly authored articles, guest lectures and presentations, or professional staff appointments at research and training centers.

Above all, we must stay close to the reality and experience of those we seek to understand.

#### References

- Goffman, E. (1961). Asylums. Garden City, NY: Doubleday.
- Hahn, H. (1987). Advertising the acceptably employable image: Disability and capitalism. Policy Studies Journal, 15, 551-570.
- Linton, S. (1994). Disability studies vs. Disability policy studies. Disability Studies Quarterly, 14(2), 23-26.

#### Bibliography

##### **Selected Annotated Bibliography on Disability Studies and Mental Retardation**

*Compiled by Steve Taylor and Perri Harris*

#### **History**

- Blatt, B., & Kaplan, F. (1974).

Christmas in purgatory: A photographic essay on mental retardation. Syracuse, NY: Human Policy Press.

This is a reprinted edition of Blatt and Kaplan's 1966 photographic expose of conditions in America's institutions. Shot with a hidden camera, Christmas in Purgatory depicts overcrowded and dehumanizing conditions found at eight institutions in the Northeast. Blatt was one of the few professionals to speak out against institutional warehousing in the 1960s.

Bogdan, R. (1988). Freak show: Presenting human oddities for amusement and profit. Chicago: University of Chicago Press.

A social history of the depiction of "human oddities," including people with disabilities, for amusement and profit. Freak Show is a classic study of depictions of disability in popular culture.

Ferguson, P. M. (1992). Abandoned to their fate: Social policy and practice toward severely retarded people in America, 1820-1920. Philadelphia: Temple University Press.

A historical study of social policy and practice toward people labeled "idiots" or "severely retarded." Ferguson examines the problem of "chronicity" and shows how people with the most severe disabilities have been and continue to be excluded from reform movements.

Gelb, S. A. (1995). The beast in man: Degenerationism and mental retardation, 1900-1920. Mental Retardation, 33(1), 1-9.

Gelb describes the chain of scientific and theological reasoning that led to the perception of people with mental retardation as a social menace prior to the eugenics movement around the turn of the 20th century. According to degenerationism, the "feebleminded" formed a missing link between humans and lower species.

Gould, S. J. (1981). The mismeasure of man. New York: W. W. Norton & Co.

This is a history of attempts to define and measure the illusive concept of intelligence. Gould does a masterful job of demonstrating the ideological assumptions underlying psychological science.

Smith, J. D. (1985). Minds made feeble: The myth and legacy of the Kallikaks. Austin, TX: PRO-ED.

Debunking Goddard's infamous Kallikak study that purported to show the hereditary transmission of "feeble-mindedness," Smith traces members of the Kallikak family and demonstrates how facts were twisted by the eugenicists to prove their theories.

Trent, J. W. (1994). Inventing the feeble mind: A history of mental retardation in the United States. Berkeley: University of California Press.

A sobering historical analysis of institutions and mental retardation. Arguing from a political economy perspective, Trent locates the source of abuse of people with mental retardation in the tendency to equate moral worth with economic productivity.

Wolfensberger, W. (1975). The origin and nature of our institutional models (Rev. Ed.). Syracuse, NY: Human Policy Press.

This is an analysis of the development of, and growth in, institutions in the 19th and 20th centuries. The book examines institutionalization in terms and philosophies of leaders in the field of mental retardation. This book contains the foundations for Wolfensberger's influential writings about "normalization" (now called social role valorization).

### Theory

Biklen, D. (1988). The myth of clinical judgment. Journal of Social Issues, 44(1), 127-140.

This article challenges the primacy of professional decision-making and argues that

clinical decisions are influenced by other factors such as economics, bureaucratic exigency, politics, service traditions, and societal prejudice.

Bogdan, R., & Biklen, D. (1977). Handicapism. Social Policy, 7(4), 14-19.

The authors introduce the concept of handicapism as a way to understand disability as a social construct. They define it as a "set of assumptions and practices that promote the differential and unequal treatment of people because of apparent or assumed physical, mental, or behavioral differences." Handicapism results in prejudice, stereotypes, and discrimination.

Dexter, L. (1994). On the politics and sociology of stupidity in our society. Mental Retardation, 32, 152-155.

This is a reprint of an article originally published in the early 1960s. Dexter offers one of the first discussions of the social meaning of mental retardation. Using labeling theory and a social constructionist approach, he argues that traditional notions of mental retardation and intelligence need to be more critically examined.

Nibert, D. (1995). The political economy of developmental disability. Critical Sociology, 21(1), 59-80.

The article outlines the history of the treatment of people with disabilities from a historic materialist perspective. Framing his discussion around issues of political economy, the author argues that the experiences of people with disabilities, from work to cultural devaluation, stems from the political and economic context. He further asserts that exclusion of people with disabilities from the labor force and society, and by making them scapegoats for economic and social problems, have served to legitimate 20th century American capitalism.

## Social and Cultural Studies

Bercovici, S. (1983). Barriers to normalization. Baltimore: University Park Press.

Focusing on people with mental retardation living in seven residential care facilities, Bercovici discusses how the human service system employs practices that promote dependency, passivity, fear, and incompetence for the people receiving these services. She links these problems to the larger service delivery system and to a dominant culture that oppresses and controls a subordinate group's aspirations to achieve a normal life style.

Bogdan, R., & Taylor, S. J. (1989). Relationships with severely disabled people: The social construction of humanness. Social Problems, 36, 135-148.

The authors discuss how nondisabled people define their caring and accepting relationships with people with severe disabilities. The authors frame their discussion around a sociology of acceptance and identify four dimensions which maintain humanness of the people with severe disabilities: attributing thinking to the other, seeing individuality in the other, viewing the other as reciprocating, and defining social place for the other.

Bogdan, R., & Taylor, S. J. (1994). The social meaning of mental retardation: Two life stories. New York: Teachers College Press.

The concept of mental retardation is challenged through life histories based on in-depth interviews with former inmates of institutions for people labeled retarded. The authors argue that mental retardation is not a real entity, but rather a social construction.

Edgerton, R. B. (1993). The cloak of competence: Revised and updated. Berkeley: University of California Press.

This updated edition of a classic ethnography in mental retardation focuses on

former inmates of institutions for people with mental retardation. The author addresses stigma, passing, and the role for normal benefactors.

Edgerton, R., & Gaston, M. A. (Eds.) (1991). "I've seen it all!": Lives of older persons with mental retardation in the community. Baltimore: Paul H. Brookes Publishing Co.

The authors offer life histories of nine elderly people who have lived independently in the community for at least thirty years. These qualitative studies are based on participant observation and highlight each person's background, family history, institutional experience, and community life.

Ferguson, P. M., Ferguson, D. L., & Taylor, S. J. (Eds.) (1992). Interpreting disability: A qualitative reader. New York: Teachers College Press.

A compilation of qualitative and interpretive studies of people with disabilities or their families. The chapters are divided into four parts: disability at the edges of life, disability and the schools, disability and the community, and disability and culture.

Goode, D. (1994). A world without words: The social construction of children born deaf and blind. Philadelphia: Temple University Press.

Based on his study of two girls who were born with rubella and are deaf-blind and mentally retarded, Goode argues that despite a use of formal language, human beings can communicate and be understood through other means. He shows how the children created their own set of symbols to construct their reality using senses other than sight and sound.

Goode, D. (1992). Who is Bobby? Ideology and method in the discovery of a Down Syndrome person's competence. In P. M. Ferguson, D. L. Ferguson, & S. J. Taylor (Eds.), Interpreting disability: A qualitative reader (pp. 197-212). New York: Teachers

College Press.

Goode uses an "emic" approach to the study of people with developmental disabilities. This approach is contrasted with typical "etic" or medical/objective approach. An emic approach is a subjective or insider point of view that may offer a better understanding of the competency of a person with a developmental disability.

Groce, N. (1992). "The town fool." An oral history of a mentally retarded individual in small town society. In P. M. Ferguson, D. L. Ferguson, & S. J. Taylor (Eds.), Interpreting disability: A qualitative reader (pp. 175-196). New York: Teachers College Press.

Groce explores the life of Millard Fillmore Hathaway, an individual labeled mentally retarded who lived in a small northeastern town in the late 19th and early 20th centuries. Groce reports that villagers categorized Millard as the town fool, although he was an accepted part of the community.

Langness, L. L., & Levine, H. G. (Eds.) (1986). Culture and retardation. Dordrecht, Holland: Reidel.

This compilation of ethnographic articles focus on the life experiences of people labeled mildly mentally retarded. They stress that mental retardation is more of a socio-cultural phenomenon than a medical/psychological one. The articles cover the subjects' lives in terms of their childhood, patterns of adapting to everyday life, and their response to the label of retardation. In addition, the editors offer a discussion about life history research of people labeled mentally retarded, as well as a discussion about anthropological contributions to this type of study.

MacEachen, E., & Munby, H. (1996). Developmentally disabled adults in community living: The significance of personal control. Qualitative Health Research, 6, 71-89.

The authors explore issues in community living from the perspective of people with mild developmental disabilities. Participants report imposed control by service providers and isolation from the community. Most important, they wanted to be independent and in control of their own lives.

Mercer, J. (1973). Labeling the mentally retarded. Berkeley: University of California Press.

Based on an 8 year study that used IQ tests to screen 7,000 people for mental retardation, Mercer discovers that schools label people mentally retarded more than any other institution, that minorities are over-represented in the category of mental retardation, and that after leaving school most people are no longer included in this category. Mercer examines the social and cultural aspects of being labeled mentally retarded, but does not question the construct itself.

Taylor, S. J., & Bogdan, R. (1989). On accepting relationships between people with mental retardation and nondisabled people: Towards an understanding of acceptance. Disability, Handicap & Society, 4, 21-36.

The authors discuss a "sociology of acceptance" as a theoretical model for understanding relationships between people without disabilities and people with mental retardation. They state that family, religious commitment, humanitarian sentiments, and feelings of friendship are all sentiments expressed by nondisabled people who have relationships with people with mental retardation.

Taylor, S. J., Bogdan, R., & Lutfiyya, Z. M. (Eds.) (1995). The variety of community experience: Qualitative studies of family and community life. Baltimore: Paul H. Brookes Publishing Co.

The editors present qualitative case studies that focus on people with disabilities



living in communities and assuming roles as full members of society. The studies present the perspectives of the people with disabilities or their families, rather than service providers. This provides the opportunity to understand how people with disabilities make choices, earn a living, form friendships, and maintain family relationships.

### Law and Policy

Braddock, D., Hemp, R., Bachelder, L., & Fujiura, G. (1995). The state of the states in developmental disabilities (4th ed.). Washington, DC: American Association on Mental Retardation.

Published by the AAMR, this book provides a financial analysis of mental retardation and developmental disabilities services on a state by state basis. The information is statistical and is presented in the forms of graphs, charts, and tables. Information covers the last 16 years, and includes an analysis of trends in developmental disability services, profiles of resource allocations and service delivery, and technical information. Topics covered include institutional services, closure of institutions, trends in community services, and costs of care.

Lakin, K. C., Braddock, D., & Smith, G. (Eds.) (1994-2000). Trends and milestones. Mental Retardation.

This is a regular one-page feature of the journal, Mental Retardation. "Trends and Milestones" summarizes current national data on issues such as institutional closures, state and national deinstitutionalization trends, and federal and state expenditures for developmental disability services.

Rothman, D. J., & Rothman, S. M. (1984). The Willowbrook wars. New York: Harper & Row.

Documents events that occurred after

court ordered reforms of Willowbrook, an institution for people labeled mentally retarded. Rothman and Rothman follow events at Willowbrook from 1975 to 1982 in an attempt to understand social reform and its implications for people being institutionalized.

Taylor, S. J. (1988). Caught in the continuum: A critical analysis of the principle of the least restrictive environment. Journal of The Association for Persons with Severe Handicaps, 13 (1), 41-53.

This article examines the principle "least restrictive environment" and the associated "continuum" concept which have served as frameworks for the design of residential, vocational, and special education services for people with developmental disabilities. The author identifies the conceptual and philosophical flaws underlying these notions and argues for the need to develop new concepts and principles to guide the development of services.

Wehman, P. (Ed.) (1993). The ADA mandate for social change. Baltimore: Paul H. Brookes Publishing Co.

Contains articles that explore the importance of the ADA and its impact for people with disabilities and specifically people labeled mentally retarded. The articles explore such issues as educational reform, family empowerment, employment opportunities, reasonable accommodations, and attitudinal changes.

### Parent and Family Issues

Ferguson, P. M., Ferguson, D. L., & Jones, D. (1988). Generations of hope: Parental perspectives on the transitions of their children with severe retardation from school to adult life. Journal of The Association for Persons with Severe Handicaps, 13, 177-187.

This study explores how parents interpret the events and relationships

surrounding the transition of their children with severe cognitive disabilities from school to adult life. The authors show how transitions are complex, socially constructed processes that need to be understood in both their historical and their cultural context.

Foster, S. B. (1987). The politics of caring. Philadelphia: The Falmer Press.

Foster studied 13 admissions to the Weston Center, an institution for people labeled developmentally disabled. She also studied four people whose applications for admission were denied. She offers discussions on institutionalization and deinstitutionalization, the limits and powers of professionals, and private troubles such as family involvement or lack of involvement.

Turnbull, H. R., & Turnbull, A. P. (1985). Parents speak out: Then and now. Columbus, OH: Charles E. Merrill Publishing Co.

The editors offer a compilation of essays that present the perspectives of parents or relatives of people with disabilities. The essays illustrate that having a child with a disability is not invariably a burden to the family. This second edition offers updates from families profiled in the first edition as well as three new essays.

### Contemporary Issues

Dybwad, G., & Bersani, H. Jr. (Eds.) (1996). New voices: Self-advocacy by people with disabilities. Cambridge: Brookline Books.

Documents the self-advocacy movement through a collection of papers by both advocates and self-advocates. It examines the status of self-advocates with developmental disabilities and projects the future of the movement as it expands worldwide. Topics include the historical setting, the self-advocate experience,

worldwide views, critical views, and future work in the movement.

Exchange of opinion on the risks and benefits of facilitated communication. (1994). Mental Retardation, 32, 299-318.

A series of commentaries on the potential risks and benefits of Facilitated Communication (FC). The first commentary by Levine, Shane, and Wharton is a critical analysis of FC by leading opponents of FC. This is followed by reaction papers by Ferguson and Horner, Goode, Halle, and Hitzing, none of whom are identified with a pro or con position on this technique. Levine, Shane, and Wharton provide a response to the reaction papers at the end. An editorial introduction provides background on this mini-symposium.

Ferguson, D. L. (1994). Is communication really the point?: Some thoughts on communication and membership. Mental Retardation, 32, 7-18.

This article examines communication interventions as one example of professional efforts to ameliorate the effects of severe disability. The author argues that the real point of such efforts is not so much improved communication as membership in society and that attention should shift from changing behavior to insuring that membership is achieved.

Kennedy, M. J. (1994). The disability blanket. Mental Retardation, 32, 74-76.

Written from the perspective of a person with a disability, Kennedy discusses the problems of being an individual in a service system that invades privacy and takes away choices. He argues that the people with disabilities should be allowed to be in control of their own lives, to receive services when and where they want them, and have professionals consult with them rather than answering to professionals.

Mank, D. (1995). The

underachievement of supported employment: A call for reinvestment. Journal of Disability Policy Studies, 5(2), 1-24.

Despite the thousands of individuals benefiting from supported employment, access to these programs is limited and investment in change is lessening. Mank provides recommendations for change such as new alliances with people with disabilities, investing in community and employers, putting greater control into the hands of people with disabilities, and rejecting the segregation of the current system.

Jacobson, J. W., Mulick, J. A., & Schwartz, A. A. (1995). A history of facilitated communication: Science, pseudoscience, and antiscience. American Psychologist, 50, 750-765.

This article is must reading for anyone interested in understanding the controversy surrounding facilitated communication. According to the authors, facilitated communication is an example of postmodernist trends that have challenged the supremacy of psychological and clinical decision-making. The article demonstrates why facilitated communication has aroused such passionate opposition among certain professionals.

Perske, R. (1995). Deadly innocence? Nashville, TN: Abingdon Press.

Perske documents the life of Joe Arridy, a man labeled "feeble-minded" who was forced to confess to the rape and murder of a teenage girl. Despite little evidence, Arridy was convicted and executed in 1939. Perske examines the case against Arridy and the possible connections between being labeled "feeble-minded" and confessing to crimes. His arguments offer implications for the present day criminal justice system.

Meyer, L. H., Peck, C. A., & Brown, L. H. (Eds.) (1991). Critical issues in the lives of people with severe disabilities. Baltimore: Paul H. Brookes Publishing Co.

This is an edited book sponsored the Association for Persons with Severe Handicaps (TASH). The book includes TASH resolutions on major policy issues confronting people with severe cognitive disabilities as well as literature reviews and essays authored by major TASH leaders. The contributions to the book provide an excellent summary of recent trends and current thinking on community living, supported employment, social relationships, inclusive education, nonaversive behavioral interventions, and advocacy.

O'Brien, J. (1994). Down stairs that are never your own: Supporting people with developmental disabilities in their own homes. Mental Retardation, 32, 1-6.

O'Brien discusses the recent changes in living for people with disabilities from group home residences to homes of their own. Meeting the challenges of supported living requires new relationships among people who provide and receive supports so that people with developmental disabilities can establish a sense and security of place and of personal control over their own homes and over the assistance they require.

Special topic on facilitated communication. (1994). Journal of The Association for Persons for Persons with Severe Handicaps, 19, 149-199.

This is an exchange of opinion between leading proponents, Biklen and Duchan, and opponents, Shane and Green, of facilitated communication. The exchange of opinion is followed by reaction papers commenting on the pro and con positions.

Taylor, S. J., Bogdan, R., & Racino, J. A. (Eds.) (1991). Life in the community: Case studies of organizations supporting people with disabilities. Baltimore: Paul H. Brookes Publishing Co.

The editors provide qualitative case studies of organizations that support people with disabilities in community places. Topics

covered include organizations supporting children with severe developmental disabilities, and organizations supporting adults with developmental disabilities in their own homes.

(Steve Taylor is Professor and Coordinator of the Disability Studies Concentration in Cultural Foundations of Education and Director of the Center on Human Policy at Syracuse University. Perri Harris is a doctoral student in the Disability Studies Concentration. Preparation of this article and annotated bibliography was supported in part by the National Resource Center on Community Integration, which is funded by the National Institute on Disability and Rehabilitation Research. Of course, the authors' opinions are their own.)

