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## Accessing the Issues: Current Research in Disability Studies

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A publication of  
**The Society for Disability Studies**

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**The Edmund S. Muskie Institute of Public Affairs**

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## The Society for Disability Studies

The chapters in this book are extended abstracts of some of the presentations given during the April 1995 annual meeting of the Chronic Disease and Disability Section of the Western Social Sciences Association and the June 1995 annual meeting of the Society for Disability Studies, both of which were held in Oakland, California.

The Society for Disability Studies (SDS) is a nonprofit scientific and educational organization established to promote interdisciplinary research on humanistic and social scientific aspects of disability and chronic illness. The Society works to create forums for the exchange of information relevant to the experiences of individuals with disabilities and to promote the full participation of persons with disabilities in society.

Founded in 1982 as the Society for the Study of Chronic Illness, Impairment, and Disability (SSCIID), the organization was renamed the Society for Disability Studies in 1986. The Society maintains affiliation status with the Western Social Science Association (WSSA) through its Chronic Disease and Disability Section. SDS currently has several hundred members from the U.S. and other countries.

The Society, in conjunction with the Center on Disability Studies at the University of Hawaii at Manoa, and Suffolk University of Boston, Massachusetts, publishes the Disability Studies Quarterly, a journal founded and, for many years, edited by Irving K. Zola, a Founding Member and the first President of the SDS. The current editor of this journal is David Pfeiffer, another of the Society's past presidents.

In addition, the Society has published the Proceedings of each year's annual SDS meeting--from 1986-1992 with the assistance of Willamette University, Salem, Oregon; and from 1993 to the present with the assistance of The Edmund S. Muskie Institute of Public Affairs of Portland, Maine. (The tables of contents of all available SDS publications can be found on the Society's website.)

For further information on the Society or on the Society's Annual Proceedings, contact The Society for Disability Studies via its website ([www.wipd.com/sds](http://www.wipd.com/sds)) or by mail c/o Richard K. Scotch, Ph.D., School of Social Sciences, The University of Texas at Dallas, Box 830688, Richardson, TX 75083-0688. For further information on the Disability Studies Quarterly, contact David Pfeiffer, Ph.D., Center on Disability Studies, University of Hawaii at Manoa, 1776 University Avenue, UA 4-6, Honolulu, Hawaii 96822.

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Our special thanks also to the many authors who were not only willing to share the information which they presented at the SDS and WSSA meetings, but who were also willing to put forth the considerable extra effort necessary to prepare their presentations for publication in this book; and to Kay Schriener, Editor of The Journal of Disability Policy Studies, for her generosity in allowing us to reprint four SDS presentations originally published in her journal.

Last, but certainly not least, we extend our gratitude to Andy Coburn and Larry Glantz of the Edmund S. Muskie Institute of Public Affairs at the University of Southern Maine, and to Betty Robinson, Nancy Whitehouse, Paula Caggiula, and the many wonderful student assistants who work at the Lewiston-Auburn College Computer Lab. Without the cooperation, encouragement, and considerable patience of these many fine individuals, this book could not have been produced.

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## Section I

### Irv's Legacy

In the past few years, disability rights, disability culture, and the Society for Disability Studies (SDS) have lost a number of people important to the movement. People like Irv Zola, Ed Roberts, Kirk MacGugan, John Clogston, and Howie the Harp have left us through their deaths, but their legacy lives on in the members of the SDS and the disability rights movement. We all embody their spirit in our research, our activism, our literature, our art, our future. During the 1995 Society for Disabilities Studies conference, former students and colleagues acknowledged the impact of one of the SDS's founders, Irv Zola, through personal reflections and analyses of his many contributions.

Lynn Schlesinger was a sociology graduate student at Brandeis University who worked with Irv. She explains how exceptional a mentor he was to her and to a whole generation of disability scholars. She says this is how we must continue Irv's legacy, by passing on knowledge and perspectives on disability issues to future generations. The work of the people in the Society for Disability Studies will continue Irv's legacy.

Barbara Altman of the Agency for Health Care Policy and Research and Gary Kiger of Utah State University discuss the sociological legacy of Irv Zola. His socio-autobiographical style made a significant contribution to the discipline by "providing a richness of detail or a sensitivity to nuances that would be missing without the added perspective that experience could provide" (p. 9). Irv's personal interest in mystery stories added to the understanding of media portrayals of disability. He made the links between media depictions and public perceptions and individual interactions with people with disabilities. In areas as diverse as medicine and independent living, Irv's scholarship helps us to understand the problem of the medicalization of disability and the empowerment of self help and independent living. Irv added a focus on aging to his work as he delineated the connections between disability and aging in terms of the health care crisis. According to Altman and Kiger, Irv never forgot the place of disability in the political sphere. His work contributed not only to sociology, but to advocacy, policy, and disability studies in general.

Marsha Saxton of The Project on Women and Disability addresses Irv Zola's contribution to self help and advocacy. Irv's awareness of his own disability identity led him to found the Boston Self-Help Center. That one center sowed the seeds for the Massachusetts Coalition of Citizens with Disabilities, the Project on Women and Disability, and other activist organizations. His philosophy of advocacy, Saxton says, was related to his personal trait of caring and his ability to form loving relationships with people. He was also a role model, showing that taking care of oneself leads to more effectively helping others. But Saxton adds, Irv was not a deity; "he was always just a regular guy" (p. 28), which made him accessible to everyone.

Sharon Barnartt of Gallaudet University concludes this section with her reminiscences as one of Irv's early students, during which time she saw his transformation to disability awareness and feminism. Irv took to heart the adage, "The personal is political." He also believed that sociology was imbedded in everyday experiences. Irv was suspicious of sociology's heavy reliance on statistics. He saw research as an active, human process that could not be divorced from personal values or experiences. This philosophy made him an unusual sociologist, and a memorable and distinguished one.

## Memories of a Righteous Man

Lynn Schlesinger  
SUNY-Plattsburgh

Scene 1--an office crowded with books, piles of papers on the table and desk, a knapsack nearby--a phone rings and is answered by "Zola here."

So many times in the last two years, I have wanted to dial the number long memorized, to hear that response, to picture that scene. And so many times I tried to write the presentation which I gave at the 1995 Society for Disability Studies (SDS) meeting, wondering how to convey the ways in which Irving Kenneth Zola was a teacher--and a learner. In my imagination I have talked to Irv, as I know others do. I looked for guidance, for his laughter and encouragement when my contract was renewed, for his political savvy and diplomatic skills when department politics got tough, for his sadness and support when my father died.

It seemed quite strange to be representing an entire group, Irv's students, especially when many of them were in the room when I gave my presentation. I could only hope to find some of the commonalities, the pleasures, and the challenge of studying with Irv. While the memories are intensely personal, perhaps they also represent patterns, perhaps they will also resonate with you.

I entered Brandeis University as a graduate student in sociology in the fall of 1977, straight from college. For some reason I missed class the day Irv spoke to our pro seminar, the one required course in the program, during which first year students get to know each other and the faculty. I received vague reports, how Irv talked about having polio, his car accident, his new consciousness of being a person with a disability. At the time I thought, "Well, that's nice." Bear in mind that my high school biology teacher had reminded us in almost every class of the accident he had had, how the only thing he remembered was the sound of the door being ripped off the hinges. And so, knowing little about medical sociology, and certainly nothing about disability studies, I regarded Irv with a combination of awe (he certainly had presence) and skepticism (here we go again with car accident stories--what does that have to do with sociology?).

I am not sure when I developed a conscious interest in medical sociology. Conversations with Irv led to my entering a graduate seminar, keeping a health diary (a course exercise; I wonder where that is now and whether I am blackmailable), writing a piece on hyperkinesis--so many of the key elements of Irv's teaching can be illustrated by that one course.

-- Irv encouraged students to take risks, to use our own experiences and observations as data, to study the "classics" with a critical eye and a respect for a discipline's history.

- Irv had a wonderful, and sometimes annoying, way of knowing before you did what you might study, what decisions you were struggling with--personally and professionally--what paths you might take, and the consequences. How many times did a student present a proposal, suggest a topic, discuss a career move--hesitantly, exploring--to be met with Irv's "ahah!" Yet Irv was not condescending, a modern prophet. Rather, he knew that everyone had to follow her own process, to arrive at decisions in her own time.
- And Irv practiced what he preached to others. He, too, continued to learn and to change, to reflect. He shared that process with his students, even when it meant acknowledging ways in which professionally or personally he had come to reconsider past actions, research results, and so on. With Irv I explored literature on pain, the personal meanings of living with fibromyalgia, my own changing definitions of disability and myself as a person with a disability. He respected and nurtured that continuing process.