**Inclusion and Issues of the  
Disabled Identity**

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There are many approaches to the issues surrounding inclusion. The minority group model argues that, as a minority group, the disabled are oppressed (Hahn, 1988; Peters, 1993). The application of this model to inclusion would indicate that disabled students have a basic civil and moral right to be in schools and classrooms with their age-mates. Within this framework, minority groups have the same rights to access to public institutions and regular school programs that majority groups have. The American civil rights movement is the standard bearer in this way of understanding disability. On the other hand, the disability culture model might argue

along slightly different lines, claiming that the experience of disability binds people together into a community or subcommunities that share a common culture and that pulling those community members apart (as happens in inclusion) disrupts their right to socialize with their community of choice. This is often the model cited in discussions related to deaf students, many of whom understandably prefer to be in school with other deaf people. All models have their limitations and so do these or any others used to understand the complexities of disability and inclusion.

This article examines a supplemental way of understanding the disabled identity, a way of approaching identity challenges that sheds light on another way of thinking about inclusion. At its core, this article is about conceptualizing the disabled identity in a new and flexible way and then applying that to inclusion problems and possibilities.

The notion of constructivism has been around awhile and it is a helpful place to begin when examining identity. Robert Bogdan and Steven Taylor (1982/1994; 1989) offer an account of the disabled identity that is consistent with constructivist ways of thought. In their model, we are all without identity until we are constructed by others. And in that construction, we can be perceived as disabled or not disabled, but in the end we are constructed as human or not human by those with whom we interact (1989). For Bogdan & Taylor, and their study participants, humanness is constructed in the way in which others perceive us. In this sense, Harlan Hahn might agree with Bogdan & Taylor when they claim that disability is constructed in the social perception of others.

Like the minority group and disabled culture models, constructivism falls a bit short when we try to apply it to inclusion or other real problems of life with or without a disabled identity. Constructivism might explain why

things are the way they are, but it does not give us a way to move forward. For that, Michel Foucault's work is helpful. I now closely examine some Foucauldian concepts. Later I bring us back to inclusion and identity.

Supporting and facilitating construction of the disabled identity, and assisting us in making the connection between disability and inclusion policy, lie social processes which can be, to a certain degree, described. Foucault's examination of the circulation of power throughout social institutions is relevant to issues of identity and inclusion. His analyses of institutions and their control over the body (where "body" refers to both individuals and the larger social body) is central to the intersection of inclusion and disability identity. Although many of Foucault's works could be utilized, I use Discipline and Punish (1979) and The Birth of the Clinic (1973) for two reasons. First, they both trace the development of institutions that are directly related to the foundational philosophies and values of Western institutions that interact with students with disability. Special education and medicine are disciplinary institutions in the Foucauldian model. Second, discipline (as conceptualized by Foucault) and medical-clinical methods are currently utilized as processes that affect the lives of students identified as disabled and considered for inclusion.

In The Birth of the Clinic, Foucault develops a theory with which Peters and Hahn appear to agree. The body itself is perceived as ill and disease is believed to be located within the body (p. 3). Nineteenth century medicine developed, in part, due to the fear of disease and the glorification of normality (p. 34-36). The ideological preference for normality over "pathology" remains important in medicine and education today. This perceived tension between normality and pathology was the result of the "convergence between the

requirements of political ideology and those of medical technology" (p. 38). (Here I consider educational technology with the medical because special education still functions under the medical model.) Medicine as an institution, Foucault suggests, developed out of an ideological desire to protect the normal against the abnormal in combination with the technological ability to do so. The clinic, in turn, developed as the site of medical learning and intervention, thus producing the notion of the clinical method that has evolved to its present meaning synonymous with the medical model: diagnosis, prescription, treatment that is focused on the individual. This individual focus, this Foucaultian "gaze" that rests upon individuals, was for Foucault an artifact of scientific ideology that believed in observation as a logical, analytical tool of science (p. 109). For Foucault, observation of the individual is to science what words are to discourse and the discourse of medicine is the language of pathology.

Discipline and Punish extends our understanding of Foucault where the body now becomes the site for the exercise of socio-political control in the form of discipline. Whereas medicine uses the body as the site of control of normality against pathology, discipline's "gaze" is one of surveillance by continuous observation with the purpose of "correct training" (p. 170-174). In this aspect of Foucault's work, the body is an "object and target of power" (p. 136). "The body that is manipulated, shaped, trained, which obeys, responds, becomes skillful and increases its forces" (ibid.) is docile, is coerced into submission by the very presence of the disciplinary gaze. Here in the disciplinary institution (to which I claim special education belongs), perhaps even more than in the clinic, the individual body becomes an element that may be placed, moved, articulated on others. Its bravery or its strength are no longer the

principal variables that define it; but the place it occupies, the interval it covers, the regularity, the good order according to which it operates its movements. (p. 164)

Discipline, then, is good training, and the school building is a "mechanism for training" (p. 172). And although for Foucault power is essentially corporeal, fundamentally fixed within the individual body, power is most effective when it appears to those receiving power as noncorporeal (p. 177), as in consequences for actions of examinations in schools (p. 184-185), or deciding who can and cannot be involved in special education, inclusion, or neighborhood schools.

The disciplined individual in Foucault's framework is an object, a describable, analyzable "case" whose individual features are maintained through documentation (Foucault calls this the "power of writing"), and who is dominated by the very act of individualization because individualization allows power to become functional. Foucault notes that "those on whom it [power] is exercised tend to be more strongly individualized" (p. 193). In this sense, power produces reality, an individual form of reality. And "the individual is carefully fabricated" in a society that produces reality in this way (p. 217).

An attempt to understand how disability is construed as an essential human experience requires a closer look at Foucault. Here we can see the relationship between Foucault's clinic and clinical applications to disability in education where disabilities are diagnosed through observation, through the testing process, and through the application of categorical labels to qualify students for special education services. Abnormal (disabled) students are separated out from normal ones in public schools today just as medicine has sorted the normal from the abnormal.

Discipline in education is perhaps an

even more insidious process. "Correct training" (*Discipline and Punish*, p. 170) requires the manipulation of the body in ways that cause it to cooperate, to submit, to obey. Those who do not obey are punished. Those who cooperate are rewarded. The "placement" of the body regulates it (ibid., p. 164). Schools and the military are two primary examples used by Foucault. Although Foucault did his research prior to the advent of regulated special education, I believe he would argue that special education is the punishment given to students who do not cooperate, who do not submit. If this is true, what, then, is inclusion?

So this is the special education heritage and, by default, the heritage of inclusion. Special education as an institution is wholly dependent on its ability to identify individuals who are disabled. Inclusion, too, is dependent on that identification. We would not even call it inclusion if a student with no "labels" were in general education full time. We would call it education, or school. Even the possibility that a student might be identified as a disabled individual through the special education testing process suggests the presence of surveillance, and, in turn, discipline.

Power, bodies, discipline, and training are all potent concepts. They bring very real images and memories to mind and it is probably easy to agree with Foucault that power can be a negative force. But one thing Foucault claims seems too inconsistent with the best ideals in education today. He suggests that the individualization of the body, the singling out of people, the documentation of individual traits, is an exercise of power. Yet, even the most humanistic teaching philosophies advocate for such processes. Running records are used to keep narrative accounts of individual children's growth and development. Early childhood educators believe that children develop at individual rates

and that these rates should be recognized. Classroom teachers are often reminded that children are all different and they must not expect all children to act the same, learn the same, have the same interests or motivations. Special education, itself, is founded on a belief that each disabled student should have an individual educational program. This individualization process is written into special education regulations and is required to be performed on an annual basis. I have always thought this was one of the good things about special education and that we should keep it at all costs. How is this ideal in education, an ideal that appears so humane, completely deconstructed by Foucault? Is individualization really the tool of body power he claims it is, and how does this apply to inclusion?

The problem, it seems, is in who is doing the individualizing. If a person in authority (doctor, teacher, judge) is individualizing, then the humanity, the essence of the one who is being individualized is vulnerable to the construction of another. The individualization might be improperly done, or might devalue the person being individualized. The authority, the exerciser of power, then, is not only constructing the essence of another, but is also fixing upon that person's body the reality perceived by an outsider. If, however, a person individualizes herself, if she says, "Here is what is unique about me," or "Here is how I want to be understood," then no other authority is constructing her. She is, then, in control of her own body.

This may seem esoteric, but it has very practical and broad significance in our understanding of disability, special education, and inclusion. It takes us back to the minority group model that argues for a conceptualization of disability as a socio-political movement. It reminds us of Harlan Hahn who argues that his disability

exists only in the perception of others. It suggests that inclusion, with its dependence on special education identification, may be another tool of power. But rather than a punishment for non-cooperation, it suggests that inclusion is a reward for good behavior, for obedience, for the appropriate response to coercion in special education. But this view of inclusion is only true if it is the educational institution making identification, eligibility, and inclusion decisions.

If, on the other hand, students are given the freedom to choose a disabled identity, to even choose a particular type of disability as their identity, then inclusion (and even special education) become strategies available to those students who prefer them. In this way of viewing inclusion, we can no longer identify someone as disabled (and therefore needing inclusion) unless they first self-identify. This poses a significant challenge to schools. How can schools educate all children without labels unless those children self-identify? It directs us to examine our ideology and ask why it is that we individualize, and when it is more important to perceive similarities rather than differences in students. It also presses us for facilitating the equal participation of students and others with disability in the policy processes that impact eligibility for special education and identification of educational disabilities.

But Foucault's work and the concept of self-identification also poses real systemic and organizational problems. How would any educational system function effectively without the imposition of individualization for students who struggle to meet educational demands? Likewise, how do we facilitate self-individualization or self-identification with students who have significant cognitive or communication limitations? And, when facilitating these matters, how can we be sure we are not imposing our perceptions of their

identity upon them? And what would happen if disabled students, some of whom have self-injurious or dangerous behaviors, chose to be in regular school environments because they chose to be de-individualized? Should some students be more free to self-identify than others? If so, how do we decide who they may be? And what would we do about the very young children who are not developmentally ready to make such decisions?

On the one hand, Foucault leads us to the realization that the disabled identity should begin at the individual level with self-identification. If self-identification is a requirement, if a disabled identity is contingent on such self-identification, and if the power to claim that identity is based solely on the perception of a disabled experience by an individual, then special education and inclusion are only applicable to those individuals who decide to be considered disabled and who choose those programs. But this turns the entire educational system on its head. On this hand, schools, teachers, and parents are expected to allow students to have the freedom of choice. It gives students choices about whether they feel disabled and, if so, in what capacity. It gives them options for schooling and makes special education and inclusion items on an educational menu that any student might select. It moves schools from where they are now to places where people construct (to the greatest degree possible) their own identity. It gives students options to create communities more by choice and less by the imposition of identity perceptions of others. It suggests that in some schools or districts special education might evolve or become extinct while in others it might flourish as is.

In the final analysis, the incorporation of Foucault's cautions against individualization pose serious challenges to the educational

system. But the challenges are worthwhile and should be explored. This article gives some philosophical reasons for that exploration. But it also raises questions of cultural beliefs about children, childhood development, children's rights and the view of "smart" disabled people about "retarded" disabled people. Even if disability scholars and activists were able to convince others that self-identification is a human right, those others might not agree that minor-age children should be free to make such decisions. Nor is it clear if the disabled community and its subcommunities could agree that people with cognitive differences (those labeled mentally retarded, for example) are capable of these decisions. The disabled identity is only one inclusion issue. Others remain unresolved and largely unexplored.

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## **Mental Retardation Historiography and the Culture of Knowledge**

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As with most - but not all - disabilities, mental retardation has not received a lot of historical attention. It is interesting to speculate about the reasons for this relatively undeveloped stature of the field's history. If one begins with the assumption that the research agenda within any field is never set in a cultural vacuum, then the relative neglect of the historical aspects of mental retardation becomes a cultural artifact as much as a disciplinary oversight. Society's attitude towards mental retardation, as well as the relationship of professionals within mental retardation to the larger academic community, both influence and reinforce the scholarly agenda for research within the field. There is nothing unique about this. It is generally the case that the intellectual topography of a field of study (especially within the social sciences) is not a map of a simple search for knowledge no matter where it dwells, but rather reflects the concerns of society and the professional assumptions of the field. Given such motives, exploration of the thickets of the history of disability - and mental retardation in particular - has promised little reward or "payoff" in the scientific marketplace. This "scientific" perspective dominates mental retardation. Within this perspective, history is usually an inconvenient afterthought: a comfortable reassurance in moments of depression about how far the field has progressed from the quaint beliefs of our primitive ancestors. However, the status of history in the social sciences has recently been rising. As a field within social science, mental retardation has

slowly learned the lessons of its own past.

As an inherently interdisciplinary undertaking, the historiography of mental retardation can begin from either of the two obvious perspectives: history or mental retardation. From the perspective of history one can speculate about why the topic of mental retardation has remained so largely ignored by academic historians. From within the field of mental retardation, one can ask how researchers in the field can be satisfied with a grasp of history that seldom reaches back further than the personal recollections of the field's elder dignitaries. A review of the literature in mental retardation history, then, must go fairly far afield and bridge many gaps.

What follows is my attempt at just such a review, albeit brief and selective. It will also (to my pleasure) quickly become outdated. A new group of excellent historians (e.g., James Trent, Gary Woodill, and Stephen Noll, just to name a few who have presented their work at SDS conferences) are rapidly adding to the list of well-done historical research in this area. I should also explain that some of the terms that I use in my review are properly offensive to our ears today (e.g., idiocy, insanity, moron). However, these terms are not simply less acceptable synonyms for currently preferred labels. These terms have their own contextualized meaning for their era, and so I have not avoided them.

### **Recent History and Mental Retardation**

Recent trends in social and cultural history have made at least two additions to conventional coverage of a field's intellectual history. First, attempts are now commonly made to deal more with ordinary people rather than (or, as is the case here, in addition to) the elite classes dominant within traditional intellectual history. The overused phrase

"history from the bottom up" attempts to summarize this perspective (Lemisch, 1968). Second, much social and cultural history has examined the institutions, customs, and behavior relevant to these ordinary people. In addition to wars, elections, and philosophical fashions, the social historian tends to analyze "sexual behavior; social mobility; family roles and functions; attitudes and practices relating to death; popular health and medicine, including mental illness; crime and law enforcement" (Stearns, 1983, pp. 4-5). Mental retardation would seem a natural topic, given these criteria. Yet, with some significant, recent exceptions (e.g., Ferguson, 1994; Friedberger, 1981; Katz, 1983; Luckin, 1983; Reilly, 1991; Rothman & Rothman, 1984; Smith, 1985; Trent, 1994; Tyor & Bell, 1984; Tyor and Zainaldin, 1979), historians have seldom noticed the topic except in passing.

The contrast with mental illness is striking. The two categories of mental illness and mental retardation are closely associated throughout history. Service systems for both areas have evolved on parallel, if not identical, lines, at least within medical and social service bureaucracies. Yet, as topics of historical study, the two categories of mental disability assume very different aspects, with mental illness receiving much more attention. The question is why?

#### Reasons for Neglect

The numbers game. One rather straightforward answer must not be ignored. There are simply more people labeled mentally ill than are labeled mentally retarded and there probably always have been. Historically, the institutional system for mental illness was much larger than that for mental retardation. For example the 1880 census (probably the most thorough national survey of the "defective and dependent populations" in the nineteenth century) found almost 92,000 insane people and almost 77,000 idiotic

people. Yet, when restricted to institutional populations the disparity becomes much greater. Some 38,000 people reportedly lived in insane asylums in 1880, but only 2429 people lived in idiot asylums. Even if one allows for a fifteen to twenty year time lag for developments in the field of mental retardation compared to mental illness, the rates of institutionalization remain very different. In 1860, there were 8500 people labeled mentally ill in asylums, or 35% of the total identified mentally ill population. The percentage of retarded people in asylums (either specifically for them or in insane asylums) was around 5% in 1880, and 8% in 1890. If one adds in those listed as idiotic residents of the almshouses throughout the country, the percentages come to 12% and 16% respectively (Gorwitz, 1974; Lakin, 1979; Wines, 1888). In the eastern states this disparity in numbers went beyond the institutional population to the proportions for the general populace. In New York State, for example, over twice as many people were labeled insane as were labeled idiotic in 1880 (2.75/1000 people to 1.20/1000).

The argument can be fairly made, then, that simply on a numerical basis the historical impact of mental illness touched more people and thus deserves the larger share of attention given to it by historians. What the numbers do not justify is the apparent insignificance with which historians have judged the role of mental retardation in the nineteenth century. Indeed, the profound question raised by the differing rates of institutionalization is why so many people viewed as idiots or imbeciles were left at large in the community when institutional control and rehabilitation were supposedly official policy?

Personal narrative. A second explanation of the historiographical dominance of mental illness is equally straightforward and particularly relevant to the interests of social history. It is a simple fact of history that there

is much more personal testimony left behind for historical analysis from people labeled with any of the various types of mental illness. People institutionalized as insane have often returned to society to write about both the experience of their malady and their mistreatment. Clifford Beers' A Mind that Found Itself (1908/1981) is only the most famous of a host of such personal narratives and exposes. Social historians especially concerned to avoid reliance on official writings and testimony of the keepers instead of the kept, have, in the case of mental illness, a body of written material from precisely the people whose collective voice needs to be heard (Peterson, 1982; Porter, 1987).

The history of mental retardation largely lacks such primary sources. Most retarded people did not write books. While it is not true that no such firsthand evidence exists for retarded people (the case files at many institutions, for example, have letters written to institution administrators by inmates on parole or discharged from the asylum), there is less of it and it is less accessible than for people incarcerated for mental illness. Surely, though, the silence of retarded people is not particularly greater than that of other marginal or isolated groups studied by social historians (e.g., tramps, orphans, Native Americans). Nonetheless, it is at least not surprising (if also not totally blameless) that such a fairly young field as social history should first attend to the larger piles of unexamined evidence.

Intellectual stigma. A third explanation for the lack of interest by practicing historians in mental retardation is, in fact, a repetition on a smaller scale of the very forces that deterred for so long the examination of society's underclasses in general. Social hierarchies both reflect and reinforce the intellectual hierarchies of respectable research for a given time and place. Mentally retarded people

remain stigmatized by society as largely incurable and hopeless in their supposed misery. Even within the disability community, one can sometimes encounter an implicit pecking order of disabilities with retardation at the bottom. The television movie of the week chronicles the struggle of a physically disabled young woman to get out of the institution because she is not really retarded. The unstated message is that the really retarded person should indeed remain there. Mental retardation remains, for most, the boundary condition that resides just on the other side of hope. It remains the condition one must escape rather than improve.

This continuing social stigma mirrors an intellectual stigma toward mental retardation as a useful field of historical study. Dull people make for dull history. The supposed futility of treatment translates into a futility of study. Cultural stereotypes have served unconsciously to leave the story of mental retardation largely untold.

The stereotype of mental illness has a much more appealing aura. Madness has always been the malady of choice for genius. The sensitive spirit driven insane by a heartless and less perceptive world is personified by Van Gogh painting some of his striking landscapes from the vantage of his insane asylum window. Nietzsche reminds us of the tortured philosopher whose fevered insights betrayed a mind burning up. Even on the more mundane levels of life, we chuckle at Elwood P. Dowd introducing his rabbit Harvey to an unimaginative world, vicariously enjoying his attack on logic and routine. It is a part of our cultural mythology of indomitable individualism to demand such archetypes. Surely the mystery of the distracted intellect can show some hidden part of ourselves; the dark side of our psychological moon. Retardation possesses no such revelatory cachet to attract an academic embrace for

research. An invidious intellectual pecking order seems to operate that subtly assigns worth to objects of knowledge. Some things - some people, it seems - are more worth knowing about than others.

Labels and reality. A fourth and final reason for the relative neglect of mental retardation as an appealing area for historical inquiry builds on the notions of social construction and cultural relativism commonly used today in both social science and social history. Many of social history's now classic studies (e.g., Demos, 1970; Katz, 1968; Rothman, 1971, 1980) rely heavily on the perspectives of social control and labeling theory prominently developed in the social sciences (Becker, 1973; Goffman, 1961). Oversimplified, these perspectives argue that specific categories of deviance are invented, rather than discovered, by society, and especially by that part of society most in control of the distribution of the economic and cultural benefits available. This approach fits nicely with criminality where the arbitrary nature of social definitions of lawlessness are hard to deny and vary greatly throughout history. Even with mental illness, the social construction of reality can be convincingly demonstrated by examining the patterns of incarceration (Brenner, 1973; Jimenez, 1987), or the classifications and explanations of emotional distress highlighted in different eras (Dwyer, 1987; Figlio, 1978; MacDonald, 1981; Rosen, 1968).

Mental retardation, however, often seems more refractory to such analyses because of the supposedly inescapable chronicity associated with it. This is especially true if one limits the discussion to the more severe or congenital forms of retardation. The presumed "futility" of retardation makes it seem more a matter of basic biology than social construct. Given such rigidity, mental retardation as a type of deviance becomes

much less attractive to the social theorist. One social critic sarcastically summarized this scholarly aversion in the blunt terms of the vernacular (perhaps less stigmatizing than the technical labels of the experts): "Stupid people, if they are not so low-grade as to horrify, are usually boring, especially to intellectuals. It is not so easy to glorify stupidity as it is madness, or to see the definitions as only those of social deviance and non-conformity." (Ryan, J., 1977, p. 153) Insanity, on the other hand, is thought to have "an intrinsically compelling quality" that has understandably attracted "several important historians in the attempt to unravel its complexities" (Jimenez, 1987, p. 2).

The few cases of historical attention to mental retardation bear out this argument. Where historians have examined the category they have focused on periods where previously undiagnosed people were newly named as retarded. The eugenics movement that coincided with the spread of the IQ test in the first three decades of the twentieth century illustrated the methods of controlling poor young women from spreading the results of their promiscuity and dependence to future generations (Gould, 1981; Haller, 1984; Jenkins, 1984; Ludmerer, 1972; Mottus, 1983; Reilly, 1991).

The largely implicit assumption of such analyses is that there was a legitimate category of mentally defective people to which, however, society assigned other groups of people who did not really belong, for the sole purpose of controlling these latter groups' behavior (Ray, 1983; Reilly, 1983; Selden, 1977). In other words, the category of mental retardation often becomes interesting to the social control school of historians only in its misapplication, not as a basic category of social construction. The category itself is never questioned, but rather the "bad science" that places people there who do not belong.

Thus, severe mental retardation serves both as the boundary condition for society itself, and, on a second level, for the intellectual study of that society. Severe disability, with its obvious physiological basis, has been less interesting to social historians, I would argue, at least in part because it is seemingly less subject to the vagaries of those in control of the social machinery and less susceptible to the phenomenological understanding of everyday life.

### **Historiography of Mental Retardation**

A shift in perspective from that of historical research focusing on mental retardation to mental retardation research that deals with history presents a different set of problems. There is, in fact, a substantial body of historical literature written by people within the professional fields associated with mental retardation itself. The problem here is one of content, not quantity, although even with these internal accounts the focus has remained almost exclusively on events most pertinent to the milder levels of retardation. Once again, the cultural "lag time," so often a feature of developments in this field, applies to the status of mental retardation history. Twenty or thirty years ago, the historiography of most professions such as nursing, psychology, engineering, and even teaching (to a large extent) consisted mainly of a combination of reminiscences of elder statesmen and women mixed with intellectual accounts of important discoveries and new theories. Social history and the burgeoning history of professions have radically changed that situation in most fields, with medicine and psychology being the most thoroughly altered (Bledstein, 1976; Grob, 1973, 1983, 1991; Reverby & Rosner, 1979; Scull, 1975, 1976, 1979; Starr, 1982).

Typically, the status of mental retardation history lags behind that of other professional subdivisions. Much of our information about the field in the nineteenth and early twentieth century still comes from the published memories of leading lights glancing back at the changes in their professional lifetimes (Doll, E.A. 1964; Fernald, 1924; Kuhlman, 1940/41; Wallin, 1953/54, 1958, 1960).

### **Some Recent Work**

Despite a growing number of valuable additions (Ferguson, 1994; Sarason & Doris, 1979; Scheerenberger, 1983, 1987; Simmons, 1982; Smith, 1985; Trent, 1994; Tyor & Bell, 1984; Wolfensberger, 1975), the written history of mental retardation remains more sketch than portrait with a few isolated events and some eminent personages receiving more detailed attention. In most areas the research literature is woefully inadequate. Most professionals in the field know something of Itard and Victor (the "Wild Boy of Aveyron"), and the story has been ably told in at least two recent histories (Lane, 1976; Shattuck, 1980). A hazy awareness of the eugenics period is also common. Again some excellent studies have recounted at least the intellectual history attached to that period (Gelb, 1987; 1995; Gould, 1981; Haller, 1984; Jenkins, 1984; Ludmerer, 1972; Reilly, 1991; Winzer & O'Connor, 1982; Zenderland, 1986). However, beyond these occasional flourishes of detail, the history of mental retardation is largely known only by headlines, if at all. The area of mental retardation has simply not matched the growth of attention in other areas of deviancy to the "new social history."

There are several accounts that do limit their focus somewhat and attempt to provide an interpretive framework for developments in America (Adams, 1971; Baumeister, 1970; Doll, E. E., 1970; Farber, 1986; Ferguson, &

Ferguson, 1987; Hollander, 1986; Lazerson, 1983; Trent, 1994; Wolfensberger, 1975). Most of these begin around 1850 and end around 1970 focusing almost exclusively on the institutional history of mental retardation or the development of special education classes. With the institutional histories there is usually a three or four stage model of the evolution in residential care in America. A "golden age" of reformist zeal and optimism precedes a variously divided sequence of increasing custodialism and segregation. These treatments vary in thoroughness; however, Wolfensberger's version (1975) is probably the most frequently cited within the field of mental retardation (e.g., Menolascino & McGee, 1982). All of these accounts continue to share some or all of the basic problems plaguing mental retardation history.

Finally, there are some fairly recent case studies that begin to supply a reservoir of data from which more adequate interpretive syntheses can be drawn. Some of these studies focus on particular institutions (Bragar, 1977; Dwyer, 1992; Ferguson, 1994; Graney, 1979; Royfe, 1972). Others focus on specific states such as Massachusetts (Balasalle, 1980) and Rhode Island (Rochefort, 1981). Lakin's (1979) compilation of census and NIMH data provides a readily accessible fund of basic statistics - building on Baumeister (1970), and Wolfensberger (1975) - that is important to have at hand. Nonetheless, much remains to be done if the history of mental retardation is to progress further. There needs to be a series of narrow studies examining more specific topics in more detail. Some of these need to be local histories, narrow in their geography. Others need to examine more specific aspects of mental retardation, such as family life or the role of physical disability in mental retardation - narrow in their concept. Otherwise, the problems of past historiography will never disappear.

### Problems of Mental Retardation History

There are four specific problems with the existing literature beyond its basic inchoate stature. Each of these problem areas influences the nature and goal of this study.

A lack of detail. First, most of the work has tended to survey large chunks of history. One of the more ambitious, histories begins its account at 1,000,000 B.C and works forward (Scheerenberger, 1983). Needless to say, such breadth almost mandates some shallowness in places. Large, synthesizing treatments of the past can be insightful, of course, by omitting detail to make the basic outline newly visible. Indeed, much of the best social and cultural history of recent years consciously adopts such an approach. Usually, however, this sweep of time covers decades, not centuries (Stearns, 1983), and the survey can rely on an ample accumulation of detailed case studies and local histories. Unfortunately, in most modern survey treatments of mental retardation history, omissions overwhelm the insights. Some of these books are simply superficial outlines of history (Kanner, 1964; Simmons, 1980). A few gloss over great spans of time to concentrate on the most recent decade or two at length (Davies, 1923, 1959). Others become little more than useful chronologies of events filigreed with details in place of interpretation (Scheerenberger, 1983, 1987; Sloan & Stevens, 1976). One of the more useful, recent efforts limits itself largely to developments in Ontario, Canada (Simmons, 1982). An interesting case study of the Willowbrook institution on Staten Island (Rothman & Rothman, 1984) concentrates on the events of the last 20 years. Even if one excuses an institutional bias in most of these histories, there still exists an absence of interpretive or illustrative case histories for specific, important institutions similar to those done in mental illness (Dain, 1971; Dwyer,

1987; Grob, 1966; Tomes, 1984), criminology (Rothman, 1981), and nursing (Mottus, 1983). For the history of mental retardation to progress there needs to be a series of narrow studies that examine local developments more intensively and from creative perspectives.

The lack of everyday reality. The second specific difficulty is that most mental retardation history written so far has been more of a history of psychological thought. There are numerous intellectual histories of the concept of intelligence (e.g., Mann, 1979; Robinson, 1976; Vernon, 1960), with mental retardation often serving as a boundary definition. Even when focused more exclusively on mental deficiency, the studies have remained well within this "headlines and heroes" structure, attending to a few famous psychologists, superintendents, and educators and the main ideas they argued (Doll, E.E., 1962; Kanner, 1967; Luckey, 1967; Spitz, 1986; Talbot, 1964, 1967; Whitney, 1949/50, 1952/53). The psychometricians from Goddard to Doll to Wechsler have had their battles chronicled (Blanton, 1976; Doll, E. A., 1964; Kuhlman, 1940/41; Linden & Linden, 1968; Zenderland, 1986). Developments in epidemiology, organization, or treatment "regimens" have also had their recorders (Davies, 1959; Doll, E. E., 1970). What one finds in the literature is a history of mental retardation, not a history of mentally retarded people. We know much more about Itard and Goddard than we do about Victor and Deborah Kallikak. This is a fatal flaw for modern history. "A litmus test for the success of socio-historical inquiry is whether it adequately conveys the experiences of the people being characterized, independently of (though not necessarily in opposition to) the activities of dominant institutions or the canons of high culture" (Stearns, 1980, p. 213). How theory translates into practice is never a transparent process. Attention in

mental retardation must be given to what people did in order to complete our understanding of what they thought.

The lack of severity. A third problem with this area of history is its overarching concern with mild retardation almost to the exclusion of severe retardation as a sustained consideration. There are, and always have been certainly, more mildly and moderately retarded people than severely retarded people. When dealing with devalued or marginal populations, the more people included under a given label, the more attention they are likely to receive from historians just as much as politicians. Furthermore, most severely handicapped people have never, until recently, had reason to hope for change. Innovations in services did not occur often for this population except in purely medical terms.

There is, also, the problem of historical definition. As already mentioned above, one can not simply transfer modern terminology back one hundred years without confusion and distortion. Even if one discards the term "severely disabled" or "retarded," it is still difficult to know sometimes when writers in the nineteenth century use the term "idiot" in the narrow sense of the lowest level of cognitive functioning or the more popular sense of all feeble-mindedness.

None of this explains the degree of neglect of severe retardation as a topic. In his account of residential asylums, for instance, Baumeister (1970) comments on the early exclusion of severely retarded people, but passes over it with an unquestioning acceptance: "It is clear that certain types of severe retardates were regarded as completely intractable [sic] and that educational efforts should be directed toward those with the prospect of being cured or, at the very least, who showed promise of considerable improvement." (p. 9) Wolfensberger (1975) also notes that "only some retarded children

were seen to be proper candidates for institutional education" (p. 25), yet fails to develop the topic.

The rise of custodial asylums after 1875, unavoidably involves severely disabled people in any historical account. The whiggish tendencies of most mental retardation history simply recounts the stated rationales of asylum superintendents for the overwhelming flood of untrainable inmates. One often cited account of the rise of custodial asylums repeats the official explanation enthusiastically. The disruptive social conditions in the last half of the nineteenth century stemmed from the rapid industrialization and urbanization of society. Suddenly, "a vast array of social pathology resulted from the rapid and severe dislocations in patterns of living. It soon became clear . . . [that] the young retarded adult or adolescent would be unlikely to remain intact for long in the harsh and chaotic social conditions prevailing outside [the asylum], unless he was able to return to an exceptionally stable and sympathetic environment." (Adams, 1971, p. 25)

This evolution of large, custodial asylums was not only inevitable, says Adams, but was a tribute to the dedication and vision of the asylum leaders: "The pace and variety of developments in the 90-odd years after Massachusetts is a testimonial to the professional people in the field who were committed to struggling for these necessary changes" (pp. 43-44). The problem, of course, is that nothing really changed for severely retarded inmates, except, perhaps, how far from the main entrance their back ward residences were pushed.

Finally, the whole eugenic era from roughly 1890 to 1925, really focused on those perceived as mildly retarded. Severely retarded people were almost never sexually active (i.e., low-grade imbeciles and idiots) and were not viewed even at the time as

threats to perpetuate their defects or prey upon society through crime and vice. This does not mean, though, that idiocy did not play a role in evoking the eugenists' fears or give form to their claims. Yet, this role has gone largely unexamined in any of the prominent historical examinations of the period.

As a category, then, "unteachable idiocy" emerges again as analogous to the categories of chronic deviancy mentioned before, that occurred in almost every devalued group by the beginning of the twentieth century (Rothman, 1980). Some criminals were viewed as incorrigible. Some lunatics were quickly classed as incurably insane. Such chronic groupings always constituted a minority of the specific deviant class. However, their caretakers usually portrayed them as consuming a disproportionate amount of social services and support. The influence of this common dimension of "chronicity," particularly as it related to what was called "custodial" care, is poorly understood. This is especially true of those seen as "unteachable idiots."

#### The lack of historiographic currency.

A fourth and final problem of mental retardation history is the most distressing. Most work in this area (Trent's work is a notable exception) is written in an apparent cultural vacuum. Little or no consideration occurs of the last 25 years of developments in the social and cultural history of related fields. Wolfensberger (1975) complains of the lack of "interpretive" histories in mental retardation (p. 24), yet never discusses any of the relevant debates among historians of deviant populations that would seem so crucial to contemporary interpretation. He states in passing that "attitudes toward retardation paralleled those toward a number of other deviancies" (p. 62). Yet, again, he neglects to tell us whether he means the development as



interpreted by Deutsch (1937), Grob (1973), or Rothman (1971), each of whom defends a different interpretation of both the nature and source of those attitudes. Another recent author proclaims it a virtue that he tries never to refer to a secondary source (Scheerenberger, 1983, p. xiv). This is a myopic vision of scholarly independence at best. At worst, it degenerates into a feverish, antiquarian obsession with "the first," or "the most complete." The context is left shadowy and relevant discoveries or creative methods from related areas go unnoticed. Good history tries to avoid such disciplinary isolationism. Processes take pride of place over events.

"Single events like battles or individual cases of epidemic diseases rarely cause major or durable changes in the way ordinary people behave or in the ordinary activities of life - or, at least, so most social historians assume." (Stearns, 1983, p. 6)

We are left, then with some continuing complaints, but a growing optimism about the state of mental retardation historiography. Until recently, social and cultural history has had little at all to say about the topic. At the same time, mental retardation as a field has had more to say about its own development, but has understood even less. This absence of dialogue is all the more unfortunate because it seems abundantly clear that each has much to contribute to the research of the other. The optimism comes that such a dialogue is beginning, and is even more developed in the area of mental retardation than in other branches of disability history.

The future of the past looks bright.

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### Book Reviews

Aron, Laudan Y., Loprest, Pamela J., and Steuerie, C. Eugene. Serving Children with Disabilities: A Systematic Look at the Programs. Washington, DC: The Urban Institute Press, 1996, 182 pages, \$22.50 softcover.

Serving Children is a policy document resulting from a close examination of data on several major public programs relevant to children with disabilities. These programs include Supplemental Security Income (SSI), Medicaid, special education, early intervention programs, Maternal and Child Health Block Grants, Developmental Disability programs, mental health programs, Head Start, and

family support programs. Of these, special education, SSI, and Medicaid are the programs with the greatest expenditures and those that reach the largest number of children. Therefore, much of the book discusses these three programs using statistics that, given this genre of policy document, are as up-to-date as possible.

While the current statistics about prevalence rates, size and scope of programs, and expenditures are helpful to disability policy scholars and students, this text is even more useful for its conceptual contributions to the field of disability policy. Its first contribution is the illumination of the problems of definition and measurement. The authors not only point out the obvious here (that it is difficult to define disability), but they examine the problem further. They highlight the fact that, across agencies and programs, there is no consistent definition of disability. This complicates measurement to the extent that predictable errors and inconsistencies will occur in any program. The authors note that "no single definitional or classification system has been used by service providers or others in the childhood disability community. Differences in the way children with disabilities are diagnosed and classified remain a continuing problem that affects choices in medical, educational, social, and rehabilitative services. These differences complicate decisions about eligibility, transitioning across programs, program funding, and documentation of program impact" (p. 13).

The greatest numbers are served and the greatest expenditures are made in the area of special education, according to the authors. Special education has been a growth industry for many years, although the authors do not offer this critique. Yet, the authors clearly note that, while that program's aspirations might be acceptable, its realities are riddled with inconsistencies and identification

problems.

To minimize difficulties of definition, measurement, limited resources, and allocation decisions, the authors provide a set of guiding principles that they suggest could be followed when setting priorities and allocating resources for any program serving children with disabilities. This is their second conceptual contribution to the field, and it is consistent with policy movements in education as well. Guiding principles, or standards, are in some ways the post-modernist's answer to modernist prescriptive policies. But the authors ironically create as many problems for themselves in this part of their text as they make contributions to the policy field. On the one hand, they argue that guiding principles give policy makers and practitioners the assistance they need in making tough decisions. That sounds appealing. Yet, on the other hand, they support this claim with a faulty one that states, "The principles set out here reflect common-sense notions of promoting fairness, effectiveness, and individual development" (p. 40). This suggests that everyone is sure to agree with what they consider "fair," "effective," and promoting of "individual development." It also suggests that everyone will agree that policy should be fair and promote individual development when it comes to children with disabilities. And while I read their five principles and nodded in agreement that if, indeed, we have to make tough decisions, then these guidelines are helpful, I also balked at the way they bought into policy language that devalues children with disabilities. An example follows: "If individuals could be ranked on their differing abilities and advantages, the progressivity principle argues that those at the top of the scale would transfer the most assistance and those at the bottom would receive the greatest transfers" (p. 41). Even when money and other resources are concerned, when terms

such as "ranking" and "scale" are used to describe people with disabilities, I become concerned. How does a policy analyst who uses these terms really feel about children who have disabilities? That question needs answering.