Scene 2--a book signing, crowded, joyous. Irv has published Missing Pieces (Zola, 1982). On the inside cover of my copy he writes: "To Lynn, I look forward to the time when you will sign one of these to me." And he meant it.

With students Irv truly was a mentor. He was constantly sharing knowledge, tips, articles, conference notices, grant information with current and former students. I miss the envelopes arriving from Brandeis, with "Zola" in the upper corner. He encouraged students to participate in professional activities, to have fun (we shared a love of mystery novels), to persevere. He shared joy and sadness, the birth of his daughter Kyra (as he passed photographs around our dissertation seminar), his grief when those close to him became ill, died. Irv and Judy's wedding was the closest I will ever come to a royal affair, a melding of dynasties and traditions, of social movements, religious rituals, music!

Irv was not perfect--and he knew it. His ego was, shall we say, strong! In classes and one-to-one Irv would sometimes get so carried away with his thoughts that the words would come out faster than he could organize them. It was important for students to understand that it was all right to ask questions, to request clarification, to say, "Huh?" Irv would slow down, provide an example.

He would also chastise students--sometimes gently, sometimes not--if we tried to use fear of Irv's reputation or our own desires to be "perfect" as justifications for writer's block, course incompletes, risks not taken.

Gary Kiger and Barbara Altman (in this section of these Proceedings) discuss Irv's contributions to sociology. I would just like to mention two of those contributions, as they relate to teaching and students.

Since the late 1960's, the sociology department has had more than 200 dissertation committees. Irv Zola served on at least 48 and chaired at least 27. That number does not include the current graduate students who might not have formed a dissertation

committee, but who worked with Irv on their "guidance and accreditation" (Brandeis' version of qualifying exams) and in courses. As I look through the list of committees and think about the current graduate students, I can see Irv's own personal and intellectual development from medical sociology to disability studies. In some ways my cohort represents those transition years, receiving a grounding in medical sociology and growing with Irv as we explored issues of disability, living with chronic illness, the independent living movement, disability rights, and disability policy.

Just skimming through the 1994 SDS program will give you some idea of Irv's contribution to a new generation of disability scholars, his relationship to Brandeis students and faculty. Miriam Hertz, Bonnie O'Day, Hannah Gershon, Martha McGaughey, and Susan Foley presented papers, as did Brandeis alums Sharon Barnartt and me. Other Brandeis students attended the conference. Jeanne Calabro, a current graduate student, has been an active SDS member, and has used her intellectual, political, and personal skills to highlight disability-related issues at annual meetings of the American Sociological Association and the Society for the Study of Social Problems.

Irv's contribution to undergraduate study of disability is perhaps best represented by his course on the sociology of disability, and his support of and role modeling for students with disabilities. His course profoundly influenced many undergraduates--Bonnie Gracer, an SDS member, could tell you how that class, and Irv, helped change the direction of her life. He continued to change the course, to share his knowledge, and to learn from others. The teaching workshops at SDS provided a wonderful forum for these exchanges.

Scene 3--a conference at Gallaudet in the early 1980's. Irv is the keynote speaker. I am there to present a paper, one I would not have submitted had Irv not shown me the notice. For the first time I meet Sharon Barnartt, John Christiansen. And John Seidel, whom I introduce to Irv. From that meeting came Irv's association with SSCIID, the Society for the Study of Chronic Illness, Impairment, and Disability. That organization grew to become the Society for Disability Studies or "SDS," as Irv liked to announce with a sly grin. This coincidence is one of the reasons I am so committed to the Society--like a midwife, wanting to see how the child grows.

We last spoke the Saturday before Irv died. I asked Irv how he liked being back at school after his sabbatical. He said he liked it, but he had so many other things he also wanted to do, and you never know how long you are going to live. Irv had never spoken about his own mortality to me before. Illness, pain, frustration with inaccessible hotels, yes. Other people's death and dying, yes. Not his own. We agreed to meet in two weeks. I cried after hanging up the phone.

Scene 4--running into the department office, sobbing, telling a colleague that my dissertation advisor had died, and immediately saying, "No, that's not it. He wasn't just my dissertation advisor; he was a teacher, mentor, colleague, and friend." I am unable to teach the "Family" class and, instead, read a story by Irv, "And the Children Shall Lead Us" (Zola, 1982). Later that day a colleague remarks, "Well, at least he waited until you

finished your dissertation." Tasteless? Perhaps, but not without an edge of dark humor that Irv would have appreciated. I imagine him laughing, and with tears I laugh, too.

Irv's influence continues in death as in life. His enthusiasm touched students and faculty around the world. Those of us who benefited from his mentoring, I hope, will take some responsibility for supporting those students who are in the middle of or just beginning their studies.

Scene 5--an office empty, no "Zola" answering the phone; in fact, I just tried calling, and a female packaged voice said that no one subscribes to that "voice-mail" address.

Well. Well, well. Then, in the best Zola spirit, it is time to pick ourselves up and move ahead. Yes, Irv was patient--yet he did not suffer foolishness gladly, nor did he have much patience for self-pity. I imagine him applauding, hugging us, proud of himself, and of us, a part of his legacy. May his life inspire us to live fully, with passion, with compassion, always open to new knowledge and perspectives, and may we through our teaching--in whatever context that may occur--pass on Irv's legacy from generation to generation.

Part of Irv's legacy was in the room where I gave my presentation for SDS, the organization he helped to develop and grow, in the students he nourished, in the publication we, as a society, are committed to continuing.

As a reform Jew I do not believe in an afterlife; our immortality resides with those we leave behind, through the way we live our lives. Teaching is not limited to classrooms and institutions. We can all contribute to and continue Irv Zola's work--as we teach and learn from each other, as we listen carefully, as we challenge each other to push the limits of our personal and professional understandings of disability, politics, life, and love. There is a saying in Hebrew: Zekher Tzadik Levrakha. May the memory of the righteous be a blessing. May Irving Kenneth Zola's memory be a blessing and an inspiration.

#### References

- Altman, B., & Kiger, G. (1995). Interpreting the Zola legacy in sociology: Now and in the future. Journal of Disability Policy Studies, 6(2), 39-54.
- Zola, I.K. (1982). Missing pieces: A chronicle of living with a disability. Philadelphia, PA: Temple University Press.
- Zola, I.K. (1993). And the children shall lead us. In I.K. Zola (Ed.), Ordinary lives: Voices of disability and disease (pp. 34-37). Cambridge, MA: Applewood Books.

### Acknowledgment

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## Interpreting the Zola Legacy in Sociology: Now and in the Future

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From some of his earliest work, such as his 1962 study of gambling in a lower-class setting, to his 1994 work on disability policy, Irv Zola was invested in his work. By this we do not mean merely that he worked long and hard, although he did. By "invested" we mean Irv put his body, soul, and mind into his research and writing. This is perhaps nowhere more apparent than in his address "Bringing Our Bodies and Ourselves Back In: Reflections on Past, Present, and Future 'Medical Sociology'" (Zola, 1991a). This investment is his legacy.

Irv had a disability. He had polio and then was hospitalized after an automobile accident. These events profoundly shaped his view of the world and his subsequent experiences. Rather than shoving these experiences out of the way, Irv brought them front and center and appreciated the pain and growth they brought. He shared with others that having a disability is not to be "invalid."

Irv self-consciously wrote in the style he termed "socio-autobiographical." By this he meant recognizing and accepting how an individual's life experiences shape and inform how he or she perceives events, chooses topics to research and explore, and makes sense of them. It is a style that he felt contributed to our knowledge by providing a richness of detail or a sensitivity to nuances that would be missing without the added perspective that experience could provide.

Irv also invited us to learn from our experiences and to look at the world in fundamentally new ways. For example, we remember Irv telling us about being called as an expert witness in a legal case. A man had been hit by a car, and, consequently, both legs had been amputated. The man, a high-ranking university administrator, sued the driver. The administrator's lawyer wanted to play the pity card—professional struck down in the prime of life. The client would have none of it. He wanted his dignity. Irv helped plot a strategy to locate the problem not with the "pitiable" victim, but with the larger society, which would now treat this professional with a disability with less respect than before. The strategy worked.

Irv began his long and distinguished career during interesting times for sociology as a discipline. From the 1920s, social scientists tended to have an abiding faith that scientific social science could solve social problems. It was a matter of proper social engineering. This viewpoint was firmly held in the human relations program where Irv pursued

graduate work at Harvard University. But during this time there were other voices that cautioned of unanticipated consequences of even well-meaning social programs. Thomas Szasz and Rene Dubos were social critics who influenced much of Irv's critical thinking and writing. When combined with the fieldwork-oriented, interactionist influence of Everett C. Hughes, with whom he came into contact at Brandeis University, Irv's unique experientially-based perspective was released and encouraged (Conrad, Brown, & Bell, 1995).