There are, though, good things that come from this book, and these things make it recommended reading. First is the authors' use of principles as ideas that can "bound a reasonable set of policy alternatives" (p.45). The principles they propose are good starting places for disability policy, even though the way these principles play themselves out might not be as consensus-bound as the authors suggest. Second is the idea that policy principles are flexible and can be utilized regardless of the definitions of disability that evolve in society. This has intuitive appeal and gives me ideas for future inquiry.

In all, while this book reads as a traditional policy text, and while the authors make little headway in the social understanding of childhood disability, the book is useful for its current statistics and its "policy as principles" proposal.

(Susan Gabel, Michigan State University, College of Education, Department of Teacher Education, Curriculum, and Educational Policy/Social Analysis, East Lansing, Michigan)

Boyd-Franklin, Nancy, Steiner, Gloria L., and Boland, Mary G. Children, Families, and HIV/AIDS: Psychosocial and Therapeutic Issues. New York, NY: Guilford, 1995, 334 pages, \$40.00 hardcover, \$19.95 softcover.

This book provides a comprehensive overview of the issues involved in working with children and families with HIV disease. An edited collection of readings designed for professionals in mental health and other therapeutic fields, the volume covers a wide range of subjects and provides a wealth of

valuable, practical information on an understudied and important topic.

In keeping with current thinking in the human service field, the book takes a family-centered, culturally-sensitive, multisystems approach that stresses the empowerment of the service user. The book also reflects current research, which suggests that HIV infection/AIDS, although ultimately terminal, should be treated as a long-term, chronic illness thanks to advances in drug treatment and other therapeutic modalities. I am aware of no other up-to-date source that provides so much useful information in a form accessible to nonmedical practitioners. Topics covered include: the epidemiological and medical context, the psychosocial context, therapeutic approaches, service deliverers and systems issues, and research and public policy.

Because the book takes a "micro-level" approach, that is, it addresses issues of relevance to direct service providers, it does not address the larger "systems" issues related to etiology such as poverty and its attendant social problems that, in some cases, result in HIV infection. A "macro-level" focus would place more emphasis on issues of social (rather than individual) change. This comment is not intended as a criticism of the book but, rather, as an affirmation of the book's underlying clinical perspective.

The relation of this volume to the field of disability studies is readily apparent. HIV infection/AIDS is clearly a chronic disease and has been included under the ADA and other statutes. People who are HIV-positive have been subject to considerable stigma in society, even when they have been asymptomatic. In addition, AIDS, especially in children, often leads to cognitive and other disabilities that are stigmatized as well. Like other disabilities, AIDS affects the entire family, and, even more than other disabilities, it typically has a devastating, multigenerational impact. Those

who view disability from a social, rather than a medical, perspective may be put off by this book's clinical approach and lack of inclusion of any chapters by members of families experiencing HIV disease; however, the clinical component of AIDS is undeniable, and professionals working in this field would benefit greatly from a book that expands their knowledge and ability to empathize with families in this difficult situation.

(Rosalyn Benjamin Darling,  
Department of Sociology, Indiana University  
of Pennsylvania)

Capute, Arnold, and Accardo,  
Pasquale (Eds.). Developmental Disabilities in  
Infancy and Childhood. Baltimore, MD: Paul  
H. Brookes Publishing Co., 1996, 2 volumes,  
1159 pages, \$195.00 hardcover (2 volumes).

Developmental Disabilities in Infancy  
and Childhood (Second Edition) is a two-  
volume textbook geared mainly for  
pediatricians. However, it also makes an  
excellent guide for any primary care  
practitioner interested in caring for a child with  
developmental disabilities.

Publishing this second edition is timely,  
as managed care has hastened a shift toward  
primary care practitioners and away from  
specialists assuming the pivotal role in the  
medical care of children with disabilities. To  
assist in this shift, there are few publications to  
update generalists in their knowledge base in  
this complex medical field. However, this  
textbook successfully provides that update.

Volume I consists of 34 chapters  
providing an overview of developmental  
disabilities: their scientific basis, etiologies,  
assessment tools, practice approaches, and  
associated topics. Particularly salient are the  
chapters reviewing developmental assessment  
tools, including neurodevelopmental  
examinations and screenings as well as formal  
tests. There are also chapters with excellent



discussions on legislative mandates and nonstandard therapies. A chapter on computer technology includes useful information such as possible funding sources and a listing of addresses and phone numbers of information resources. Perhaps the third edition could include a list of internet resources.

The 34 chapters in Volume II span a variety of specific diagnoses in depth. Most chapters begin with a historical overview of a disorder followed by a review of its genetic and pathophysiological etiologies. However, what makes these chapters especially helpful to the practitioner is its clinical management sections, particularly those in the chapters on Cerebral Palsy, Down Syndrome, and Attention Deficit Disorder. These sections guide the primary care practitioner through the basic management of a child with the disability being discussed, including addressing various medical, psychosocial, and therapeutic issues. What is most unusual and helpful about these sections is that they mesh discussions of neurological, orthopedic, and the interrelatedness of these issues in practice. Many chapters also include practical reviews of alternative therapies as well as related legal and ethical issues.

By providing an excellent comprehensive review of the treatment of children with various developmental disabilities, this textbook should be on the bookshelves of all pediatricians and all primary care physicians who are involved in the medical care of these children.

(Dora Anne Mills, M.D., Farmington, Maine)

Dryfoos, Joy G. Full-Service Schools: A Revolution in Health and Social Services for Children, Youth and Families. San Francisco, CA: Jossey-Bass Publishers, 1994, 291 pages, \$28.00 hardcover.

The time has come, according to the

author, for a seamless system of quality education and support services under one roof. Preferably that roof is a public school building that allows maximum responsiveness to the community as well as accessibility.

Edward Zigler of Yale University speaks of schools that function as community centers; they are already owned by the community and should remain open to meet the needs of its residents from 7 a.m. to 6 p.m. Agreement is strong that the school should be an active partner in the collaborative efforts towards the integration of education, health, and social welfare.

In the late 1800's the large cities faced incredible challenges as the impact of immigration, industrialization, and urbanization hit our society and forced many social changes. The early 1900's brought about the development of school health programs; school nurses were employed in many cities, and poor children were given complete medical exams. This clearly challenged the medical profession's concern regarding socialism. The AMA launched a campaign to discourage the medical profession and the society from supporting any proposals that might threaten private fee-for-service medicine. A strong emphasis was placed on identifying schools to educate children and not for the provision of health services.

The vision of comprehensive services that can be brought into schools as support services fades in and out of the picture; health clinics, counseling services, employment offices, legal aid centers, and adult education, after-school, and summer recreation programs are but a few possibilities mentioned in this chapter. Further into the readings is the commitment to school-based health clinics which can be found primarily in high schools. What prompted their development between 1984 and 1993 was the rising incidence of the new morbidities among young people and a

movement toward the improvement of adolescent health. The focus was on making health care more accessible to poor children and reducing the rates of teen pregnancy. Not all states bought into this concept easily, and this book gives an in-depth accounting of the array of sources for funding these clinics and the struggle and controversy surrounding school-based services.

The research has been difficult to document because of the multicomponent programs. The population most likely to benefit is a shifting population which moves from one place to another, therefore, making the cost of the evaluation as much as that of the prevention. However, without the hard data to support the cost of doing business, the programs could lose funding, as so often happens.

The book reviews twelve states and their varying approaches with a range of agencies, and how collaboration of funding can sometimes be the key factor that brings the best resources to the people being served. However, as the author so pointedly states, without a commitment from the administration to school-based services, the youth of this country will continue to have serious and unaddressed mental and physical health problems as we enter the twenty-first century.

(Estelle Rubinstein, Executive Director, Androscoggin Head Start and Child Care, Lewiston, Maine)

Kingsley, Jason, and Levitz, Mitchell. Count Us In: Growing Up with Down Syndrome. San Diego, CA, and New York, NY: Harcourt Brace & Company, 1994, 182 pages, \$9.95 softcover.

The authors of this book are two friends on the cusp of manhood who tell of their views, experiences, and future plans as teenagers with Down Syndrome. Their story

is a groundbreaking one in that their parents, who were advised to institutionalize their sons upon birth in the early 1970s, instead welcomed them into their families and started a network for parents of children with Down Syndrome. The goal of the parents was to assist their children to reach and even to expand their potential. The convictions and actions of these parents flew in the face of the conventional wisdom of the day.

The words of the young authors capture their position as early crusaders for people with Down Syndrome, highlighting both the benefits and the drawbacks. One of the goals of the disability movement is pride in disability gained through acceptance of difference, but rejection of stigma attached to difference. However, a main intention of the authors of this book is to celebrate their similarity to people without disabilities. Jason says: "I was born with Down Syndrome, and I said to my parents that I have overcome my disability. I believe that I've come so far and that's been very successful. I believe that I did overcome, by being successful, having Down Syndrome" (p. 13).

The authors' personal interest in striving to excel is generally laudable and constructive, given the great barriers they face. However, inherent in constantly working to overcome disability are dangers of backlash against the self-esteem of people with disabilities as well as the public's tendency to see over-achievement as the solution to societal prejudice and discrimination.

Indeed, whether they wish it or not, these young crusaders for people with Down Syndrome have had the eyes of many upon them. Each has already had a public career; one has appeared on television and on film while the other has been recognized for his involvement in politics and government. These are not the accomplishments of most teenagers, whether they have disabilities or

not, and some of the authors' life goals seem extraordinarily ambitious. Mitchell talks about becoming President of the United States; Jason wants his parents to assist him in getting acting roles on Broadway. That they may have difficulty accepting their disabilities is shown clearly in their discussions about girls. Mitchell prefers to date girls without disabilities, saying "I want . . . to be in one of those tracks that other people have, that other people are involved in instead of worrying about Down Syndrome" (p. 79). In a similar vein, Jason maintains that Tami [his girlfriend] has Down Syndrome but with no disability (p. 78).

It is only in some passages in the book, and these appear in the final chapters, that the young men grapple with what they feel may be limitations upon their lives. Among various issues, they discuss whether or not they will be able to own and drive their own cars, how and whom they will be able to marry, and what jobs they can be trained for and hired to do.

It is evident that the authors of Count Us In feel the double weight of being role models for others with Down Syndrome as well as leaders in the fight against stereotyping and prejudice. Recognizing their seminal position, they have endeavored to overcome their disabilities. But, as all people, they must also eventually come to terms with their limitations.

(Miriam Hertz, Waltham, MA)

Ladson-Billings, Gloria. The Dreamkeepers: Successful Teachers of African American Children. San Francisco, CA: Jossey-Bass Publishers, 1994, 187 pages, \$25.00 hardcover.

In The Dreamkeepers: Successful Teachers of African American Children Gloria Ladson-Billings stresses integrating children's culture into their educational process. The author's ethnographic study demonstrates how

eight exemplary teachers can fulfill Martin Luther King's dream that children "not be judged by the color of their skin but by the content of their character." Much as the Civil Rights movement stimulated other human rights efforts, features of this cultural education can be instructive for disability studies.

She begins with the historical and philosophical underpinnings of her work and describes an instructional approach called "culturally relevant teaching," defined as "a pedagogy that empowers students intellectually, socially, emotionally, and politically by using cultural referents to impart knowledge, skills, and attitude" (pp. 17-18). Education, then, is viewed as a cooperative and culture-affirming process between teacher and student. The majority of the book is filled with a wide range of teacher vignettes and comments delineating the many aspects of culturally-relevant instruction. Gloria Ladson-Billings concludes with her vision for teachers and schools.

Although the book's focus is on African American education and makes little reference to students with disabilities, its examples are valuable for teaching all children. The author effectively addresses relevant topics such as inclusive education. By including all children in the educational process and having them share their culture and experience, differences among students are celebrated. With the fundamental belief that all children can achieve excellence (in their own way) and that group effort is more important than individual achievement, the class becomes an exciting community of learners who "dig out knowledge" from each other. One teacher states, "I want to know what they know so that we can make some natural and relevant connections to their lives. . . . Their experiences have to be a part of our curriculum, too" (pp. 52-53).

While a disproportionate number of African American and other ethnic minority students are placed in special education, this critical issue is oddly omitted. Though the book is smooth reading, it would benefit from a clearer structure; for example, its chapter titles are creative and catchy, but leave the reader adrift. Also, the author briefly mentions her theory of "afrocentric feminist epistemology" in Appendix A, explaining "some readers are less interested in the theory . . . and may see the theory as a way to delimit the research" (p. 154). But such a discussion at the beginning of the book would provide a needed theoretical foundation for her pedagogy.

The Dreamkeepers' strong contribution is its identification of key elements of culturally-relevant teaching and its illustration of innovative instructional strategies. Teachers could learn from the many interesting personal stories, children could be enriched by such experiences, and, as Gloria Ladson-Billings argues, this type of instruction could help level the educational playing field for African American pupils.

(Laurie R. Lehman, Department of Education, Long Island University, Brooklyn, NY)

Mazurek, Kas, and Winzer, Margret A. (Eds.). Comparative Studies in Special Education. Washington, DC: Gallaudet University Press, 1994, 477 pages, \$55.95 hardcover.

To study special education well is to study it comparatively. Comparability is important for two reasons: 1) to learn from the achievements and mistakes of school systems other than one's own; and 2) to appraise educational issues from a global rather than an ethnocentric perspective (Bereday, 1977). That is, as educators, we need to be aware of special education systems

throughout the world to better understand our own.

In their book Comparative Studies in Special Education, Kas Mazurek and Margret Winzer facilitate the study of comparative education which seeks to highlight similarities and differences among educational systems. "Facilitate" is the key word here since the book provides extensive materials for comparative study, but it stops short of actual comparative analyses. Thus, the title might suggest to potential readers that the book aims primarily to compare issues in special education. However, the title is somewhat misleading because the book refrains from any kind of cross-comparative discussion. Rather, the editors of Comparative Studies in Special Education provide an in-depth historical account of 26 different special education systems in relation to each individual country's cultural, social, economic, and political situation.

In the introductory pages, Mazurek and Winzer summarize comparative education and its importance to improving education for children with disabilities. To show us how various special education systems develop, they stress six characteristic assets of comparative education studies. Such studies can often inform and improve regional practices, provide a data base, and facilitate theoretical understanding. Additionally, they help the reader delineate pressing issues by better understanding the social context of regional practices and, thus, being able to make appropriate value judgments about cultural practices. For example, according to one functionalist approach, the quantity and quality of a nation's special education system can be linked to its social, political, economic, cultural, and religious structure.

Efforts to address the development of special education in relation to a country's social, political, cultural, and religious

structures is important, given the extremely high prevalence of disability in certain parts of the world. According to UNICEF, an estimated 140 million children globally have disabilities. Of these, 120 million live in developing countries: 88 million in Asia, 18 million in Africa, and 14 million in Latin America. In addition, 13 million reside in Europe, and 7 million in North America. In fact, in many nations, the lack of a strong economic and educational infrastructure makes the educational system severely limited and inaccessible to many children. These limitations further contribute to poverty and poor health conditions, which closely interrelate with problems of access to general education. Against this background, the specialized educational needs of children who have disabilities present an even graver picture in some parts of the world.

According to Mazurek and Winzer, the policy of many countries has been to address general educational opportunity first and face issues of inequality (i.e., access to services) later. That is, there are few compensatory provisions for children with disabilities, since their needs have a lower national priority. Given the numbers of children who have disabilities and the low priority they are given, the editors have made a timely contribution to the field of international special education.

Despite the considerable literature on comparative education, very few studies have focused on the worldwide development of special education. Most, if not all, of these studies pertain to special education in the Western industrialized countries: the United States, the Scandinavian countries, England, and Australia. Only recently have researchers begun looking at newly-industrialized countries such as Japan, South Korea, Taiwan, and China. To study special education in these countries and others, researchers sometimes use a comparative approach to study their

special education systems, often with the United States as a base of comparison.

Thus, this book has filled a major void in the literature as it pertains to both developed and developing nations. As the editors state, they seek to remedy this problem of fragmentation by looking at 26 case studies; taken together, these include the special education provisions for the majority of children in the world today.

The book is divided into five parts, each representing a specific model of special education practice. Each part includes an introduction and four to nine chapters on individual countries written by distinguished national educators. Each chapter provides a perspective of the past, present, and anticipated future of the special education system within the given country.

The data include: 1) number and types of children with disabilities served in special schools; 2) geographic locations of special schools; 3) funds allocated to special education; 4) quality of services provided; and 5) efforts to pass advocacy laws, and successful legislation. Following this presentation of data are detailed analyses and discussion of the current special education situation and recommendations for how it can be improved.

Each chapter in Comparative Studies in Special Education supports the concept that all individuals with disabilities have a basic right to an education. Expanding on this fundamental theme, the book's five parts focus on how this concept plays out in different countries.

For example, Part I is entitled "Limited Special Education," since the economic, social, and political problems in some regions of the world are so overwhelming that special education can be only a peripheral priority (p. 3). South Africa, Papua New Guinea, Senegal, and the West Bank and Gaza Strip

are grouped together in this section due to their similarly constrained circumstances regarding racial inequalities, poverty, lack of basic health services, and civil unrest. Such conditions severely limit the level of rehabilitative and special education services available for their populations of people with disabilities.

In Part II, nine countries (Nigeria, Iran, Brazil, Indonesia, Egypt, Pakistan, China, India, and Uruguay) are grouped together because of their "Emerging Special Education" systems. Although these nations, like those in Part I, are compromised in their efforts to achieve universal access to primary education by a variety of internal problems, they have at least taken more visible initiatives to provide educational services for persons who have disabilities. For example, legislative efforts and policies to ensure rehabilitation, care, and education for children with disabilities are very apparent in these countries.

Part III, "Segregated Special Education," looks at nations that primarily use separate educational environments for those within their populations who have disabilities. The countries in this section (including Japan, Taiwan, Russia, Czechoslovakia, and Hong Kong) have well established legislation and implementation policies. They have also achieved virtually universal education.

The movement to place children with disabilities in "normalized" regular classrooms and community settings, rather than in segregated classrooms, is the editors' rationale for grouping Israel, Poland, Australia, and Canada together in Part IV, "Approaching Integration."

The last and final part, "Integrated Special Education," includes chapters on Finland, Norway, Sweden, the United States, New Zealand, England, and Wales all of which are striving to integrate all children with disabilities into regular classrooms. Although

many children with disabilities in these countries are served by special education programs, the United States, for example, still has its limitations; among these limitations, most American special education programs include a disproportionately high number of minority students. Overall, all the 26 countries discussed in this book face significant challenges in their efforts to improve the lives of individuals with disabilities, regardless of their stage of development and the model used.