Irv's contributions were many, from his academic writings to his community service establishing counseling services for persons with disabilities. Irv's work has influenced many sociologists, and his intellectual force can be detected in the work of many writers--Peter Conrad's work on the medicalization of deviance or Fred Hafferty's and Susan Foster's work on disability in detective novels, to name only a few.

We have chosen to focus on his legacy to sociology and, most especially, sociology of medicine, and disability studies. His writing on public policy, aging, research methods, and media was particularly influential.

#### Methodology and Statistics

Irving Zola employed a range of methods in his social research during his long, distinguished career. In arguably his most prestigious publication, an article that appeared in the American Sociological Review (ASR) (1966), Irv reported on a quantitative, empirical study of how members of different ethnic groups experienced, interpreted, and acted on symptoms of illness. Much of his work was ethnographic in character, from his "Observations of Gambling in a Lower-Class Setting" (Zola, 1963) to his book Missing Pieces (1982), an account of his time spent with residents of Het Dorp, a Dutch residential community for persons with severe disabilities. Irv was also no stranger to interpretive analysis of literature, current events, or policy debates. Of particular note were his writings on "The Portrayal of Disability in the Crime-Mystery Genre" (1987c), "Multiculturalism, Chronic Illness, and Disability" with Nora Groce (Groce & Zola, 1993), and "The Sleeping Giant in Our Midst: Redefining Persons With Disabilities" (1993c).

In a time when turf battles raged over a researcher's methodological approach, Irv provided a sanguine voice. He understood the power of quantitative studies. If we were to develop government policies around disability rights and services, we needed information from a large number of people. That information was best gained from large-scale surveys. Irv acknowledged in his writings (e.g., Zola, 1993a) the important work done in this area by researchers like Lois Verbrugge (1990) and Mitch LaPlante (1991), to name only two.

At the same time, Irv appreciated the limitations of quantitative methods and large-scale surveys. He consistently pointed out that a researcher's findings were only as good as the data and the research design of the study. No high-powered statistical techniques could save a study that was poorly designed or included lousy data. Irv's own quantitative

studies (e.g., Zola, 1966) were elegant in their simplicity. His ASR article on cultural interpretations of symptoms included nothing more complex than contingency-table analysis. But his findings, that Jews, Italian-Americans, and Anglo-Saxon Protestants interpreted symptoms differently, were clearly presented and provocative in their implications.

Another limitation of survey research on which Irv wrote extensively was question-item construction. If we are to get an accurate picture of disability in society, how we define disability has a lot to do with what we will find (Zola, 1993a). Irv wrote, "The number of people with a disability varies considerably depending on the definition/measure used; for example, chronic condition versus functional limitations versus activity limitations" (Zola, 1993a, p. 12). The questions survey researchers ask are typically, albeit unintentionally, morally loaded. The emphasis on deficit and disability gives researchers one look at impairments, chronic disease, and functional limitations. Posing questions like, "All in all, with such types of external support (e.g., assistive devices), how would you rate your ability to do . . . ?" would give researchers quite different information. Irv admonished us constantly to ask ourselves, what do we want to know and for what purpose? For example, analyzing disability statistics has powerful policy and political implications. Statistical arguments made around the passage of the ADA cited a figure of 43 million Americans with disabilities (Scotch, 1990). Irv argued for moving beyond the politics of numbers and thinking carefully about the issues of disability rights and services. To point up the folly of the "numbers game," he observed that the disability category with the highest frequency is "sinusitis"; a category with a low frequency is multiple sclerosis. Should we develop a policy toward disability services and rights based on these numbers?

In Socio-Medical Inquiries (1983b), Irv developed a methodological approach that he termed "socio-autobiography," that is, "the role that personal and social events play in how one comes to understand the social world" (p. 3). Irv guided himself by the recognition that his experiences shaped the research questions he asked, the research tasks he undertook, and the interpretations he derived from his findings.

Every social researcher must come to terms with the problem posed by Max Weber (1913/1978). We cannot be value neutral in our research, so how do we achieve some modicum of objectivity and fairness? Weber's reply was to seek *Verstehen*, or sympathetic understanding with the persons we study. Too, we should admit our biases, up front. Irv, taking Weber's challenge seriously, wrote, "I am having serious doubts about how much social and emotional separation is necessary from those we study" (Zola, 1983b, p. 199).

Irv wrote about how his upbringing in a Jewish, working-class neighborhood outside Boston shaped his research interests "in religious and ethnic identity" (Zola, 1983b, p. 5). His working-class roots, for example, gained him entree to research settings where he could study gambling, an activity he learned about from his father. Irv talked and wrote extensively on how his lengthy hospitalizations with polio and following an auto accident profoundly influenced his views on social networks and medical authority. Irv understood

only too well that sociologists needed not only to identify patterns of behavior, but also to discover meaning that people brought to their experiences. Irv sought this meaning in his qualitative interviews with respondents from gamblers to patients.

Irv's acknowledgment that everyone's perspective is shaped by personal and social events was not always a popular observation in a discipline that wants to claim objectivity in its research. However, Irv always asked the question posed by Alvin Gouldner (1968): "Sociology for what? Sociology for whom?" Perhaps this was why Irv's work was solidly grounded in advocacy, counseling, and community service. By getting close to the people he studied, he gained an intimate knowledge of their concerns that could not be generated by an outsider. For example, in one of his qualitative endeavors, he learned quite a lot about sexuality, intimacy, and anger among persons with severe disabilities by living among the residents of Het Dorp in the Netherlands (Zola, 1982). Irv's personal stamp is everywhere apparent in his research and policy writings. His publications bear titles like "Disability Statistics, What We Count and What It Tells Us: A Personal and Political Analysis" (Zola, 1993a); "Bringing Our Bodies and Ourselves Back In: Reflections on Past, Present, and Future 'Medical Sociology'" (Zola, 1991a); or "When Getting Into the Field Means Getting Into Oneself" (Zola, 1979b). While Irv acknowledged that this was not the only kind of worthwhile research, it was the sort of research that he chose to pursue.

### Images of Disability

Reports of disability statistics, then, tell us, as a society, a lot about how we culturally view disability. For Irv, an equally powerful source of cultural imagery about disability came from media sources. In his "Depictions of Disability: Metaphor, Message, and Medium in the Media: A Research and Political Agenda" (Zola, 1985), Irv examined how portrayals of disability in media send messages--sometimes overt and sometimes subtle--to consumers. Disability can be a metaphor for evil, pity, or "super-crip" achievement. Stereotypes may easily form the basis for discrimination.

Quite apart from portrayals of disability as metaphor, Irv explored how persons with disabilities in everyday life were depicted by the media. It is rare to view or read portrayals of characters with disabilities that give a deep, rich description of their lived experience. How do they use assistive devices to get through their day? What are their relationships like with significant others, quite apart from the portrayal of emotional crises surrounding their disability? What about experiences of sexuality, intimacy, and anger? More often than not, persons with disabilities are singled out for dramatic effect and rarely appear as ordinary players in the story.

Irv further observed that public perceptions of disability are influenced differentially by the type of medium. Media consumers experience portrayals of persons with disabilities quite differently if the depiction is via television versus novel, versus stage production, versus film. Our ability to absorb and reflect on the message is greater with portrayals in novels, where we can reread and imagine visual images, than with portrayals on television, where ready-made visual images move by us quickly.

One medium that Irv adopted as a case study of sorts regarding depictions of disability was the crime-mystery novel. In "The Portrayal of Disability in the Crime-Mystery Genre" (Zola, 1987c), "Any Distinguishing Features?: The Portrayal of Disability in the Crime-Mystery Genre" (Zola, 1987a), and "How's Your Sex Life, Ellery Queen?: Portrayals of Disability in the Crime-Mystery Genre" (Zola, 1989a), Irv argued that, because of the enduring, ubiquitous character of crime novels, this medium provides an exceptional source of information about public perceptions of disabilities and persons with disabilities. Surprisingly, Irv noted that crime-mystery novels are replete with characters with disabilities (four or five, on average). But the characters are not always realistically portrayed. The rich description that is the hallmark of crime-mystery novels was often curiously absent when a protagonist had a disability. Description was much more detailed if the "bad guy" had a disability.

All of these media depictions, of course, have ramifications for interactions between persons with and without disabilities. Stereotyping, social distance, and cultural discomfort are the topics of Irv's "Communication Barriers Between 'the Able-bodied' and 'the Handicapped'" (Zola, 1981). Difficulties arising when a person with a disability tries to communicate to a nondisabled person what the disability experience is like are grounded in the social/symbolic isolation of people with disabilities. While people with disabilities are not typically confined in contemporary society, they are socially isolated, an experience exacerbated by adults who become uncomfortable around persons with disabilities and admonish their children, "It is not nice to stare . . ." (Zola, 1981, p. 355). Persons with disabilities become a tangible reminder to the person without a disability that he or she, too, will likely acquire a disability. For the person with a disability, the cultural notion of personal responsibility makes having a disability a sign of personal failure.

### Medicine as an Institution of Social Control

How we as a community view and understand disability is a social construction. Disability may be infused with a multiplicity of meanings. It may have medical, health, religious, moral, political, and psychological meanings, among others. How we construct meaning around disability has everything to do with how we view disability and how we respond to a person with a disability.

Irv was particularly interested in the medicalization of American society. He argued that "medicine is becoming a major institution of social control" and that its jurisdiction is spreading by "'medicalizing' much of daily living" (Zola, 1972, p. 487). To the extent that the institution of medicine can define health, illness, and disability in medical terms, this definition then implies a solution to the "problems" posed by health, illness, and disability. As Howard Becker (1963) noted, it is an important political question as to which group has the power to make its "definition of trouble" stick (p. 47).

Medicalization is characterized by a number of positive attributes. This lends it a particularly insidious quality. Conrad and Schneider (1980) note that medicalization is associated with a humanistic view of differentness. Rather than punish difference, illness

or disability is treated. Medicalization, too, is optimistic. If difference is defined as medical trouble, then a "cure" is implied. Irv was especially concerned about the pervasive and expanded use of technology to treat illness and disability (Zola, 1972). With technological and surgical practices expanding, medical professionals can declare more and more conditions under their jurisdiction to "fix." Whether these conditions fall under the category of aging, disability, or cosmetic concerns, physicians have positioned themselves to define what is healthy and what is normal.

Relatedly, Conrad and Schneider (1980) echo Irv's caution about the "darker side" of medicalization. One of the major ironies of medicalization is that it removes responsibility from the individual for his or her condition and then subtly reintroduces blame. Irv highlighted how the medicalization view understands illness or disability as not the fault of the individual. Yet, medicine tends to view illness and disability as a pathology within the individual. Environmental and social factors associated with illness and disability remain largely unexamined. Illness and disability imply human intervention, social relationships, and moral meanings. The individualized, pathology model of illness and disability misses how disability and illness may come to represent personal failure for which the individual is ultimately responsible (Zola, 1972).

The antidote to the process of medicalization is perhaps found in some of the chapter titles of Irv's Socio-Medical Inquiries (Zola, 1983b). They are variously titled "Getting Involved as Well as Concerned" and "Helping One Another: A Speculative History of the Self-Help Movement," among other titles. In these chapters Irv admonishes us to raise our consciousness, understand the medicalization process so that, to some degree, we can manipulate and control its effect, and, on the basis of this knowledge of medicalization, enter into the values and political discussions that should properly surround the growing phenomenon of medicalization.

### Self-Help and Independent Living

Irv's attention to self-help appears to have grown out of his concern for the insidious spread of medical control, but it also was tied closely to his own experience with disability. As early as 1977, he noted that the increasing involvement of medicine in the "problems of the soul . . . now . . . located in the psyche" combined with modern living arrangements results in a reduction of informal networks of help (Zola, 1977, p. 58). At that point he sensed, rather than elaborated, that not only were individuals giving up control to the medical profession, but this process was one that continued the existence of the problems rather than solved them. The idea that "awareness" was necessary before the web of political, economic, and social psychological forces supporting the process of medicalization could be halted or reversed was the beginning of his concerns with consciousness and consciousness-raising that run like a thread of light through much of the work in the years to follow.

This consciousness-raising was the political function of the self-help movement that Zola (1987b), along with Katz and Bender (1976), saw as absolutely central to such movements. According to Zola (1987b), recognition of the power imbalance in the professional-patient

relationship becomes the centerpiece of the politization of self-help groups, at both the micro and the macro level. From the first stage of the demystification of the "problem"--be it disease or disability--through knowledge sharing, to more activist endeavors in the political arena in an effort to create formal alternatives, Zola documented and supported the self-help movement.

An important component of the self-help movement that Zola both experienced and wrote about was independent living. He identified the independent living movement as "the latest incarnation of an old theme in American life--the idea of self-help" (Zola, 1983a, p. 49). He bridged the self-help idea back to society by introducing the concept of interdependence as a complement to independence. In examining the power question at the individual level, which argues that independence for persons with disabilities can only be defined by the individuals themselves, he emphasized that it was more important to have full control over one's life than over one's body (Zola, 1983a).

The examples that fill Irv's writings in this area are often his own experiences. In his discussion of the limitations of professionals' ability always to know what is best for a patient, he illustrates with a story about a prosthetist who had been in the business for over 50 years. The prosthetist shows Irv a cane and asks him to try it. Irv does so, and replies that it seems solid enough. The prosthetist then takes the cane and pushes a little button about three inches from the handle, and out pops a twelve-inch blade. Before Irv can say a word, the prosthetist goes on and shows him one that he says is even handier. Taking out another cane, he again presses a button and now brandishes what might be called a 10-inch iron blackjack. "You know," he says, "in times like these, with so much crime in the streets, this self-defense cane should come in pretty handy." Irv replies in his best tongue-in-cheek fashion, "Yes, particularly if the thief lets me lean on him for support while I dismantle my cane."

His elaboration of the concept of independence places less emphasis on mobility and the ability to accomplish physical tasks and more on the ability and freedom to make personal and economic decisions related to life choices. Such choices bring with them the opportunity to succeed or to fail and also introduce risk as a natural component of daily social functioning. The real significance of independence is epitomized in the human dignity encompassed in risk (Zola, 1982; 1983a). For Irv, one form of risk-taking was his "continual neglect of seat belts and an almost congenital inability to keep to the fifty-five-mile-an-hour speed limit." He boasted of being in the process of collecting a speeding ticket in every state in the union (Zola, personal communication).

Along with his recognition of the sterility of life without risk, Irv's examination of the experiences of independence raised questions about the technology invented to replace bodily parts or to assist persons with any number of functions. His observational skills discerned the psychological ramifications of such dependence on technology and raised the issue of the overtechnicalization of care and the objectification that can result from such an emphasis on technology. His concern with the integrity of the humanity of the individual as the centerpiece of independence is a tribute to his sociological sensitivity and reflexivity.

Within the discussion of self-help and independent living, Irv saw the roots of the disability movement, which has spawned national coalitions and advocacy groups such as Disabled in Action, the American Coalition of Citizens with Disabilities, and the Disabled Rights Education and Defense Fund, and national legislation such as the Americans With Disabilities Act. Ultimately, he saw this type of effort "looping back to academia" in the form of disability studies courses in a variety of disciplines and professional schools and multidisciplinary professional organizations, such as the Society for Disability Studies (Zola, 1987b). The Society has been a viable force in the field for seven or eight years now, disability coursework has been offered at universities for at least twice that amount of time, and we appear to be coming closer to establishing actual disability studies programs.

### Aging and Disability

In later years, as his experience grew, Irv also developed a reflexivity to his work. Ideas and concepts he developed were applied to new areas or were re-examined in terms of his new learning and experience. Thus we see his ideas on medicalization expanded and applied in an ever-broadening circle of writing and action. An indication of this continuous reflection and reexamination was the revelation of totally new insights into an article that he had published 15 years earlier. In his speech on the occasion of receiving the Leo G. Reeder Award for Distinguished Scholarship, he revealed how he had come to recognize a flaw in one of his highly referenced works in ethnicity and health (Zola, 1991a). In this specific case, his hypothesis was that a patient's social background, which influenced his presentation in the medical setting, influenced his diagnosis. In the course of creating the categories for that analysis, Irv had found that too few males fit the criteria and, therefore, only analyzed the data for the females in the sample. It was only years later, after the women's movement had changed his consciousness, that he recognized that the categorization he had created had held a definite female bias.

The first appearance of aging as a topic in Irv's writing was in his first solo-authored publication (Zola, 1962) on older persons' feelings about age. Irv did not return to the topic until 1986 when "Reasons for Non-Compliance and Failure of the Elderly to Seek Care" appeared (Zola, 1986). This was also the year that Irv participated in a Wingspread Conference and presented a paper on the medicalization of aging and disability. This is the beginning of his work examining the split between persons who are aging and people with disabilities and questioning the sensibility of conceptualizing them as two separate human conditions (Zola, 1986).