In his "Framework for Policy and Action in Special Education: An International Perspective," Gall (1986) makes a statement that is pertinent to this recent book: "It is presumptuous to expect that the authors achieve closure and consensus on a single model to shape the future of special education. Perhaps the only consensus possible is in the process and not product domain: a commitment to rigorous intellectual and emotional energy as we pursue the best of all possible worlds for children with disabilities" (p. 33).

Given the different starting points for the development process in these 26 case studies, some countries are far more advanced than others. Mazurek and Winzer wisely refuse to state that one special education system is better than another since such a presumption would further widen gaps among educators around the world. Rather, their book serves as an opportunity to present all possible models in order to increase awareness among all educators.

The editors' work itself has many strengths. First, the introduction is most insightful. Here, Mazurek and Winzer discuss the core principles needed to understand comparative special education. Particularly helpful is the section at the end of the introduction which lists recurring themes found among the 26 case studies. Indeed, this

is the only cross-comparative component of the text and it includes two tables that list factors that facilitate, as well as those that hinder, special education developments and the number of countries affected by each factor. It is interesting to note, for example, that the top-ranked factors hindering special education among the countries studied are "major rural-urban inequalities" and "limited financial resources," while the top factors facilitating special education include "teacher-training program in place," "universal access to schools," and "high priority on preventative programs." Although this is a minor criticism, the editors could have eased the reader's burden somewhat by arranging the factors in these tables in some kind of numerical order. They could also have made these tables more useful by listing the specific countries to which these factors apply rather than simply tallying the number of countries. Nevertheless, the second strength of this book is that the information is presented clearly within each chapter according to the following subtopics: Prevalence of Exceptional Children; Identification of Exceptionalities; Labeling the Handicapped Population; The Social Context of Special Education; The Legislation Policies; Teachers, Schools, Curriculum and Pedagogy; and Major Controversies and Issues in Special Education and Emerging and Future Trends. This well-defined layout should help researchers find specific data within or across different countries.

Moreover, the editors provide the academic and professional background for each chapter's authors. This should prove useful to readers who want to establish international resources and personal contacts. In addition to an exhaustive presentation of information, each chapter concludes with an extensive bibliography.

While much useful information is presented in Comparative Studies in Special

Education a few omissions are worth mentioning. First, Mazurek and Winzer present no clear purpose. In their Foreword, they state that the book is an attempt to fill a void in the literature available to students and scholars in both special education and comparative education. Later, they state that every effort was made to avoid being prescriptive. In fact, they expressly "rejected the temptation to write a summative concluding chapter" - a regrettable omission. In other words, Mazurek and Winzer have chosen not to evaluate, critique, or judge any special education systems; they leave it up to the reader to put the picture together from the presented case studies.

While taking such an approach is admittedly a valid goal, the editors are asking the readers to wade through nearly 500 pages of data-heavy text and come up with their own interpretations. The editors would have made this book far more meaningful if they had pointed out the trends, problems, and themes common to all systems. Such an analysis could help educators and policy-makers pull out ideas that might help improve educational practices for individuals with disabilities within their own systems. Moreover, while the editors selected a variety of countries, they neglected to explain how and why they chose these particular 26 nations.

In presentation, this book is very encyclopedic in nature and competes head-on with other encyclopedic sources such as the International Handbook of Education Systems (1983-1984), the International Yearbook of Education (1994), and, finally, the World Education Encyclopedia (1988). However, this book is unique in focusing entirely on special education systems.

Ultimately, what links the diverse chapters of this book is our local and global need to improve special educational provisions by observing, studying, and understanding

special education systems across the globe as well as the unique cultural conditions that foster them. While the strength of this link depends somewhat on the reader's effort, the book is nevertheless a welcome addition to the existing literature. Despite its interpretative limitations, it is a landmark book on special education systems worldwide.

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(Rooshey Hasnain, Boston University)

Means, Barbara, Chelemer, Carol, and Knapp, Michael S. (Eds.). Teaching Advanced Skills to At-Risk Students. San Francisco, CA: Jossey-Bass Publishers, 1991, 287 pages, \$32.95 hardcover.

The editors have brought together a number of notable researchers and practitioners in advanced skills instruction and compensatory education programs. The term "at-risk" is used to refer to children living in poverty who come to school poorly prepared for the kinds of literacy and numeracy

activities that predominate in traditional school environments.

The book presents six instructional models rooted in cognitive psychology which describe alternative approaches to the teaching of mathematical reasoning, reading comprehension, problem solving, and written composition. Each chapter is followed by a practitioner's comments on the model with suggestions on how it could be incorporated into classroom practice.

Each chapter challenges popular notions of compensatory education and urges educators to reexamine the premises underlying the instructional methods and curriculum offerings provided to disadvantaged and at-risk students. The models reflect a new attitude toward the teaching of these students, and they provide suggestions for reshaping the curricular offerings and for the application of new instructional strategies. The models and procedures described could be adopted as long-term professional development activities for a school staff.

The chapter commentaries are very clear in pointing out the strengths and pitfalls of each of the models. The final chapter, written by the editors, is excellent. They list and discuss how the models share common ground in the psychology of learning and how there is both theoretical and empirical support for their use. Nonetheless, schools are not rational organizations, and the editors do a superb job of commenting on issues of motivation, linguistic and cultural concerns, limits as to what can be taught directly, teacher attitudes and preservice training, administrative support, financial support for resources and inservice training, and, unusually for a book such as this, the role of paraprofessionals.

The theories presented in the book will be familiar to educators, but the models



outlined contain good ideas for changing educational practices in order to improve the schooling of at-risk and disadvantaged students. This volume serves as a reminder to professional educators that positive, field-tested instructional alternatives do exist, and one can borrow and then tailor a specific program rather than having to start from the very beginning.

(Venta Kabzems, Education and Disability Consultant, Edmonton, Alberta, Canada)

Schwartz, Sue, and Miller, Joan E. Heller. The New Language of Toys: Teaching Communication Skills to Children with Special Needs. Bethesda, MD: Woodbine House, 1996, 289 pages, \$16.95 softcover.

In its intent - to show how to use toys and other play activities for purposes of stimulating a child's language development - this book is inherently promising to parents and educators. Whether or not it fulfills its promise is largely dependent upon the special needs of a particular child. Parents and educators of children with "speech delay" will likely find the book chock full of specific and useful ideas; those whose children experience speech difficulties associated with motor impairment, on the other hand, may find themselves frustrated and, in places, even offended.

The New Language of Toys is an updated version of an earlier work. It offers an introduction to language development, a discussion of the value of play, and a summary of teaching techniques. The largest section consists of descriptions of specific toys the authors recommend for enhancing language development; they suggest ways to best use the toys, and they give examples of language dialogues that could be used in conjunction with each toy. The point is made clearly that

playing and teaching take place together; in this way, the book is sensitive to parents' desires to be involved in therapy but also just to have fun with their children. Toy descriptions and dialogues are organized by developmental age. A strength of the book lies in its specificity; it provides brand names and photographs as well as addresses of toy companies and an annotated bibliography of developmentally-appropriate books.

The authors give lip service to the notion that kids develop differently, and parents are encouraged to choose toys on the basis of their child's developmental, rather than chronological, age. Nevertheless, the authors annoyingly persist in using time-specific language, implying a correlation of chronological age and development. We are told that "You will be astonished at how active your baby becomes in this last part of her first year" (p. 65); "As he moves along toward his first birthday, you will see a dramatic rise in your baby's comprehension" (p. 10); and "There is no place that she cannot get to at this time" (p. 91).

Perhaps even more disturbing is that, within each developmental age category, the authors seem to assume that all domains of development are congruous: "At the developmental age of three, your youngster . . . is now quite steady on his feet" (p. 141); "When he is four, you will really begin to see a vast improvement in his fine motor skills" (p. 175). Determining a child's developmental age, thus, becomes confusing. And for the parent of a child with impaired mobility, reading that it is now time to "put away that crystal vase" (p. 10) is hurtful and counterproductive. Parents of children with disabilities are all too often made to feel that they are outsiders to "real" parenthood and that the pervasive array of childrearing advice books can never speak to them. It is unfortunate that a potentially valuable book

designed for use with children with special needs should unintentionally perpetuate this loneliness.

(Gail Landsman, University at Albany, State University of New York)

Slaughter, Diana T. (Ed.). Black Children and Poverty: A Developmental Perspective. San Francisco, CA: Jossey-Bass, 1988, 123 pages, \$19.00 softcover.

Black Children and Poverty is part of the New Directions for Child Development monograph series. The six chapters, Editor's Notes, and Epilogue originated from a symposium on the contributions of research on minority children to the field of child development. The chapter authors were instructed to "critically summarize important new knowledge in the contributor's research area - knowledge that was generated partly in an effort to understand better how poverty could potentially affect Black Children," to "describe some of the theoretical and methodological redirections that were required to produce this new knowledge," and to "speculate, given the research history, on future linkages between child development research and social policies that specifically address Black children and poverty" (p. 5). The research areas include language socialization (S. Brice-Heath), patterns of information requests (W.S. Hall, E. Bartlett, and A.T. Hughes), self-concept development (M. Beale Spencer), and cognition (D. Miller-Jones). J.U. Ogbu's opening chapter is an excellent review of the relationships between cultural diversity and human development. The fifth and sixth chapters, by D. Miller-Jones and V. Washington, respectively, comment more directly on the relationships between studies of Black children and the fields of child development and public policy.

A theme running through the monograph is the contrast between the

magnitude of poverty experienced by Black children and the nonetheless limited attention paid to research that could be applied and further pursued in order to provide useful frameworks for understanding impoverished Black children's needs and resiliency factors. Researchers and policy makers alike have been too quick to respond to statistics concerning high rates of poverty among Black children - for instance, in the 1980's, approximately half of all Black children lived in "severely impoverished environments," (p. 2) - with stereotypic assumptions of fundamental deficiencies in Black children's development and in their families (cf. Brice-Heath's discussion of Black English vernacular and language socialization.)

The authors review research as well as propose additional studies in which the variables of race and socioeconomic status are separately considered, developmental perspectives are appropriately applied and/or scrutinized, naturalistic research methods are increasingly employed, and contextual variables bearing on culturally-valued competencies and models of child rearing among Black families and their larger cultural settings are fully considered.

Miller-Jones effectively makes the case for how research originating with concerns over "minority" experience not only refines understanding of Black children's development but has fed back into the central body of research and theory in developmental psychology. The research methodology and findings described within these chapters, thus, will be informative for researchers and clinicians concerned with the identification of and response to disability among Black children; more fundamentally, this monograph conveys the important message that contributions to theory and research can emerge from careful study of children who appear to differ in significant regards from the

developmental course described in Eurocentric and in other ways "normatively" focused accounts.

(Jan L. Hitchcock, Social and Behavioral Sciences, Lewiston-Auburn College, University of Southern Maine)

Stray-Gunderson, Karen (Ed.). Babies with Down Syndrome: A New Parent's Guide (Second Edition). Bethesda, MD: Woodbine House, Inc., 1995, 340 pages, \$15.95 softcover.

Babies with Down Syndrome is a must read for parents and family members of babies with Down syndrome. It presents a comprehensive exposition of vital information and provides a basic introduction to Down syndrome. A full range of topics is covered in the book and includes an explanation of what Down syndrome is, how to cope with the fact that a baby has Down syndrome, how to deal with potential medical concerns, daily care, family life, development and education, and legal rights. Babies with Down Syndrome was originally published in 1986. The second edition, reviewed here, is clearly reflective of the evolution in the treatment and care of children with Down syndrome that has occurred during the past nine years and will not disappoint readers looking for up-to-date information. A comprehensive resource guide is provided that will be invaluable to parents wanting this type of information.

The book is extremely comprehensive, yet it is not intimidating in the least. Two factors contribute to its engaging nature. First, Babies with Down Syndrome is well organized. It systematically brings families through a process of addressing immediate concerns, issues, and needs for information, to focusing on future considerations. Second, the style of writing is empowering for families. Information is presented frankly without appearing watered down. When professional

jargon is used, it is always explained.

A relative strength of Babies with Down Syndrome resides in the pervasive, positive tone of the writing. Negative outlooks and outdated assumptions about what the future holds for children with Down syndrome are dispelled. Many of the contributing writers reiterate that mental retardation does not mean unintelligent. Nor are parents bolstered with unreasonable expectations. It is clear that children with Down syndrome have limitations, but within those limitations exist abilities, capabilities, and an individual with unique characteristics. If anything, the book encourages families not to limit their expectations and provides plenty of substantiation for such encouragement.

The chapter introducing early intervention was somewhat disappointing in comparison to the comprehensive nature of the other chapters, with specific regard to the relatively brief descriptions of available programs or models of service delivery. Home-based and center-based options were discussed superficially without providing the reader with a rationale for the existence of different models or the benefits and drawbacks of different models. Parents need this depth of information to make appropriate choices. Likewise, although not apparent from reading the chapter "Teaching Your Baby with Down Syndrome," a number of different models of inclusion are presently available for children and families. These options vary on the amount and type of support a child receives in the community setting. Parents would benefit from knowing about models such as Special Education Itinerant Teaching (SEIT) and the use of aides, either full or part-time. Finally, a great deal of valuable information about the IFSP, observing babies, and teaching strategies was presented within the chapter and should not be overlooked.

Babies with Down Syndrome is highly

recommended reading for parents, family members, and any other individuals desiring a comprehensive, easy-to-understand, contemporary introduction to Down syndrome.

(Nancy Vitalone-Raccaro, Ph.D., New York Medical College, Valhalla, NY)

Ysseldyke, James E., and Thurlow, Martha L. (Eds.). Educational Outcomes for Students with Disabilities. New York, NY: The Haworth Press, Inc., 1994, 208 pages, \$39.95 hardcover.

This collection of articles generally focuses on outcome-based assessment, outcome-based accountability, and outcome-based education and its precise value to students with disabilities. The contributions of related services personnel is supported, and the broadening educational outcomes beyond academics are addressed.

Although the articles are well-written and thorough, the text is disappointing, since all but one chapter is written from a disability studies perspective. Focusing on outcome-based education for students in special education without addressing the very foundation of special education in self-contained classes only props up the received wisdom that most children with disabilities require segregated special education classes. No distinction is made between outcomes of special education in an integrated setting and outcomes in self-contained settings.

Vanderwood and Erickson, for example, discuss the importance of everyone involved with the child being part of the accountability system based on outcomes, but not the importance of involving people with disabilities who have been educated through the special education system and can bring an expertise which is typically excluded. Hyde's chapter on the contribution of related services personnel to school reform efforts is

disappointing because it fails to take into account the socio-political model of disability and its influence on educational impact.

Although this text is sound if one still subscribes to a medical model/special education system, it has serious shortcomings for those who know that the special education system is seriously flawed and has little relevance to the future of a quality education for students with disabilities.

(Phyllis Rubenfeld, Hunter College of The City University of New York)

### Other Books of Interest

Atkinson, Donald R., and Hackett, Gail. Counseling Diverse Populations. Madison, WI: Brown & Benchmark, 1995, 390 pages, \$37.33 softcover.

The stated purpose of this book is to "call the attention of mental health practitioners to the unique experiences and needs of four groups within the American society that, along with ethnic minorities and selected other groups, share the common experience of oppression. Those four groups are persons with disabilities, elders, women, and gay people" (p. ix). The book's intended audience is students of rehabilitation counseling and other mental health professions. Its thesis is that "Mental health practitioners need to be aware of the unique experiences of these groups in order to effectively intervene on their behalf" (p. ix). In order to accomplish the book's purpose and to explicate its thesis, the authors have written an introductory chapter that discusses how traditional psychotherapeutic approaches have ignored the experiences of these groups and have failed to meet their needs, provides a rationale for identifying these groups as minorities, and presents a profile of each of the groups. Chapter 2 reviews society's treatment

of each group across history and, perhaps justifiably, takes psychology's treatment of persons with disabilities to task for not being more activist and for being too person-centered. Chapter 3 then presents brief, superficial evidence of continuing discrimination for each of the groups by discussing social, economic, and environmental discrimination along with some data on abuse. In the section on attitudes about disability, there is a major omission. There is no discussion about the behavioral interactions between persons with and without disabilities resulting from these attitudes, a very important part of discrimination and a necessary aspect of "the unique experiences" of people with disabilities of which the authors want us to be aware. There is also no mention of successful attempts to change attitudes about disability through contact and education. The whole body of knowledge on the social psychology of disability is completely ignored.

Chapters 4 through 15 are selected readings chosen to provide insight into the experiences of the four groups and to offer suggestions for meeting their mental health needs. This review will focus on the disability material.

The first selected reading on disability is entitled "Application of Personality Theories and Counseling Strategies to Clients with Physical Disabilities." It presents concepts, general intervention strategies, adaptation to disability-related interventions, and criteria for change for nine approaches or theories applicable to working with people with disabilities. These are Psychoanalysis, Individual Psychology, Person-Centered Therapy, Gestalt Therapy, Rational-Emotive Therapy, Cognitive Therapy, Reality Therapy, Behavior Therapy, and the Somatopsychological Approach. It then relates each of these approaches to the eight stages of adaptation that the authors propose.

Although the review of the approaches is accurate, and their application to disability seems appropriate, one would think that students of mental health will have already had an exposition of these theories. Furthermore, the artificial assignment of techniques to theoretical orientations only confuses students and others who are trying to learn about the systems. There is so much overlap between systems in terms of the techniques used that this classification is meaningless. The editors wish counseling to go beyond traditional approaches, but there is no discussion of team-oriented treatment, milieu therapy, peer counseling, community psychology, the independent living movement, etc., all ways of getting around the counselor-in-a-room-with-a-patient approach.

The next chapter, "Roles of Counseling in Enabling Persons with Disabilities," makes the claim "that society (rather than the client with a disability) may need adjustment" (p. 121), but the chapter seems to be mainly an exposition of the varied roles of counselors and provides obvious examples, simplistic suggestions, and no concrete recommendations.

The third chapter on disability, "An Agenda for Professional Practice in the 1990s" presents perspectives on disability policy, explication of the inconsistencies in public policy (which may reflect the ambivalence in attitudes about disability), how politics influence disability programs, and how counselors can influence the development of a more unified national disability policy. This material is a well-written, clear summary of these issues and certainly important for students to know.

The last chapter discusses diversity imperatives in counseling practice, training, and research, and is more intended for professionals in the field rather than for students, but it offers no more specific

suggestions than previous chapters.

In general, I cannot recommend this book to readers of this journal or their students. It is an introductory textbook somewhat suitable for rehabilitation counseling students, and an overview and review of political, economic, social, and psychological thought. Perhaps \$37.33 is a bit much for students. Moreover, I do not think students will gain new insights into the experiences of people with disabilities. The issues discussed are, maybe, not so obvious to students, but certainly this current readership does not need the awareness or suggestions on any of the topics on disability covered here.