Unifying aspects of disability and aging that Irv put forth focused on four issues: (a) the increasing size of the population that the two groups encompass; (b) the complexity of changes that occur when persons with disabilities live longer; (c) the highly technological nature of care developed and imposed on this combined population and the latent functions of increased dependence on technology; and (d) the expansion of medical influence and morality within this combined population and the reactions to that expansion (Zola, 1988a; 1988b; 1990; 1991b). Irv was optimistic that the universality of needs across the aging and disabled populations could overcome the age-specific, disease-

specific mindsets that focus on group membership and tend to conceal the common identity and mutual benefit of recognizing that commonality.

The four issues ultimately addressed the most important element of the commonality between aging and disability, which is the current crisis in care: its cost, availability, and structure. Irv particularly questioned the technicalization of care that allows scarcely any consumer input. He felt that one downside of the glamorization of high-tech solutions is that it distracts from the importance of necessary improvements in low-technology aids such as wheelchairs, crutches, and things necessary to daily existence. He was philosophically concerned that the faith in technological cure leads to the false belief that all problems have a technical solution. This, in turn, creates a preference for solving problems that can be described in objective terms over the more social, psychological, and political aspects of problems, which do not lend themselves to technical solutions and which can be much more difficult to solve.

Because of this concern about the technicalization of care, Irv found the home-care revolution, the shift out of the hospital and away from institutionalized care, a "good, necessary and even inevitable phenomenon" (Zola, 1990, p. 95). Though this shift might come too late for many, and while the process would continue the feminization of caregiving, Irv saw the home-care movement strengthening the national system of personal assistant services and enhancing the independence and control of the recipient of such services. He saw the combined needs of aging persons and disabled persons as the impetus to design a more flexible world that will "have meaning for all of society's tomorrows" (Zola, 1990, p. 96).

### Disability Policy

In Irv's continued examination of medicalization, he described the moral authority of medicine to use labels of health and illness and to locate the source and treatment of problems in an individual. In effect, he found that medicalization depoliticizes the issues and effectively closes off other levels, such as social or political, for addressing the problem. To counteract that influence, Irv felt it was essential to focus on the political aspects of every issue from every vantage point. The primary political issue, basically, is one of choice and control, but there are many others as well.

The codification of Irv's perspective on disability policy in the areas of housing, transportation, and employment appeared in a special supplement to The Milbank Quarterly that was published in 1989 (Zola, 1989b). However, unlike many other medical sociologists, Irv had been incorporating a policy perspective in his work for years. He was extraordinarily able to elaborate a process or problem at the micro or individual level and, at the same time, to recognize how that micro circumstance would play out in the larger scene or at the macro level.

An example of this continued concern with policy implications is evident in discussions of biotechnology and genetics, the entry into and the departure out of this life (Zola, 1991b), the politicization of the self-help movement in the health arena (Zola, 1987b), the

political rhetoric associated with names and language (Zola, 1993b), and the social and political definitions of independence (Zola, 1982). Even the socio-autobiographical experiences of the built environment at Het Dorp found political interpretation in the concepts of flexibility and adaptation later applied to issues of housing and transportation (Zola, 1983b).

Ultimately, one of the most complicated and policy-influencing activities of all is the conceptualization and measurement of disability. In "Disability Statistics, What We Count and What It Tells Us" (Zola, 1993a), Irv skillfully examines the political implications of the current conceptualizations of disability as a fixed status and a dichotomous characteristic. While recognizing the usefulness of such an approach to the conceptualization of people with disabilities as a minority group and the need to play the numbers game in order to pass the Americans with Disabilities Act, he acknowledges the limitations of the minority group approach. In the end, he foresees that the high-priced political decisions relating to mass transportation and long-term care require that the needs be seen as general or universal rather than limited to a minority (Zola, 1993b).

### Conclusion

This paper examines Irv Zola's intellectual contributions not only to sociology, but also to disability studies, advocacy, and policy, based on the sociological perspective from which he worked. His legacy for now and for the future is firmly established in the body of work that he has left behind and among the students he trained and supported. From our perspective, his most important and lasting contributions can be summarized as follows:

- Disability is not a specific entity, but a continuum that ranges across age, ethnic groups, and diseases.
- Measurement of a phenomenon such as disability is a tool, never an answer to what are ultimately moral and political decisions, not scientific ones.
- The value of self-help lies in its development of consciousness or awareness that allows the individual to counter the social control of the medicalization process.
- The awareness of the political nature of almost everything makes it necessary to think of the problems of health, disease, and disability on a basic social-political-economic level and to recognize the universality of policy development in these areas.
- The acknowledgment that even our most prized work can be flawed necessitates that we are constantly on the alert to new insights that can provide even more information.

### References

Becker, H. (1963). Outsiders. New York, NY: Free Press.

- Conrad, P., Brown, P., & Bell, S. (1995). Obituary: Irving Kenneth Zola (1935-1994). Social Science and Medicine, 41(2), v-vi.
- Conrad, P., & Schneider, J.W. (1980). Deviance and medicalization: From badness to sickness. St. Louis, MO: Mosby.
- Gouldner, A. (1968). The sociologist as partisan: Sociology and the welfare state. American Sociologist, 3, 103-116.
- Groce, N.E., & Zola, I.K. (1993). Multiculturalism, chronic illness, and disability. Pediatrics, 91(5), 1048-1055.
- Katz, A., & Bender, E. (1976). Self-help groups in western society, history and prospects. Journal of Applied Behavioral Science, 12, 265-328.
- LaPlante, M.P. (1991). The demographics of disability. In J. West (Ed.), The Americans with Disabilities Act: From policy to practice (pp. 55-77). New York, NY: Milbank Memorial Fund.
- Scotch, R.K. (1990). The politics of disability statistics. Disability Studies Quarterly, 10(3), 14-15.
- Verbrugge, L.M. (1990). The iceberg of disability. In S.M. Stahl (Ed.), The legacy of longevity (pp. 55-75). Newbury Park, CA: Sage.
- Weber, M. (1913/1978). Value judgments in social science. In W.G. Runciman (Ed.), Weber: Selections in translation (pp. 69-98). London, England: Cambridge University Press.
- Zola, I.K. (1962). Feeling about age among older people. Journal of Gerontology, 17, 65-69.
- Zola, I.K. (1963). Observations of gambling in a lower-class setting. Social Problems, 10, 355-361.
- Zola, I.K. (1966). Culture and symptoms: An analysis of patients presenting complaints. American Sociological Review, 31, 615-630.
- Zola, I.K. (1972). Medicine as an institution of social control. Sociological Review, 20, 487-504.
- Zola, I.K. (1977). Healthism and disabling medicalization. In I. Illich, I.K. Zola, J. McKnight, J. Kaplan, & H. Shaiken (Eds.), Disabling professions (pp. 41-69). London, England: Marion Boyars.

- Zola, I.K. (1979a). Helping one another: A speculative history of the self-help movement. Archives of Physical Medicine and Rehabilitation, 60, 452-456.
- Zola, I.K. (1979b). When getting into the field means getting into oneself. New England Sociologist, 1, 16-30.
- Zola, I.K. (1981). Communication barriers between "the able-bodied" and "the handicapped." Archives of Physical Medicine and Rehabilitation, 62, 355-359.
- Zola, I.K. (1982). Missing pieces: A chronicle of living with a disability. Philadelphia, PA: Temple University Press.
- Zola, I.K. (1983a). Developing new self-images and interdependence. In N. Crewe & I.K. Zola (Eds.), Independent living for physically disabled people (pp. 49-59). San Francisco, CA: Jossey-Bass.
- Zola, I.K. (1983b). Socio-medical inquiries. Philadelphia, PA: Temple University Press.
- Zola, I.K. (1983c). Toward independent living: Goals and dilemmas. In N. Crewe & I.K. Zola (Eds.), Independent living for physically disabled people (pp. 344-356). San Francisco, CA: Jossey-Bass.
- Zola, I.K. (1985). Depictions of disability: Metaphor, message, and medium in the media: A research and political agenda. Social Science Journal, 22(4), 5-18.
- Zola, I.K. (1986). Reasons for non-compliance and failure of the elderly to seek care. In R.W. Moskowitz & M. Haug (Eds.), Arthritis and the elderly (pp. 75-86). New York, NY: Springer.
- Zola, I.K. (1987a). "Any distinguishing features?": The portrayal of disability in the crime-mystery genre. Policy Studies Journal, 15(3), 485-513.
- Zola, I.K. (1987b). The politicization of the self-help movement. Social Policy, 18(2), 32-33.
- Zola, I.K. (1987c). The portrayal of disability in the crime-mystery genre. Social Policy, 17(4), 34-39.
- Zola, I.K. (1988a). Aging and disability: Toward a unifying agenda. Educational Gerontology, 14, 365-387.
- Zola, I.K. (1988b). Policies and programs concerning aging and disability: Toward a unifying agenda. In S. Sullivan & M.E. Lewin (Eds.), The economics and ethics of long-term care and disability (pp. 90-130). Washington, DC: American Enterprise Institute for Public Policy Research.

- Zola, I.K. (1989a). How's your sex life, Ellery Queen?: Portrayal of disability in the crime mystery genre. In G. Kiger & S.C. Hey (Eds.), Emerging issues in impairment and disability studies (pp. 14-18). Salem, OR: The Society for Disability Studies and Willamette University.
- Zola, I.K. (1989b). Toward the necessary universalizing of a disability policy. The Milbank Quarterly, 67 (Suppl. 2), 401-428.
- Zola, I.K. (1990). Aging, disability and the home-care revolution. Archives of Physical Medicine and Rehabilitation, 71(2), 93-96.
- Zola, I.K. (1991a). Bringing our bodies and ourselves back in: Reflections on past, present, and future "medical sociology." Journal of Health and Social Behavior, 32(1), 1-16.
- Zola, I.K. (1991b). The medicalization of aging and disability. In G. Albrecht & J. Levy (Eds.), Advances in Medical Sociology, Vol. 2 (pp. 299-315). Greenwich, CT: JAI Press Inc.
- Zola, I.K. (1993a). Disability statistics, what we count and what it tells us: A personal and political analysis. Journal of Disability Policy Studies, 4 (2), 9-39.
- Zola, I.K. (1993b). Self, identity and the naming question: Reflections on the language of disability. Social Science and Medicine, 36(2), 167-173.
- Zola, I.K. (1993c). The sleeping giant in our midst: Redefining persons with disabilities. In L.O. Gostin & H.A. Beyer (Eds.), Implementing the Americans With Disabilities Act (pp. xvii-xx). Baltimore, MD: Paul H. Brookes.

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## Irv's Legacy: Advocacy and Self-Help

Marsha Saxton, Ph.D.  
The Project on Women and Disability

### Disability Identity

Irv Zola was a friend of mine and a fellow advocate in the Boston disability rights community. As he did for so many people, Irv had a big impact not only on my concept of advocacy, but on my sense of self as an activist.

When I first met Irv in 1977, I had just begun to realize that I had a disability. Those surgeries and hospitalizations had happened when I was a child, a long time ago, I had rationalized. In a support group Irv was leading at the Boston Self Help Center in the late 70's, I first grappled with the idea that being a "person with a disability" was not a thing to be hidden or ignored.

In preparing for my presentation at the Society for Disability Studies 1995 meeting, I spoke with several of Irv's friends and family members. I also quoted from the memorial service at Brandeis University, December 6, 1994. As one of his best friends, a fellow sociologist at Brandeis, Gordie Feldman, said:

In the late 60's and early 70's, I watched a remarkable transformation. In addition to opposing the war in Vietnam, Irv came out as a disabled person. Somehow, he explained, when this started happening, he had relied so much on his strengths that he had denied the reality of his physical condition. But, after months of field work at a Dutch village built to accommodate disabled people, Irv really started dealing with himself as disabled.

One impetus for Irv's transformation was a series of rumors in the late 60's. Irv told me with impish delight that students were spreading rumors that he limped because of World War II injuries. He had been a hero--a fighter pilot to be exact. In one version, Irv was captured by Nazis and held prisoner. As he was ten when the war ended, I urged him to let these enchanting rumors flow. But they made him realize he had kept his polio secret.

This was the beginning of a new era in Irv's life. It was Irv's intense and creative struggle with disability identity that delivered him to the disability community. As a sideline to his social observer role, Irv had been working as a counselor at Greenhouse, a counseling collective in Cambridge, Massachusetts. Together with some of his Greenhouse friends, spurred by his growing disability identity, Irv went on to create the Boston Self-Help Center.

## Advocacy and Self-help

I was part of that early crowd at Boston Self Help. I got to watch Irv do what he loved best. Sharing stories with others with disabilities was a powerful step forward, Irv recognized, not only in challenging the discrimination against people with disabilities, but in helping everyone face up to vulnerability, physical differences, and needing help. Irv's group leading skill and his knowledge of the issues were remarkable. It was his ease in sharing about his own disability, and his excitement in hearing from us that made the difference.

Irv often referred to the Boston Self Help Center as a "springboard" where individuals shared support and training with peers and then moved on to create new advocacy projects. For example, out of Boston Self Help Center grew the Massachusetts Coalition of Citizens with Disabilities, the Project on Women and Disability, and other activist groups.

## Philosophy of Advocacy

Irv's vision for social change was the marriage of counseling and advocacy, the personal and the political, where we gained the support for our personal struggles as people with disabilities to empower us to take on the systemic discrimination.

Irv was deeply committed to the concepts of self help and mutual aid: defining our own problems, using the tools of consciousness raising, sharing experiences and resources. Irv believed in the primacy of personal experience, trusting our instincts, expressing our feelings. For Irv, the self-help groups were a well-spring, the source of compelling stories from the lives of people with disabilities, the arena of personal reflection, which allowed him to transcend the sociologist's observer role and become a key spokesperson for the disability rights movement.

Irv's philosophy of advocacy and social change was reflected in the way he related to people. One of Irv's gifts was his deep and spacious caring, his remarkable ability to help people feel loved. People from around the world felt Irv's caring over distance and time, sometimes only through his scribbled notes at the top of an article he had sent. Many people describe Irv as one of their closest friends and mentors. As a housemate of his, Mary Fillmore, said, "Irv was a bonfire." He was wonderfully effective in connecting people to each other, sharing his friends and colleagues in an ever widening circle of interconnected communities. As his long time friend Norma Swenson Meras put it, "Irv never allowed our roles to define our relationships."

Irv was a lover. Irv believed that the essence of social change is believing and trusting in the goodness of human beings, knowing that your adversaries will eventually come around to your point of view. There will be a meeting of minds and perspectives, and solutions will be found. In the context of love, we can depend on things like common sense, mutual respect, humor, caring, commitment, and people doing the right thing.

Yet Irv was rooted in the real world. He got outraged. In my mind I can easily hear him say, "Those bastards!"

One community which benefitted from Irv's advocacy was the women's community. Irv had a unique appreciation of women's issues. His wife, Judy Norsigian, said, "He learned how the personal is political from the women's movement, but I think this insight [about sexism] was with him far earlier, gained during his experience with polio and disability."

Norma Swenson said that Irv "showed women what it was we wanted from men." But his unique compassion for the impact of sexism was not just reserved for women. Ellen Feinberg, a member of Irv and Judy's Lamaze class that became a supportive parenting group, described Irv's encouragement to the other fathers in the group that "we could be better fathers by being more physically affectionate with each other as men."

In the early 1980's Irv and Judy fell in love and got married, and the Boston disability community also became engaged to the Boston Women's Health Book Collective. This was a tremendous boon to the work of many of us in the newly emerging women and disability movement. Irv was wonderfully supportive to us in the disabled women's community. Eager to describe himself as a feminist, Irv was a man who uniquely understood women's issues, in part because he had taken the time to explore his own experiences as a man with a disability.

### Mentoring

He recognized that an essential part of advocacy is supporting and training new leaders. Irv was with me the first time I spoke in public in 1979. I was nervous. As he has done for so many people, Irv encouraged me by matter-of-factly expecting I would do fine. When I have needed a listener, a contact to an agency, an advisory board member, a good quote, an opinion on a dilemma, I have often thought automatically, "Ooh, let me call Irv." Irv supported so many people in leadership by promoting their speaking and writing. Irv adamantly resisted the notion that disability could ever prevent someone from taking leadership. Boston activist Connie Panzarino said, "Irv understood that none of us could do it all." If disability or fatigue created limits, "there was always an 'Ah,' from Irv, saying, 'You could do it some other way or in some other role.'"

I have a stack of Irv's writings yet to read and many to reread. He will still be my mentor for many years to come. Many of Irv's closest associates are themselves leaders, mentors, caregivers to severely oppressed communities. We work so hard to fight discrimination, to make the world work better. Irv spoke to us in the place where leaders need help. Irv was not only a leader, but a mentor to other mentors.

### How Irv Helped Advocates

He was eager to use his other roles to forward advocacy causes. As much as Irv would joke about his humble origins and his Dorchester accent, for us advocacy types, he was often the most respectable person around to lend credibility to our projects. We would

call on Irv to go to the funders, sit on boards, or sometimes just be the name that signed the letter or accepted the check. He often helped us find something in the literature to legitimize our claims or to document the need for our work.