(Michael Dunn, Ph.D., Spinal Cord Injury Service, Department of Veterans Affairs Medical Center, Palo Alto, CA)

Blalock, Ann Bonar (Ed.). Evaluating Social Programs at the State and Local Level: The JTPA Evaluation Design Project. Kalamazoo, MI: W.E. Upjohn Institute for Employment Research, 1990, 410 pages, \$29.00 softcover.

This book is the product of a large project the aim of which was to develop materials and methods of evaluation that could be used by state and local governments to fulfill their oversight obligations under the Job Training and Partnership Act (JTPA). In the recognition that states and localities often lack the expertise and the infrastructure for evaluation, this project developed 20 volumes of materials to support these new evaluation responsibilities. This book is a distillation of ideas from the project materials; its aim is to provide general assistance for state and local evaluation of social programs - using JTPA as a case example.

Although the project comes from the early 1980's, and the book itself was published in 1990, the rationale for both the initial project and the current volume are even more

pertinent today. While the early 1980's was a time of decentralization of federal programs, the mid-1990's may witness an even greater downward transferral of program responsibility and oversight. Thus, the assessment of the impact of policies and programs may rest, to an even greater degree, with states and localities. It is undoubtedly still the case that many states lack the expertise and infrastructure required to evaluate the impact of the various cuts and changes they are implementing in programs that serve poor children, the elderly, and people with disabilities.

The six chapters of this edited book cover the various topics and models of program evaluation: an overview of basic concepts, net program impact (did the program "work"?), gross program outcomes (what happened to participants?), implementation (how did the program work?), the contextual issues for success or failure in evaluation, and utilization and dissemination of findings and methods for sustaining a commitment to evaluation within programs. Each chapter begins by presenting general information about the evaluation methodology that is its focus, and then provides lengthy specific advice about how to implement the methodology for a JTPA project. This combination makes for a book that is very useful if you are evaluating a JTPA program, but of less interest if you have a different evaluation application. Despite the potential connections between JTPA, job training, and employment issues for people with disabilities, disability as a variable in the evaluations is mentioned only briefly in an appendix. In short, while this may prove a useful book to state and local personnel charged with the evaluation of JTPA, those interested in evaluation techniques that are sensitive and applicable to state and local programs that serve people with disabilities should probably

seek other resources.

(Nancy R. Mudrick, School of Social Work, Syracuse University, Syracuse, NY)

Davis, Leonard J. Enforcing Normalcy: Disability, Deafness, and the Body. London, England: Verso, 1995, 204 pages, \$17.95 softcover.

A professor of English at Binghamton University, and son of deaf parents, Davis published two books on the origins and ideology of the novel (Factual Fictions: The Origins of the English Novel, 1983; Resisting Novels: Ideology and Fiction, 1987), and co-edited Left Politics and the Literary Profession (1990). His article about deaf people warehoused in institutions, "Hear Ye! The Prisoners of Silence," which appeared in the Nation in 1993, was a token of his mid-life return to the issues of deaf people. In his newest book, he theorizes historical and social paradigms of disability with a focus on deafness and explores the perverse and pervasive marginalization of people who are deaf and/or have other disabilities.

One has only to consider the etymology of the word "absurd" or realize that the wording on Gallaudet University's seal refers to a healing in the gospel of Mark (Ephphatha - "Be opened") to imagine how relentlessly oppressive society can be toward deaf people. Davis grounds this oppression in a socioeconomic matrix; until I read his chapter on nationalism and deafness, I had not considered the possible correlation between my father's job and my birth complications, just one of many insights gleaned from his book.

Unfortunately, Enforcing Normalcy will reach only academic audiences partly because of such sentences as the following (from the introductory chapter, "Disability, the Missing Term in the Race, Class, Gender

the anterior logical ground for originary myths of signifying practice" (p. 17). His decision to "denarrativize" disability and deafness is a logical "initial tactic" in his desire to address the "under-theorized" study of disability, but one problem is that many academics are themselves the most close-minded regarding efforts to square the triad of race/class/gender by adding the overarching topic of disability.

Another problem is the minuscule number of deaf academics, who suffer from limited access to professional training, advancement, and interaction with their peers; Davis recounts, for instance, how the inability of hearing sign language interpreters to translate theoretical discourse at a Modern Language Association conference session disabled the deaf participants. Davis presumably does not want to restrict his often brilliant analyses and theoretical contributions on the subject(ion) of deaf people to primarily hearing academics, but he wants the informed members of the Deaf community to see how cultural and ideological forces affect every aspect of their lives, in the hope that they will then consider their obligations to their "brothers and sisters." He can have greater influence by addressing a wider readership with a book in which he "renarrativizes" disability and deafness.

(Bruce A. White, Department of English, Gallaudet University, Washington, DC)

Evans, Robert G., Barer, Morris L., and Marmor, Theodore R. (Eds.). Why Are Some People Healthy and Others Not? The Determinants of Health of Populations. New York, NY: Aldine De Gruyter, 1994, 334 pages, \$52.95 hardcover, \$23.95 softcover.

Asklepios, Greek god of health, bore two daughters, Hygeia and Panakeia. Hygeia, the goddess of natural order, taught Greeks to

moderation. Panakeia, the goddess of healing, used drugs and other interventions to achieve cures. The editors of Why Are Some People Healthy and Others Not? maintain that Panakeia in the form of modern medicine and technology has eclipsed Hygeia. Modern medicine, health care, takes far too much credit for improvement in health. Public policy in the industrialized world favors the demands of technology and medicine over other equally important and well-documented determinants of health.

This volume presents research which confirms the equal importance for health of Hygeia and Panakeia. The editors build a scholarly case for a change in the models we use to describe the determinants of health. They start with a fascinating overview of the anomalous findings in many areas of research about health status. Differences in average health status related to social class, geographical regions, educational level, historical eras, and occupations must be viewed in contexts beyond the individual to be understood.

Multiple factors affect health and illness. Empirical medical science tends to simplify cause and effect and place them in a linear progression. Many articles reveal the complex linkages at play between genetics, social context, and physiology in the development of any disease.

Politics and policy form the focus of another section of the book. Articles trace the movement from sickness care insurance meant to improve health to the health promotion movement which is driven by the desire to contain costs. A fascinating chapter exposes differences in physician practice and notes, as we all know intuitively, that these differences arise because physicians know less about what works than they care to admit. The final chapter presents a look at alternative futures, some pretty dismal.

Why Are Some People Healthy and Others Not? offers an important model of a new way to think about health and presents exhaustive documentation for a change in policy to better reflect the real determinants of health. The book proposes new priorities, priorities which could assure that all people, including people with disabilities, can live healthy and productive lives.

(Sallie Nealand, Assistant Professor, Community Nursing, Lewiston-Auburn College, Lewiston, ME)

Falaris, Evangelos M., Link, Charles R., and Staten, Michael E. Causes of Litigation in Workers' Compensation Programs. Kalamazoo, MI: W.E. Upjohn Institute for Employment Research, 1995, 137 pages, \$24.00 hardcover, \$14.00 softcover.

In the United States, the workers' compensation program is our oldest social insurance program providing disability benefits. Workers' compensation was established during the Progressive Era as an attempt to rationalize compensation to victims of industrial accidents by taking resolution of disputes out of the courts and providing a more scientific basis for redressing claims through an administrative process at the state level.

Ironically, this long-standing system may also be a model for the post-modern social policy of the Gingrich era. Workers' compensation programs are products of state government. They vary widely from state to state in generosity of benefits, administrative process, and the basis on which compensation is determined. These differences reflect differing local conditions and traditions, but also the relative power of the various interest groups in state legislatures, including employers and unions representing different industrial sectors and firms of varying size, insurance companies, and attorneys



representing plaintiffs and defendants.

This book is an econometric study of workers' compensation programs in two states, Delaware and Michigan. The great majority of cases in both states are resolved without litigation; others are contested and lead to administrative hearings. The authors, Evangelos Falaris, Charles Link, and Michael Staten, develop a statistical model incorporating several factors that influence whether claims will be resolved with or without litigation, and the size of compensation awards in contested and uncontested cases. Their findings are that the likelihood and outcome of litigation are significantly influenced by the type of industry and whether or not the employer is self-insured, the firm's geographic location, the age and wages of the claimant, the part of the body affected by the injury, and the nature of the injury. Comparisons between Delaware and Michigan also suggest that regulation of insurance premium rates and the method of calculating wage loss have significant effects on the process.

While its methodology appears sound, and its results are clearly presented, the book is rather technical in its approach and narrow in its conclusions; its appeal will be primarily to economists, attorneys, and others interested in modelling the outcomes of compensation disputes, a rather limited component of the DSQ readership. There is no explicit discussion of the current policy dilemmas involved in workers' compensation reform, nor of the political forces that have led to the current hodgepodge of a system.

The analysis, however, does have important implications for the field of disability studies, for it demonstrates how the economic and political context in which disability is defined and measured has profound implications. For example, individuals filing claims against the automobile industry, which

is highly unionized and largely self-insured, were found to be far more likely to resort to litigation for resolution of their cases, while public sector employees were less likely to litigate. Similarly, the position in the labor market of the claimant is significantly related to the likelihood of litigation, with older and better paid individuals more likely to be involved in more prolonged disputes. The variations in policy outcomes across jurisdictions, employment settings, and types of workers demonstrated by this book constitute a case study in the political economy of disability, and they confirm the socially constructed and institutionally mediated nature of disability and its consequences.

(Richard K. Scotch, School of Social Sciences, University of Texas at Dallas)

Filipovski, Jasmine. The Handicapped: Taking a Second, Closer Look. Las Colinas: Ide House, 1995, 75 pages, \$8.00 softcover.

Marketed to the general public, The Handicapped: Taking a Second, Closer Look attempts to describe "all forms" of disability and to explore "every issue facing the handicapped." The book's 12 chapter titles, several of which seem to cover the same topic, promise a discussion of definitions of disability, attitudes/attitude change, employment issues, federal assistance programs, and interpersonal dynamics of living with a disability. Unfortunately, this thin volume falls short of its stated goals, leaving the reader more perplexed than informed.

Written more like a journal entry or opinion piece than a factual guide for the lay reader or a scholarly work, The Handicapped fails to provide the information or overview it promises. The writer never offers a clear definition of "disability," nor does she provide a discussion of factors that might preclude a set definition of disability and related terms. Instead, she relies on a confusing number of

terms to refer to people with disabilities, including some that many may find offensive. The book fails to give a solid understanding of federal assistance programs, employment issues, or relationship dynamics; what information is offered on these topics is often over-simplified, contradictory, or factually naive. For example, rather than investigating how language shapes the construction of disability/"the disabled," Filipovski criticizes an ignorant nondisabled majority for "turn[ing] a deaf ear or focus[ing] a blind eye upon the disabled"; and she later subverts her assertion of the independent living model of disability by utilizing only medical classifications in her chapter "Definitions of Handicaps."

These unselfconscious semantic choices point to the book's greatest weakness - the quality of the writing. Filipovski's prose is layered with burdensome, overlapping metaphors, unfamiliar idioms, contradictory statements, and hyperbolic language which obscure her ideas and confuse the reader. The text, which appears minimally edited for even basic grammatical mistakes, hinders the reader's ability to identify the book's intended audience and main themes. With few references provided, a reader new to disability studies is left with no easy way to confirm the veracity of the author's claims.

The book does succeed in providing readers with insight into one person's experience and the issues which concern her. Filipovski tells of her personal experience of employment discrimination and attempts at seeking relief, shares her opinions on Beltway politics, and offers an understanding of the frustration and anger that many of us feel in the face of anti-disability discrimination. Unfortunately, while it may be refreshing to read a non-academic text on disability and to hear the opinions of "everyday" people with disabilities, the book's factual and grammatical errors prevent this reviewer from

recommending it to DSQ readers.

(Julie E. Amberg, Social Worker and Research/Advocacy Consultant, Ann Arbor, MI)

Heinemann, Allen W. (Ed.). Substance Abuse and Physical Disability. New York, NY: Haworth Press, 1993, 289 pages, \$49.95 hardcover, \$19.95 softcover.

Alcohol and other drugs have taken an unexamined toll on members of the disability community. For those who seek a starting place to study specific problems caused by alcohol and other drugs and/or have an interest in how disability issues inform a public health issue, Substance Abuse and Physical Disability, edited by Allen W. Heinemann, Ph.D., is a beginning.

The chapters are varied. They range from a broad view of addiction to a personal perspective from an individual in recovery who has a disability. Included are unique issues presented by people with disabilities in rehabilitation settings who are abusing alcohol and other drugs, and recommendations for treatment.

This book is intended to offer the most current thinking on the intersection of alcohol, drugs, and physical disability. Unfortunately, one and one half years after publication, this remains the only text examining the alcohol and other drug problems of people with disabilities, and many of the chapters reflect the field as it was six or seven years ago.

Heinemann's sixteen chapters - with as many differing perspectives and experiences - explore the problems created by alcohol and other drugs for people with disabilities. With a few notable exceptions, articles from professionals in the Chicago and Illinois area look at the areas for treating the physical aspects of recent trauma. The collection of articles is directed at and is informed by the physical rehabilitation professional.

Two chapters contain useful practice and policy recommendations: Schaschl and Straw's "Chemical Dependency: The Avoided Issue for Persons with Physical Disabilities"; and Linda Cherry's "Institute on Alcohol, Drugs, and Disability: From Grassroots Activity to Systems Change." (I need to mention that I have served on the Board of Directors for the Institute.) Not surprisingly, given the age of the chapters, the work of Dennis Moore at Wright State, the Massachusetts' ILC collaboration, Caroline Wang's work on prevention, the Center on Substance Abuse Prevention Disability Work Group, and VSA's Resource Center on Substance Abuse and Disability go unmentioned in any of the chapters. Their presence would have made this book much more valuable for both practitioners and researchers.

Because the articles address people in physical rehabilitation settings, it ignores the large number of people living with disabilities in the community who are self-medicating, socializing, and relieving boredom by using alcohol and other drugs. Ignored, too, are the larger societal pressures of advertising and their promises of attractiveness, companionship, and fun, which resonate particularly strongly in the disability community.

If one is interested in the specific problems that alcohol and other drugs cause, or how disability issues inform a public health issue, start with Substance Abuse and Physical Disability. I would recommend using the book to see which of the sixteen chapters spark an interest; then obtain current information from the Resource Center on Substance Abuse and Disability, 1331 F Street, NW, Suite 800, Washington, DC 20077-1514.

(Anthony Tusler, Sonoma State University, CA)

Josselson, Ruthellen, and Lieblich, Amia (Eds.). Interpreting Experience: Volume 3 of The Narrative Study Of Lives. Thousand Oaks, CA: Sage Publications, 1995, 262 pages, \$48.00 hardcover, \$21.95 softcover.

This collection of nine essays is the third in a series of annual volumes which approach the international and interdisciplinary study of human experience through the analysis of narrative. The essays vary in their goals from methodological discussions to the presentation of research conclusions. The book is perhaps more satisfying, particularly to disability scholars, in the former role, as a methodological "how to." None of the essays are about disability per se. However, they do demonstrate cross-cultural applications of the close examination of narrative interviews.

As disability studies grows and matures, an important goal is to communicate the lived experience of people with disabilities. Much of recent disability research employs some type of interview data. As social scientists understand disability to be situationally defined, it is increasingly important to describe context so that subsequent quantitative research is grounded in the experiences of real people. This is particularly true of the cross-cultural study of disability, where the contexts are diverse.

The first chapter, "Taking Narrative Seriously," by Susan Chase is an elegant, easy to understand discussion of how to develop an interview style that best elicits stories. This chapter could be very useful to graduate and undergraduate students embarking on their first fieldwork. It is illustrated with passages of actual interviews and serves as a good example of the analysis of narrative. The second essay, "Imagining the Real" by Ruthellen Josselson, is also a useful, if a little more dense, presentation of the social analysis of oral discourse. The third essay,

"Biographical Work and the New Ethnography" by Jaber F. Gubrium and James A. Holstein, employs the idea of "local culture." This post-modern way of talking about "sub-cultures" could help the understanding of disability in the context of "local" ethnic cultures. The remaining set of articles in the volume are all interesting, both in their intrinsic content and in how they use narrative data, but not as methodological as the opening essays in their orientation.

Once again Sage has published a methodological volume well suited to new and continuing researchers.

(Devva Kasnitz, Research Associate, World Institute on Disability, Oakland, CA)

King, Michael B. AIDS, HIV and Mental Health. Cambridge, England: Cambridge University Press, 1993, 197 pages, \$42.95 hardcover, \$21.95 softcover.

Human immunodeficiency virus (HIV) infection is a major medical problem and a diagnosis that indicates the development of a currently terminal illness - AIDS. An estimated one to two million individuals have been infected with HIV in the United States. Therefore, it is an increasingly important cause of illness-related disability.

While significant progress has been made in HIV therapeutics (e.g., azidothymidine [AZT], which has been shown to prolong the lives and improve the quality of life for persons with severe AIDS-related complex and AIDS), great advances remain to be made. A primary aspect of quality of life is mental health. However, although clinical programs have focused with some success on the management of physical symptoms and

critical discussion of the mental health dimensions of HIV infection as it influences patients, their partners and families, health professionals, and other care givers. The writer, whose practice, teaching, and research are conducted in the department of Academic Psychiatry of the Royal Free Hospital School of Medicine in London, provides a thoughtful and objective account of the published information (through 1992) on psychological and behavioral aspects of AIDS and HIV. He argues against the opinion that persons with HIV/AIDS are disproportionately affected with mental illness. A major theme of the book is that many of the mental health problems inherent to HIV infection can be attributed to the stigma of AIDS and the issues of sexuality and drug use which surround it.

Beginning with a clear explanation of the biological and neurological effects of infection, the author explores the many complex problems experienced by patients and health workers (e.g., delusional conviction of HIV infection, psychological reaction to the diagnosis, and types of observed psychological disorders). Issues of fear and stigma are challenged, and many of the controversies in the psychiatry of AIDS, such as the impairment of cognition, are critically analyzed. Dr. King concludes that HIV-1 Associated Cognitive/Motor Complex (HACC) is a possibility for all patients with HIV infection, but, despite measurable brain changes in well, sero-positive people, significant cognitive impairment is rare.

Management options for patients are also described. The author concludes that assessment and management of persons with HIV infection is very similar to that of

needs of homosexuals in cultures which explicitly approve of heterosexual lifestyle.

Overall, this clear and considered overview of the mental health aspects of HIV/AIDS will be useful for a wide range of mental health providers including counselors, social workers, nurses, psychologists, and psychiatrists.

(J. Gary Linn, Associate Professor, School of Nursing, Tennessee State University)

Sabo, Donald, and Gordon, David Frederick (Eds.). Men's Health and Illness: Gender, Power, and the Body. Thousand Oaks, CA: Sage Publications, 1995, 334 pages, \$49.95 hardcover, \$24.00 softcover.

This anthology begins with the intriguing observation that one of the "more significant risk factors associated with men's illness" is masculinity. Most of the subsequent chapters document, through an extensive review of the literature, how smoking, drinking, unsafe driving, and other behaviors related to conventional notions of male conduct, such as aggressiveness and violence, have had a detrimental effect on their health. The solution, obviously, is to reduce the discrepancy in activities based on gender by persuading men to emulate the less dangerous life-styles of women. Without detracting from the significant progress that this conclusion represents in the development of research on health and gender, many important questions remain unanswered. How can these changes be accomplished? Can the perspectives of men with disabilities and other minorities contribute to the attainment of this goal?

Although this volume also includes a chapter on African-American men, perhaps the contribution most relevant to the readers of DSQ is an article by Gerschick and Miller on men with disabilities. Based on ten interviews, they argue that men with disabilities have an

opportunity to develop a strategy based on reformulation, reliance, or rejection of hegemonic concepts of masculinity. While these concepts may have some heuristic value, they represent a rather superficial and preliminary approach to the study of men with disabilities. Perhaps the most critical research on gender must examine interactions between men and women, including men with disabilities.

There is a significant danger that health might be a relatively restrictive basis for pursuing studies of gender. Fortunately, this volume manages to avoid many of the mistakes of the early popular books in men's studies which depicted the specter of disability as a devastating fate that should be sufficient to dissuade men from engaging in sports and other aggressive or violent activities. There seems no basis for developing men's studies as a subfield of disability studies. Yet, gender is a rich, multifaceted variable that can provide a foundation for the analysis of the social structure as well as individual behavior. Through an analysis of the manner in which differences or disabilities affect many aspects of gender relations, disability studies may be in a position to make a major contribution to research on gender.

(Harlan Hahn, University of Southern California, Los Angeles, CA)

Thornburgh, Ginny (Ed.). Loving Justice: The ADA and the Religious Community. Washington, DC: National Organization on Disability, 1994, 36 pages, \$10.00 softcover.

Loving Justice is the result of a three-year interfaith collaboration in which authorities from the field of religion, disability, and the law distilled the portions of the ADA which do indeed apply to religious institutions. This information is presented in a user-friendly format.

First comes a summary chapter of the Act's main provisions, followed by frequently-asked questions. Then comes a chapter relating the ADA to other legislation. Chapter Three reviews in question and answer format specific requirements of the law which pertain to the religious community. Finally, resources and a glossary of terminology close out this slender volume. The National Organization on Disability published the core edition; the denominational offices of the Evangelical Lutherans, Episcopalians, Methodists, and Roman Catholics issued their own volumes, complete with endorsements and resolutions specific to their traditions. (The pricing and appearance of the denominational editions vary tremendously; what they hold in common is the title Loving Justice.)

An important interweaving with the legal requirements is the moral imperative leading faith communities. Her observation that "if supermarkets and bars are more accessible than altars, then we must all bear the shame" (p. 3) is both a guide and a goad.

The clear message and intent of the book is that justice and love will triumph only when architectural, communication, and attitudinal barriers are removed. Only then can people with disabilities claim full membership in both the celebrations and obligations of their faith.

(Mary Jane Steinhagen, Catholic Charities Disability Advocate, St. Paul, MN)

Villani, P.J. (Ed.). Ethics and Values in Long Term Health Care, New York, NY: Haworth Press, 1994, 121 pages, \$24.95 hardcover.

Ethics and Values in Long Term Health Care is a collection of articles which were co-published simultaneously as a book by Haworth Press and as a special theme issue of the journal Activities, Adaptation and Aging

(Vol. 18, No. 3/4). Written by gerontological practitioners, the writings are focused on elder-care ethical issues which are of interest and concern to health and human services professionals. This short volume, which can be easily read in a few hours, contains four sections: practitioner knowledge, care giving, end of life choices, and health care reform.

In the first section on practitioner knowledge, Kimboko and Jewell have contributed the strongest chapter in the book. They provide an excellent overview of the four key moral principles: (1) respect for autonomy, (2) beneficence/compassion, (3) non-maleficence, and (4) justice. The rules of ethical care which are derived from these principles and which should guide the professional-client relationship are also discussed: (1) veracity or truth-telling, (2) confidentiality and privacy, and (3) fidelity. The chapter concludes by recommending the steps to take to establish an ethics committee in a long-term care setting. The appendix to the chapter provides helpful illustrations, using case studies, of ethical dilemmas that may be encountered. In contrast, the chapter which follows by Clair on music therapy for elderly persons provides limited information on ethical issues that concern most geriatric professionals, although it does extend an understanding and appreciation of music therapy.

The second section on care-giving is comprised of a well-written chapter by Roberto which focuses on ethical challenges and dilemmas associated with Alzheimer's Disease. The book would have been strengthened by the inclusion of a chapter addressing ethical issues associated with physical disabilities which often raise significantly different ethical dilemmas in providing long-term care services.

The third section on end of life choices contains three chapters which are poorly

integrated and contain redundancies in the ethical issues considered. Marinelle examines the multi-faceted ethical considerations in decision-making about life-ending choices from the perspectives of society, patients, and families. End of life decision-making among older adults is also reviewed by Barrett, but her discussion focuses on the principles of autonomy, non-maleficence, and beneficence, and the examples are primarily relevant to institutional settings. Jackson applies a utilitarian perspective to death and dying in a narrow interpretation. Utilitarianism is an ethical theory, attributed to Jeremy Bentham, that proposes that the best action is one which procures the "greatest happiness for the greatest number." Jackson states that most of the aging policy in the United States is based upon utilitarian ethics, and that "we consider most often what is best for the larger good which is consistently composed of non-aged persons over the general welfare of the aged" (p. 93). First, it seems clear that what is best for the non-aged often includes actions that directly improve the general welfare of the aged. For example, the non-aged benefit from aging policies that provide their elderly parents with health care and retirement income. Second, since most of the non-aged will someday be elderly, they receive some happiness from aging policies knowing that, when they become old, they, too, will receive certain economic supports and health care benefits. Third, Jackson's interpretation of utilitarianism does not explain how aging policies such as Medicare have come to pass because she suggests that the welfare of the non-aged has always taken precedence over that of the aged.

The fourth section on health care reform is comprised of two chapters. The chapter by Raber and Hawkins examines ethics and health care reform by contrasting the Clinton Health Care Proposal with current

Medicare coverage. Much of the information provided is now outdated and no longer relevant to the current health care debate. The chapter by Blake focuses on the degree to which legally guaranteed access to health care will allow the right to limit or ration treatment and, if so, on what moral grounds. This chapter does not reflect what we are learning from states, such as Oregon, which are experimenting with rationing health care.

Overall, I do not think that DSQ readers will find this book of interest because the gerontological perspective of the authors limits their focus to aging and end of life issues in providing long-term care. None of the chapters address the important ethical issues related to physical as well as cognitive disability that are encountered in receiving long-term care, and there is a lack of awareness of the contributions of the disability community to developing service delivery models for long-term care which enhance autonomy, independence, and empowerment. The editor of the book has failed to integrate the chapters by providing a unifying sense of overall purpose and coherence, and by ensuring that the chapters reflect universally ethical principles such as those introduced by Kimboko and Jewell. Moreover, the book emphasizes institutional and medical settings and, generally, does not address ethical issues encountered in the community, the context in which many practitioners will face moral dilemmas. Health care and gerontological professionals will find the quality of the chapters uneven and will gain a very limited understanding of the critical perspectives and knowledge of the ethical dilemmas that they need.

(Debra J. Sheets, Research Associate,  
Andrus Gerontology Center, University of  
Southern California, Los Angeles, CA)

Wright, Ken, Haycox, Alan, and

Leedham, Ian. Evaluating Community Care: Services for People with Learning Difficulties. Buckingham, England, and Philadelphia, PA: Open University Press, 1994, 191 pages, \$29.00 softcover.

This interesting and very readable book from Great Britain has three audiences - those interested in research methodology, policy development, and/or "learning difficulties." The authors weave a synthesis in which they discuss methods for the evaluation of community care services for individuals who have learning-related disabilities and the means by which these evaluations are applied in the development of policy. They do this with particular reference to micro-economic appraisal of health and social care.

The chapters of the book may be of varying interest to its three audiences. After an introductory chapter, Chapter 2 lays out the basics of the evaluation framework from an economic perspective, providing a clear introduction to the concepts necessary in an economic analysis (theory of production, cost benefit, cost utility, and cost effectiveness analyses). Chapter 3 provides an introduction to the status of services for people with "learning difficulties" in the United Kingdom, which appears to be considerably behind the US in a shift to community care from institutions. In Chapters 4-6 (pages 52-125), the book hits its stride with a very nice analysis and overview of the principles and practice of research design, descriptions of data collection dimensions and instruments, and qualitative and quantitative approaches to analysis, together with their application to evaluation in the field of "learning difficulties." Chapters 7 and 8 provide specific theory and application of cost concepts to evaluation, and Chapter 9 concludes the volume with the future of policy development and evaluation in the 1990's.

The literature on which the authors draw crosses national boundaries, but the

presence of a large number of sources from the UK may be a value to US readers. The authors have opted for the term "learning difficulties" on the basis of its acceptability to people with such problems and service providers, but the term encompasses those with mental retardation and learning disabilities (as used in the UK). Other differences in terminology in the two countries, as reflected in this book, are wonderful and enlightening: caregivers are "carers," case management is "care management" (approximately), normalization is "ordinary life principles," and protected funding is "ring fenced." Throughout, the UK experience regarding service funding in the context of shifting local and national responsibilities, interagency coordination, and health and social service systems may illuminate US readers regarding present and future dilemmas of possible shifts from categorical funding to block grants.

The book emanated from the authors' frustration over the lack of progress in the UK to this point (pp. 117-119), and a resulting call to action for the future, especially in terms of "user empowerment" and "service brokerage." It is an example of a policy-relevant document that includes material for researchers and those interested in developmental disabilities.

(Dorothy Jones Jessop, Ph.D., Medical and Health Research Association of New York City, Inc.)

### Film Clips

Golfus, Billy, and Simpson, David E. (Producers/Directors). When Billy Broke His Head and Other Tales of Wonder [video]. Boston, MA: Fanlight Productions (47 Halifax Street, Boston, MA 02130; 1-800/937-4113), 1994, 57 minutes, \$245.00 purchase, \$100.00 rental/week, \$50.00 rental/day.



Billy Golfus presents his personal quest and says, "This video ain't exactly your inspirational cripple story." To laugh and cry and laugh about it all again. Billy has opened a window and let out the smoke while sounding the alarm. An alarm that says not "we are desperate," but "here we are, and we're not going away." He starts at home and, in ever-widening circles, tells of the healing and frustration and how the frustration aids in the healing of broken bodies, minds, and spirits. He goes to the homes of others and asks the questions that must be asked: how do you, what do you, when do you, and have you ever? Through the answers, Billy weaves a mosaic for veterans, novices, and TABs (temporarily able-bodied) that delves deeply into the personal and political empowerment of people with disabilities. He blends interviews with peons and icons to focus the light back into the room where the house really is burning, the same room where people don't need to be rescued, but illuminated. He picks movers and shakers of all walks of life that have made great and small impacts on systems by, if nothing else, refusing to go away. Billy typifies the edict that Major Owens gave us on July 26, 1990, "Get out there, and get visible!"

Billy keeps us grounded with his continuing dialogue with his father, who espouses that, if only people who have disabilities tried a little harder, they could succeed. Dad's typical World War II generation attitude comes through loud and clear to remind us that this is a people-to-people struggle and that the final barrier will always be attitudinal.

Billy is the quintessential "a poet, a puppet, a prophet, a pawn, and a king," as he leads us through the "glass darkly" and shows us that it is no better or worse on the other side, only different.

(Jack E. Campbell, M.A., Origins Society, Tucson, AZ)

Golfus, Billy, and Simpson, David E. (Producers/Directors). When Billy Broke His Head and Other Tales of Wonder [video]. Boston, MA: Fanlight Productions (47 Halifax Street, Boston, MA 02130; 1-800/937-4113), 1994, 57 minutes, \$245.00 purchase, \$100.00 rental/week, \$50.00 rental/day.

This documentary film is a series of interviews narrated by Billy Golfus, a Minneapolis radio star who was injured in a motorcycle accident. The accident left him with a brain injury that affected both his cognitive and physical function. Although Billy had an award-winning career prior to his injury and obtained a master's degree following his injury, he becomes "as invisible as Casper the ghost." "Normal" people no longer treat Billy and the other people he interviews as competent human beings and they deny them access to jobs, information, funding, and equality. Billy speaks with artists and activists with disabilities during this hour long film. Several themes emerge from their conversations, including: 1) difference, invisibility, and resulting barriers to access and inclusion; and 2) civil disobedience as the only solution to these barriers.

The first theme is reflected in statements such as, "You're different, you're out of the game. You're not like everyone else." Ed Roberts, who sleeps in an iron lung, states he was described as a "hopeless case" fourteen years prior to getting a job as Director of the California Department of Rehabilitation. Ed adds, "We've got to be seen." Joy, a dancer, claims that she is viewed as a medical diagnosis rather than a spiritual, sexual, feeling person. She explains that those without disabilities consider people with disabilities to have justifiable cause to consider suicide. In a conversation between Billy and his father, the latter states that, if he acquired a disability as a result of a stroke, he would

throw himself off a bridge. I think that many people have thought, "I'd rather be dead than live like THAT" at one time or another. The media provides fuel for these thoughts. How? By portraying persons with disabilities as monsters and villains - "defective, not really human," states Stanford University Professor Paul Longmore. Examples include the Hunchback of Notre Dame, the Elephant Man, and on and on. Jerry Lewis tells us that "my kids cannot go into the world of work," the implication being that they are less than or not as good as those who are "normal."

Because people without disabilities are so uncomfortable when confronted by those who are different, they create barriers to keep people with disabilities isolated and out of the mainstream. Robin drives a van for people with disabilities in spite of the severe communication and physical difficulties which prevented her from getting her license for many years. Paul Longmore relates a story from Jean Stewart's book The Body's Memory about a woman who was swimming. If you looked at me, she explained, you would think I was drowning, but I knew that I was swimming. When people are defined as less than normal or different, they get things dispensed to them out of the hearts of "the normal," according to Longmore. "We have no rights," he states. "We have to fight for everything," adds Kay, who is legally blind. Kay explains that every month she must fill out a thirty-four page application which she cannot see in order to continue receiving her financial support. In another illustration of fighting to get services, Billy records a visit with his case worker where we find out that his monthly income payments are to be lowered since his total income of \$522 is considered to be too high. "Could you live on that?" he asks the case worker. "We are punished for having a disability," and "we are supposed to be grateful for whatever we do get."

Billy relates a comment that his friend with a disability made, which put things into perspective for me. "If I have a job then they don't have a job." That leads me to the next theme.

The film suggests that the only way for people with disabilities to gain access in the United States is, fueled by anger, to become barriers to the status quo. Billy interviews Wade Blank, one of the Gang of Nineteen who pioneered the formation of ADAPT, the radical arm of disability rights activists. Wade, who lived in Denver, remembered back to 1978 when the Gang of Nineteen laid down on the streets of Denver to stop the buses. If you can't get access by following the rules, Wade comments, then you have to present a barrier to those who will not listen.

As a result of stopping the buses, which prevented the bus drivers and travelers from getting their jobs done, Denver is now one city in which all buses are accessible. ADAPT's continued civil disobedience spurred the passage of the Americans with Disabilities Act. At the time of the filming, ADAPT members were fighting to get community housing and community support services as an alternative to living in nursing homes. "Why do we have to get arrested?" asks Wade. The way this writer sees the dilemma is that nursing homes are big money makers. Nursing homes supply many people, including this writer, with jobs. If people with disabilities start living in the community, what is going to happen to that big business? What is going to happen to my job? What about all the caseworkers? The status quo is going to be upset. As illustrated in the film, if they get jobs, mine is in jeopardy.

Billy Golfus' use of candor and humor as means to explore his own experience and the experience of his interviewees kindled my thoughts. Billy and the others he chronicles in this film are faced with fighting the "helping

system" to get what they need to be visible and to be included in a society which treats them as "outsiders."

(Lynn Gitlow, Program in Occupational Therapy, Lewiston-Auburn College of the University of Southern Maine)

Gould, Ron (Producer/Director), and Furman, Richard (Associate Producer). One of Us: Four Stories of Inclusion. Boston, MA: Fanlight Productions (47 Halifax Street, Boston, MA 02130; 1-800/937-4113), 1992, 27 minutes, \$195.00 purchase, \$100.00 rental/week, \$50.00 rental/day.

This video set out to improve attitudes towards disabilities, but fell short of that goal. It started out pretty well, too, but, overall, good intentions do not excuse the "we - they" and "blessed are those with disabilities" messages. My awareness was definitely raised as to how we still just don't get it.

The music and undertone became too distracting. Individuals with disabilities were either so very "special," someone the parent was "blessed with," or darn near the most perfect example of sweetness and niceness. The narrator, being an "AB" (able-bodied) professional to lead the way, "clanged" separateness and was patronizing. In fact, that seemed to be the major flaw - everyone else talked too much about the main characters, and there was not enough action to demonstrate that inclusion happened!

Having fellow classmates talk about Pete was no doubt well intended, and there were some insightful comments. Yet students talked (too much) about "them," "felt sorry for" him, and said he had a "disease"; and it was loud and clear that he was such a wonderful and likeable guy. I kept hoping for regular, boring, and that Pete would get more air time! Life is not perfect, and we all have ups AND downs; it makes it more like "one of us."

The young lady with cerebral palsy segment brought to mind how people with disabilities are often "set up" to be over-achievers and the overplay that "love" can take in relationships. A charity message came across seeing her in token appearances and not doing more meaningful activities.

Accessibility was a concept totally missing in the final segment. To see how the boy with "complex medical needs" improves his life by adaption was needed. He should "speak for himself," but there was no hint that he could or had been allowed to try. Content was so medical and "spiritual" that we couldn't see him as a viable person. Hearing the mother compare him to a "baby," and showing us that she has no life beyond her son gives the message that children with disabilities are a "special burden to bear."

(Sue Vaughn Williams, Partners in Policymaking Coordinator, The Arc of Nebraska, Lincoln)

Kahn, Harvey, and Duncan, Chip (Producers), and Goldberg, Howard (Director). Eden [film]. Santa Monica, CA: Water Street Pictures (2625 29th Street, Santa Monica, CA 90405; FAX: 310/581-1533), 1995, 106 minutes.