Irv recognized the importance of funding for small non-profit advocacy groups and helped to create Community Works, a consortium of progressive advocacy and self-help groups in the Boston area, which has formed a successful alternative to United Way for employer-based funding.

### Irv Enjoying Himself

And Irv also knew how to care for himself. Judy said, "After talking on the phone with a colleague, or reading a thesis, or helping Kyra with her homework, he would relish some delicious moments in a hot tub with his latest mystery. He knew that he could best be there for others by taking care of himself as well."

He also had a way of integrating advocacy with his favorite pastimes, eating for example. He became the restaurant reviewer for wheelchair accessible restaurants for a local disability newsletter called Together. He would often double up on tasks by setting up meetings at one of these new restaurants, selecting several of the most promising items on the menu as the delicious backdrop for a brainstorming session or helping a student or colleague with a problem.

And Irv took time for his personal life. His many published stories of his family are about playing with and learning from his children. His older daughter, Amanda, said at the memorial service, "I never felt I had to share my father with anyone."

He took ample time to sort out his own feelings. I was one of his many confidants whom he sought out to share listening time and reflections on personal dilemmas.

### Our Loss of Irv

What a loving friend and teacher! What a teddy bear. And what a big silly, as he so proudly quoted his children's description of him.

How do we handle such a great loss? What advice would we receive from our friend, Irv Zola?

Cry a lot.

Share your thoughts and feelings with others.

Get lots of hugs.

Make jokes, even about painful things.

Remember you are not alone in your pain.

Remember our greatest power comes in helping each other.

### Why We Explore Irv's Legacy

When we seek to emulate the qualities of someone we admire, when we seek a role model, we are also facing our own feelings of inadequacy.

Like Irv, I am involved in many organizations and several communities. In my multiple roles I am looked to for support by many. But I am also someone who often feels overwhelmed, who sometimes feels like I am hiding out behind my answering machine. I never asked him, but I wish I had: "Where do you get that kind of energy?!" From whence comes that deep well of caring?

I have to speculate here, but I think Irv would have said, "It's hope that gives us that extra energy to connect, a deep belief that what we're doing is working, and that we are not alone." And he would also say, "What's to worry? You're doing fine."

Why is it important for us to explore Irv's legacy? Part of the grieving process is sharing the particulars of the loss we feel when someone as beloved as Irv leaves us. Wendy Sanford, a member of the Boston Women's Health Book Collective, said that part of our grieving is to "tell each other about how we want to carry Irv on, how we have taken him into ourselves, how we want to reflect Irv in our work and in our loving."

In this process we might be tempted to exaggerate the wonderful qualities of a loved one lost. Sometimes people deify loved ones and mentors. In Irv's book Missing Pieces, he confesses how easily seduced one is when someone flatteringly inquires about the origins of his good qualities. To this sentiment he responds to us at all levels of our contribution:

to emphasize individual personal qualities as the reason for success in overcoming difficulties (and the reason for failure if the barriers prove insurmountable) is self-serving for the individual and the society. For individuals who have lost so much, it rewards them at a cost of making them ignore what they owe to some and what they share with others who didn't make it. To the society this emphasis merely allows the further disavowal of any responsibility, and more important, any accountability, for the process which makes a chronically disabled person's entry or re-entry into life so difficult. Had my family been poorer and less assertive, my friends fewer and less caring, my champions less willing to fight the system, then all my personal strengths would have been for naught. On the other hand, if we lived in a less healthist, capitalist, and hierarchical society, which spent less time finding ways to exclude and disenfranchise people and more time finding ways to include and enhance the potentialities of everyone, then there wouldn't have been so much for me to overcome. (Zola, 1982, p. 234)

I think, even if we are tempted to deify Irv, we will never really lose our perspective on the real Irv. Irv is good role model because, in his accessible humanness, he was always just a regular guy. We need more role models of regular guys.

The work we do is hard. We get discouraged. Big battles lie ahead of us. Irv and the many other heroes of our community are with us. We need to know that our own work, our own hard efforts will live on past our own lifetimes. Remembering and celebrating Irv's life can remind us of this.

Something Irv would have wanted is for us to appreciate ourselves . . . for being his community, for receiving his caring and loving him so well in return, for using what he offered us and taking it to the next level. Just think how much he would have loved to hear us speak about him today!

### Bibliography

- Zola, I.K. (1979). Helping one another: A speculative history of the self-help movement. Archives of Physical Medicine and Rehabilitation, 60, 452-456.
- Zola, I.K. (1982). Missing pieces: A chronicle of living with a disability. Philadelphia, PA: Temple University Press.
- Zola, I.K. (1983). The evolution of the Boston Self Help Center. In G. Jones & N. Tutt (Eds.), Way of life for the handicapped (pp. 143-153). London, England: Residential Care Association (357 Strand, London, WC2R OHB).
- Zola, I.K. (1985). Depictions of disability--Metaphor, message and medium in the media: A research and political agenda. The Social Science Journal, 22(4), 392-402.
- Zola, I.K. (1991). Bringing our bodies and ourselves back in--Reflections on past, present and future "medical sociology." Journal of Health and Social Behavior, 32(1), 1-16.
- Zola, I.K. (1994, March). Shifting boundaries--Doing social science in the 1990s--A personal odyssey. Presidential address delivered at the Eastern Sociological Society Annual Meeting, Baltimore, MD.

### Organizations

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- Project on Women and Disability, One Ashburton Place, Rm. 1305, Boston, MA 02108
- Community Works, 25 West Street, Boston, MA 02108
- Boston Women's Health Book Collective, 240 A Elm Street, Somerville, MA 02144

The Information Center for Individuals with Disabilities, (publishes "Disability Issues," formerly "Together Newsletter"), Fort Point Place, 27-43 Wormwood Street, Boston, MA 02116

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## Final Comments

Sharon N. Barnartt  
Gallaudet University

I am honored to be able to discuss the papers in this section remembering and honoring Irv Zola. I used to say that I was one of Irv's "old" students, and he would always chide me about exposing both of our ages. I was a student and one of his earliest cohorts. As such, I knew him almost at the beginning of his academic career, as a professor of medical sociology at Brandeis University. At that time he had developed neither the disability consciousness nor the feminist consciousness he would develop later. In fact, his disability, in the rare moments when it was referred to at all, was discussed in the context of how his experiences related to the medical sociology concepts or situations we were discussing. As we all know, his thinking progressed. However, he still had a profound impact on my sociological thinking and subsequent teaching.

Even in those times in which his thinking lacked political (or sociological) correctness, there were three themes which he emphasized back then and which he continued to emphasize in his more recent writings. The first theme was a version of the feminist slogan "the personal is political"--the personal is sociological--meaning that personal experiences can be understood as indicators of sociological processes. Even at that time he used anecdotes from his own life and the lives of other people in order to suggest sociological understandings which were both profound and original. The second theme, related to the first, was that sociological insights are everywhere. Thus, he had us read novels in sociology classes, which at that time was a fairly radical thing to do. Finally, he taught us that numbers are suspect or, in the words of the Gilbert and Sullivan song, "Things are seldom what they seem. Skim milk masquerades as cream." Overall, these insights, which guided Irv's teaching in 1967, are insights which he continued to express in his teaching, writing, and research until he died.

To me, Irv exemplified what a sociologist could be--and why anyone would want to become one. There were several sociological stances he took which distinguished him from other sociologists:

- He felt that research need not be value-neutral. Rather, research, such as his in Het-Dorp, could--and should--take a position about what is better or worse, and that such research can be academically respectable.
- He felt that one should not live just in one's office, but in the world. Irv's life influenced his research, and vice versa. He succeeded in his academic life as a teacher and as a scholar, but he also succeeded as an activist and as a force in public policymaking.

- He felt that research and activism are not mutually exclusive, but, rather, that they can influence each other. Being an activist did not make him a bad scholar--just the reverse. Some of his sociological insights were so profound that they caused in me a "click" of raised sociological consciousness similar to the click of raised female consciousness discussed by the women's movement in the 1970's.

These stances made him a somewhat unusual sociologist. However, it was precisely his integration of teaching, research, and activism which made him the teacher, researcher, activist, and friend whose memory we honor here and whom we will all miss so much.

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## Section II

### Disabling Images

Images of people with disabilities permeate American culture and cultures around the world. This is not a recent phenomenon, but one that has existed since the beginning of human existence. Ellen Steckert and Martha Edwards both document early disability images in a variety of cultures. In modern times, these images can affect teens with disabilities, people with neurofibromatosis, deaf persons, and the acceptance of the Americans with Disabilities Act.