One of the bright spots of the recent Sundance Film Festival in Park City, Utah, was Howard Goldberg's independent film, Eden. In Eden, we are introduced to Helen, who has multiple sclerosis and wears a leg brace. The year is 1965. Helen is married to Bill, a teacher at a New England Prep School. She is a stay-at-home mom with two young children. Bill is a tough authoritarian figure who presses conformity to traditional roles.

Nineteen-sixty-five spells the dawn of a new age - for Helen and everyone else. One morning Helen tells Bill of her dream in which she flew. Nothing terribly remarkable there; we've all had flying dreams. Helen then begins

to have out-of-body experiences.

The astral projections are contrasted to her daily experiences living with the uncertainties of m.s. Helen's m.s. exists alongside her frustrations with her lived experience. Bill expects her to stay home with the children, he berates her for not keeping house properly, and he forbids her to seek a position as a teacher or tutor.

Helen's out-of-body experiences are liberating physically and spiritually. Helen checks into the hospital for "rest and tests" and goes into a coma for weeks while she is out of her body. Remember, this is 1965, and Helen has no cultural context for these spiritual experiences.

It is during this period that Helen's husband, Bill, comes to terms with his wife having m.s. and his own authoritarian stance against Helen and the world. In a poignant moment, Bill speaks to his comatose wife and tells her that he thought he needed to accept her body with m.s. He did that, he tells her, but he adds, "I forgot to accept you, who you are."

This film is an interesting treatment of disability, body image, and spirit. In many films, the metaphor can get in the way of the message. I am thinking in particular of Jennifer Lynch's Boxing Helena in which an obsessed lover cuts off the arms and legs of his "object" of desire in order to control her. Or, think of Linda Wertmeuller's Swept Away, in which the gender struggles of a wealthy woman and the crew member of her yacht are supposed to represent class struggle. The metaphors are so powerful in themselves that the film viewer cannot really get beyond the metaphoric image and appreciate the message. Eden is a film where m.s. is used to help us explore mind, body, spirit, and who we are. The metaphor works.

(Gary Kiger, Utah State University, Logan, UT)

### Coming (and Past) Events

The Biennial Convention of the National Association of the Deaf will be held in Portland, Oregon, on July 2-6, 1996. Contact them at [ktjp66a@prodigy.com](mailto:ktjp66a@prodigy.com) (Internet), 503-641-6715 (TTY), or 503-643-2487 (FAX).

On July 4-7, 1996, the 13th Annual American Juvenile Arthritis Organization National Conference will be held at the Airport Marriott Hotel, San Francisco. Contact them at 404-872-7100 x6277.

The XI International Conference on AIDS will meet July 7-12, 1996, in Vancouver, Canada. Contact them at 604-631-5576.

The Third International Conference on Deaf History will meet July 8-13, 1996, in Bundoora, Australia. Contact DHI '96, National Institute for Deaf Studies, La Trobe University, Bundoora 3083, Australia.

The Native American Research and Training Center (NARTC) at the University of Arizona will sponsor a workshops on Native Americans with Disabilities Workshop, Tampa, Florida, July 10-13, 1996. Contact them at 520/621-5560 or [RSY@aurba.ccit.arizona.edu](mailto:RSY@aurba.ccit.arizona.edu) on email.

The Midwest Intensive Bioethics Course will be held July 14-19, 1996, at the Riverwood Conference Center, Monticello, MN. Contact them at 612-626-9756, 612-626-9786 (FAX), or on the Internet [holmb006@maroon.tc.umn.edu](mailto:holmb006@maroon.tc.umn.edu).

On July 17-20, 1996, the Association on Higher Education and Disability will hold its annual conference entitled Transition, Technology, and Training at the Hyatt Regency in New Orleans, LA. Contact them at 614-488-4972 (voice and TTY) or 614-488-1174 (FAX).

The National Down Syndrome

Congress will meet July 26-28, 1996, in Miami Beach. Contact them at 800-232-6372 or 404-633-2817 (FAX).

The National Fragile X Foundation will meet August 6-11, 1996, in Portland, OR. Contact David Mommener, 303-333-6155 or 303-333-4369 (FAX).

The Association for Education in Journalism and Mass Communication will meet August 10-13, 1996, in Anaheim, CA. Contact Beth Haller at bah17@psuvm.psu.edu on the Internet.

The Sixth World Congress on Down Syndrome will meet August 27-30, 1996, in Paris. Contact GEIST, 21, 38, rue des Tilleuls, 30900 Nimes, France.

The National Rehabilitation Association will meet September 5-8, 1996, in Norfolk, VA. Contact Carol Jafarr at 703-836-0850 or 703-836-0848 (FAX).

The 18th World Congress of Rehabilitation International will be held on September 16-20, 1996, in Auckland, New Zealand. Contact Richard Buchanan, P.O. Box 2009, Auckland, New Zealand.

On September 27-28, 1996, the Braintree (Massachusetts) Hospital Rehabilitation Network will present a Stroke Survivors Recovery and Rehabilitation Conference. On September 29-October 1, 1996, they will present the 17th Annual Traumatic Brain Injury Conference. Both conferences will be held at the Royal Sonesta Hotel in Cambridge. Contact the Public Relations Department of the Hospital at 617-848-5353 x2300.

On October 13-16, 1996, the Society for Medical Decision Making will hold its 18th Annual Meeting in Toronto. The deadline for submission of abstracts in May 15. Contact them at 202-994-8929 or 202-994-1791 (FAX).

The Conference on Aging and Developmental Disabilities will meet October

14-16, 1996, in Lexington, KY. Contact James Stone at 606-273-9656 or jaslex@aol.com on the Internet.

The Washington Business Group on Health will hold its Tenth Annual National Disability Management Conference and Exhibits on October 16-18, 1996, in Washington, D.C. The theme is Securing the Future and Preserving the Past. Contact Ann Makowski at 202-408-9320, 202-408-9333 (TTY), 202-408-9332 (FAX), Makowski@WBGH.com on the Internet.

The American Association of University Affiliated Programs for Persons with Developmental Disabilities will meet October 17-21, 1996, in Washington, D.C. Contact Theresa Hosinski at 301-588-8252 or 301-588-2842 (FAX).

Tourette Syndrome Association national conference, October 31 - November 3, 1996, Burbank, CA. Contact the Tourette Syndrome Association at 42-40 Bell Blvd, Bayside, NY 11361-2820.

The Center for Biomedical Ethics at the University of Minnesota will hold a conference entitled End-of-Life Care in Managed Health Care Organizations: State of the Art in Ethics and Quality of Care on November 1-2, 1996. Contact them at holmb006@maroon.tc.umn.edu.

The Brain Injury Association will meet November 3-6, 1996, in Dallas. Contact Elizabeth Rouse at 202-296-6443 or 202-296-8850 (FAX).

The Arc National Convention will be held November 6-8, 1996, in Louisville, KY. Contact them at 800-433-5255.

The American Public Health Association will meet November 17-21, 1996, in New York City. Contact them at 202-789-5674 (voice) or 202-789-5673 (TTY).

The Gerontological Society of America will hold its 49th Annual Scientific Meeting on November 17-21, 1996, at the Sheraton

Washington Hotel in Washington, D.C. Contact them at 1275 K Street, NW, Suite 350, Washington, D.C. 20005-4006.

The Native American Research and Training Center (NARTC) at the University of Arizona will sponsor a conference on NIDDM in Minority Children, Tucson, Arizona, December 6-7, 1996. Contact them at 520/621-5560 or RSY@aurba.ccit.arizona.edu on email.

The Native American Research and Training Center (NARTC) at the University of Arizona will sponsor a conference on Cancer in Native American Women, Spring 1997. Contact them at 520/621-5560 or RSY@aurba.ccit.arizona.edu on email.

### **Call for Manuscripts**

The Fall 1996 issue will be on the new economics of disability with Corinne Kirchner as guest editor. The Winter 1997 issue will be a general one on disability studies. The Spring 1997 issues will be on disability history with Paul Longmore as guest editor. The Summer 1997 issue will be on children and parents with Barbara Altman as guest editor. The Fall 1998 issue will be on oral history with Karen Hirsch as guest editor. Other future issues will be disability studies with Katherine Seelman as guest editor, deafness with Sue Foster as guest editor, and disability and queer identities with Shelley Tremain as guest editor.

### **Communications**

A masters program in Disability Studies is offered at Sheffield University in the United Kingdom. It is offered on site and by distance learning. The content and academic standards of the distance learning versions of the program is the same as those for the

residential courses. Students will be assigned tutors, with whom they can communicate by post, fax, phone or email or any combination of these. Students will normally be expected to attend three weekend courses per year in Sheffield. The cost of accommodation (but not meals) is included in the tuition fee. Exceptions to the requirement to attend these courses may sometimes be made because of distance from Sheffield or disability or other reasonable cause, in which case alternative arrangements will be made in order to impart the content of the weekend courses. The courses are structured on a part-time basis over two years. Fees are 1215 British pound sterling per year for British and European Union students and about 3099 British pound sterling or about \$4649 US per year for others.

For further information contact Judith Taylor, Centre for Psychotherapeutic Studies, 16 Claremont Crescent, Sheffield S10 2TA, fax 0114 270 0619, or j.m.taylor@sheffield.ac.uk on the Internet. Extensive information about the center, its programs and its staff is available at <http://www.shef.ac.uk/~psysc/> on the Internet.

In October 1995 the National Institute on Disability and Rehabilitation Research announced the following grants: (1) Paul Longmore, San Francisco State University, Examining the Impact on Postsecondary Students of Three Disability Studies Paradigms; (2) Frank Rusch, University of Illinois, Similar and Different: Core Concepts and the Coming of Disability Studies; (3) Stephen Lichtenstein, University of New Hampshire, Undergraduate Minor in Disability Studies; and (4) Daryl R. Mellard, University of Kansas, Accommodations for Individuals with Disabilities in Adult Education Programs.

In June 1996 the National Institute on Disability and Rehabilitation Research

announced the following grants: (1) Jeanette Harvey, University of San Francisco, Disability Rights Leadership Archive; and (2) Charles Faulhaber and Bonnie Hardwick, Bancroft Library, University of California, Berkeley, The Disabled Persons' Independence Movement: The Formative Years in Berkeley, California - A Research and Documentation Project.

The Society for Disability Studies announces a special offer on past meeting proceedings. The Changing World (1986) is offered at the special price of \$10.00. Emerging Issues (1987) is offered at the special price of \$7.00. Social Exploration (1988) is offered at the special price of \$10.00. All three proceedings can be obtained at the special price of \$24.00. Shipping costs are included in these prices for the US and Canada. For all others add \$4.00 per book for surface mail and \$14.00 per book for air mail. All orders must be prepaid in US dollars. Make out checks to the Society for Disability Studies and send your order to Elaine Makas, Lewiston-Auburn College, 51-55 Westminster Street, Lewiston, ME 04240.

"An Innovative Rehabilitation Facility: The Creative Art Center for People with Disabilities" by Elias Katz, Ph.D., National Institute of Art and Disabilities, Richmond,

CA, which appeared in the Fall 1995 issue of Disability Studies Quarterly was originally published in the Summer 1994 issue of OSERS: Disability and the Arts.

### **Announcements**

1. There will be a CDC Conference on Prevention and Managed Care. The Office of the Managed Care Coordinator (OMCC) has confirmed January 14-16, 1997, in Atlanta for the next CDC National Conference on Prevention and Managed Care. If you have specific issues for consideration by the planning committee, please contact the Conference Coordinator, Jeffrey R. Harris, MD, MPH, Coordinator, Managed Care, Office of the Director, 404/639-4500

2. Did you know you can get NCD BULLETIN free? Contact the National Council on Disability, 1331 F Street, N.W., Suite 1050, Washington, D.C. 20004-1107 voice 202-272-2004, TT 202-272-2074, Fax 202-272-2022.

3. The National Institute on Disability and Rehabilitation Research now has a World Wide Web (WWW) Test Site, URL address is: <http://inet.ed.gov/~dsti/OSERS/NIDRR/> and please send any comments Sean Sweeney at [Sean\\_Sweeney@ed.gov](mailto:Sean_Sweeney@ed.gov) on the Internet.

## The Society for Disability Studies

The Society for Disability Studies is a nonprofit scientific and educational organization. It is a multidisciplinary and international organization composed of social scientists, scholars in the humanities, and disability rights advocates concerned with the problems of disabled people in society. The purpose of the Society is to bring together people from diverse backgrounds to share ideas and to engage in dialogues that cut across disciplinary backgrounds and substantive concerns. The Society is committed to developing theoretical and practical knowledge about disability and to promoting the full and equal participation of persons with disabilities in society.

The Society for Disability Studies annual meeting is usually held in June of each year. Likely themes for disability studies papers or panels are topics such as policy, history, sexuality, law, culture, methods, politics, media, literature, pedagogy, gender, self image, cross cultural studies, family, advocacy, activism, and related topics.

Further information on membership and the 1996 annual meeting can be obtained by TDD at 617-523-3682 or by voice at 617-523-3429. The mailing address is: Society for Disability Studies, c/o Department of Public Management, Suffolk University, Eight Ashburton Place, Boston, MA 02108-2770 USA.

Dues for membership in the Society are based on income and are as follows:

Less than \$15,000	\$15.00
\$15,000 - \$30,000	\$25.00
\$30,001 - \$45,000	\$35.00
Over \$45,000	\$45.00

### Subscription Information

Disability Studies Quarterly comes out four times a year. Each volume is the same as a calendar year. Although the Quarterly is associated with the Society for Disability Studies, the subscription price for the Quarterly is not included in the dues for the Society. However, members of the Society are entitled to a reduced rate. The prices for a one year subscription are as follows.

Individual	\$ 35.00
Institution	\$ 45.00
SDS member	\$ 30.00
Student	\$ 20.00
Low Income	what you can afford

#### Additional postage:

Canadian subscribers by air	\$12.00
Other international (not air)	\$ 6.00
Other international by air	\$16.00

International subscriptions can be obtained by the exchange of newsletters and/or publications relating to disability.

Please specify if you wish to receive the Quarterly on audio tape cassette, by email, or on



diskette (IBM compatible WP5.1 and ASCII, 5 1/4" or 3 1/2", high density). There is no additional cost for an alternative format.

The Samuel Gridley Howe Library in Waltham, Massachusetts, is the repository for past issues of Disability Studies Quarterly. Irv's papers and books as well as the books, papers, and manuscripts of Rosemary and Gunnar Dybwad are also deposited there. Bonnie Stecher is the librarian at the Howe Library. The Library is available for research into all aspects of disability.

Past issues of Disability Studies Quarterly are available for \$7.00. Please specify the theme of the issue and the volume and issue number. Your request will be forwarded to the Howe Library. The Winter issue of each volume is on general disability issues. Past issues with a special focus: Technology (October 1984); Developmental Disabilities (January 1985); Aging and Disability (April 1985); Work and Related Disability Policies (Summer 1985); Women, Disability, and Gender-Related Issues (Spring 1986); Media Depictions (Summer 1986); Psychological Issues (Fall 1986); Baby Doe and Other Neonatal Issues (Spring 1987); International Comparative Issues in Disability (Summer 1987); Teaching Disability Studies (Fall 1987); Self-Help and Independent Living (Spring 1988); Historical Aspects of Disability (Summer 1988); School-Age Children and Disability (Fall 1988); The Experience of Illness and Disability (Spring 1989); Gender and Disability: Sexuality Reproduction Issues (Summer 1989); Communications Technology & Hearing Impairment Issues (Fall 1989); Cross-Cultural - Comparative II (Spring 1990); Disability Demographics (Summer 1990); Media Depictions (Fall 1990); Bioethics (Spring 1991); Disability Policy (Summer 1991); Caregiving and Personal Assistance (Fall 1991); The Body (Spring 1992); Politics of Disability (Summer 1992); Assistive Technology (Fall 1992); Rethinking Mental Illness from the Inside (Spring 1993); Genetics (Summer 1993); Young Children (Fall 1993); Disability Studies Revisited (Spring 1994); National Health Care Reform (Summer 1994); AIDS (Fall 1994); Media III (Spring 1995); Religion, Spirituality, and Disability (Summer 1995); Disability Culture (Fall 1995).

Checks for past issues or for subscriptions should be made out to the Disability Studies Quarterly and sent to David Pfeiffer, Department of Public Management, Suffolk University, Eight Ashburton Place, Boston, MA 02108-2770, USA.

### **Instructions to Guest Editors and Contributors**

Every article published in the Quarterly is invited by and reviewed by the editor, the guest editor, and/or the book review editor. Although not technically a refereed publication, scholarly and professional standards are expected from the authors.

Please submit all material in IBM compatible format in ASCII or Word Perfect 5.1. Material may be submitted either on 5 1/4" or 3 1/2" disks. Do not use footnotes on the page or any imbedded notes because they will not print correctly. All notes (if used) must be endnotes. If "References" are provided, all citations in the list must be included in the notes or the text. Any citation not included will be deleted. If a "Bibliography" is provided (which includes all references), it can contain material not cited in the text or the notes. Any appropriate and clear form of citation can be used. However, it must be consistent throughout the material.

Gender specific pronouns should be avoided unless appropriate. The form "people with disabilities" or something similar must be used. Do not use contractions or slang unless it is in the original text which is being quoted.

Corrections of grammar and syntax will be done, but every effort will be made to keep the original wording. Subheadings can be used, but remember that the published format is two columns so please avoid long subheadings.

Work previously published must be so noted with a complete citation. If a copyright was obtained on the previously published work, written permission from the copyright holder must be included. Previously published work is not encouraged.

While there is no page limitation on individual contributions, authors should discuss the number of pages with the guest editor. The overall issue length is dependent upon funding.

Contributors who are not subscribers are encouraged to subscribe. The editor will provide a copy of an issue in which a non-subscriber's material appeared. Only issues - not individual articles - will be provided.

Authors are responsible for meeting these guidelines. Guest editors are responsible for enforcing these guidelines. The editor's decision in these matters is final, but the editor is very grateful to all contributors and guest editors for their hard work.

## REVIEWS

All books and videos to be reviewed should be sent to Dr. Elaine Makas, 10 Sheffield Street, Lewiston, ME 04240. Persons wanting to volunteer to do reviews should contact her with your field of specialty.

## SPECIAL NOTICE

Since Irv Zola died many persons wondered about the future of the Quarterly. Disability Studies Quarterly will continue. For the calendar year 1996 (and longer if necessary) I will be the editor of the Quarterly. The Steering Committee feels confident that subscription and other income will provide sufficient funds to pay for its publication. We are receiving some support from Suffolk University, but we need much more.

Please consider making a donation to ensure that the Quarterly will continue during this transition time. For persons (or organizations) who can afford large contributions, please make one now. All donations are welcome, however. Make the check payable to Disability Studies Quarterly and MARK ON IT DONATION. Send it to David Pfeiffer, Department of Public Management, Suffolk University, Eight Ashburton Place, Boston, MA 02108-2770, USA. Thank you.

David Pfeiffer, Editor

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