Ellen Steckert of the University of Minnesota shows that the horror genre has long represented people who are not "healthy" as "other" or as full-blown monsters. She believes these images resonate because "contemporary culture dreads body distortion" (p. 35). She says the message of horror films' representation of shape-shifting vampires is that a young, perfect body is superior to a vampire's deformity. In the 1990s, cultural images have begun to show attention to issues of diversity, but others still remain as "others." Steckert says we must work toward cultural images of disability no longer used to invoke fear and horror and the subsequent definitions as "the grotesque."

Martha Edwards of Truman State University puts a significant historical "face" on mobility impairment in her documentation of disability in ancient Greece. She analyzes the frequency, aesthetic significance, and ranking of impairment in Greek culture. Although the types of mobility impairments were different than in modern times, there was a high incidence in ancient Greece because, during that time, a twisted ankle could be disabling. Aesthetically, mobility impairment seemed to carry little or low stigma. If a person with a mobility impairment could perform the tasks needed within the Greek culture, he/she was not "disabled." Only in terms of cosmetic appeal was stigma associated with disability, as in the case of the marriageability of upper-class women. Most importantly, however, "Mobility impairment of any degree was not considered a disability and had no pity attached to it," according to Edwards (p. 43).

Joan Ablon of University of California, San Francisco, explains the social stigma attached to neurofibromatosis, which is often misunderstood to be "The Elephant Man's Disease." She interviewed 54 adult subjects with varying degrees of neurofibromatosis and found that the stigma of the disease was a problem for more than half those respondents. This stigmatization resulted in verbal abuse from other children during early life, and impaired interaction with family, friends, and medical personnel. The American media's obsession with physical perfection and beauty and their representations of "The Elephant Man" as the antithesis of this perfection contributed to further stigma for people with neurofibromatosis. As one respondent explained: "It's the disfigurement that bothers me. Society-wise that is the most inhibiting thing" (p. 48).

Gary Kiger of Utah State University investigated, through a survey of college student attitudes, societal values and attitudes toward people who are deaf. For a comparison, the students' attitudes toward people who are homosexual were also assessed. Attitudes toward deaf persons were found to be much more positive than toward gays and lesbians. Respondents described deaf persons as "happy," "alone," "angry," or "friendly," whereas gay people were described as "sick," "weird," or "strong." Deaf persons were seen as less threatening to the nondeaf students, but that may have been in the context of the college setting. Kiger says his findings suggest that affective-specific appeals and contact will be the most effective ways to change attitudes toward deaf persons.

Our young people with disabilities are the future of disability culture, but Loren Faibisch of the University of Minnesota found that teenagers with disabilities face much stigmatization within their daily lives. Many feel like second class citizens already. Faibisch conducted in-depth interviews with 16 adolescent boys and girls with a variety of disabilities. Their narratives tell of the shame and devaluation they felt from the disability-related stigma. They told of exclusion, ridicule, and the lowered expectations of others due to their disability. The young people also faced disability-related harassment and discrimination. Faibisch's findings are a horrifying reminder of what our young people with disabilities must fight against daily.

In terms of media coverage of disability issues, Beth Haller of Towson State University extends the work of John Clogston in looking at news media coverage of the Americans with Disabilities Act. She applies Clogston's five general models of media representation and adds three new models. Her findings show that news stories represented the ADA as a civil rights issues predominantly, but also allowed a new theme to enter the discourse: that people with disabilities are costly to society. This is referred to as the business model and results from the high use of information about business concerns to counter the civil rights side of the story. Two other more positive models also enter the narrative: the legal model and the consumer model. In these models, people with disabilities are shown using the legal system and their consumer buying power to gain access to society. The results show that news coverage of the ADA has helped society to understand that access to U.S. society is not a handout, but a civil rights issue in which people with disabilities must fight against discriminatory practices.

## The Werewolf as Embodiment of (Dis)Ability: The Ideal Body, Distortion, and the Folklore of Shape-Shifting

Ellen J. Stekert  
University of Minnesota

Scholars who have written on the subject of horror have described it as an emotion or reaction elicited by the disruption of the receiver's world of known categories.<sup>1</sup> The "normal" Euro-American 20th century world has been one of balance, justice, truth, and rational understanding—one in which classifications such as "animal," "vegetable," and "mineral" cannot be violated or merged. It is a world in which those who are "normal" can recognize themselves and have identity. It is a world of "healthy" people; they occupy the unmarked category.

The horrific Euro-American world is one in which Western scientific rules of causation do not apply. It is a world of the unknown, the unexpected, the liminal, one where disruption reigns, and previously honored cultural paradigms are distorted;<sup>2</sup> it is a place where those who are "normal" have no identity. It is populated by monsters who engender physical fear and loathing; they are the embodiment of horror. It is a world of the "non-healthy," the "marked," the freakish, the disabled.

Contemporary American culture dreads body distortion. An examination of current folklore/popular culture can inform us about prevalent attitudes toward those disabilities which are perceived as distortion of, and deviant from, the physical norm. Culturally and historically specific examinations of such ignored or devalued situated expressive behaviors as folk legends and horror films offer us the opportunity to explore the thesis that disability was, and still is, seen as a horror. Ironically, instead of creating chaos, depictions of "deep horror" often play off cultural taboos to reaffirm the status quo; the trope of disability is integrally tied to the theme of horror, for it assumes societal norms.<sup>3</sup>

If we choose a type of production—or popular expressive form—that violates these societal rules, we can learn about how (dis)ability is viewed within a culture at a given historical time. The horror film (and general literary horror narratives, such as short story and novel) of the 1960s through the 1990s can be read as a gauge of views in the United States about disability. In order to be able to do such a "reading," we must situate and place

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<sup>1</sup> See Noel Carroll (1990), pages 31-35. Carroll refers to the concept of "impurity" as the identifying feature of horror, citing Mary Douglas (1966).

<sup>2</sup> The current scientific language of chaos theory is applicable here, as is the anthropological concept of "liminality" advanced by Victor Turner (1969).

<sup>3</sup> See James R. Twitchell (1985), pages 258-301.

these cultural expressions--in this case, the representation of horror--in clear historical/social/cultural context.

One theme of contemporary horror genres in the U.S. is that of transmutation (transformation/metamorphosis). Folklore scholars are familiar with this recurrent element of folk narrative and folk belief; they call it "shape-shifting." The theme is found in virtually all historical periods and in all cultures. In the international tale of the Animal Husband, which is related to the Beauty and the Beast, the protagonist (a bear, seal, hyena, or so forth, depending on the culture) lives by day as an animal and at night visits his wife in human form. Eventually his wife discovers his animal skin (when he is in human form) and destroys it. This removes the magical spell and permanently restores her "husband" to human form (a form usually ideal for the culture).

This theme, that of transformation from normative to horrific or from horrific to normative through supernatural/occult use of an exterior such as a skin, a coat, or a body has been persistent in Western tradition. It is found in early tales/beliefs about werewolves and other were-animals, and it is still with us in a variety of redactions in our contemporary horror genres, especially the horror film: from "The Stepford Wives" (1974), "The Invasion of the Body Snatchers" (1956, 1978), to Leatherface in "The Texas Chainsaw Massacre" (1974), to the original "Alien" (1979), to "The Silence of the Lambs" (1991). The werewolf has been a staple of Western horror cinema from the early Lon Chaney, Jr., in "Wolf Man" (1941) to Jack Nicholson in the 1994 "Wolf." In the 1980s the werewolf film was invigorated by new and revolutionary special effects that were first seen in "An American Werewolf in London" (1981). This new cinematic technology (with the aid of latex and hidden air pressure tubes) allowed the film werewolf to transform before the viewer's very eyes without the needed earlier stop-action photography.

It is important to note, however, that shape-shifting has not always been seen as a horror. Prior to the Middle Ages in Western Europe, for example, the werewolf was viewed as a dangerous presence which, if approached (or avoided) in the proper manner, could be rendered harmless. However, with the overlay of Christianity and the eventual ascendance of the Inquisition, the werewolf was seen not only as dangerous, but as evil/sinful. Persons suspected of being werewolves were actually tried and executed along with witches during the Inquisition. Werewolves were the "Devil's dogs." The element of judgment (evil/sin) mixed with the earlier concept of danger and produced the horrific effect. In the 14th-18th century it was far more horrifying for a person to think of losing his/her soul to the Devil for eternity than to be indisposed by a physical disfigurement during life. Physical distortion, as we define it today, was ubiquitous in that historical period.<sup>4</sup>

The shape-shifting vampire shares a long folktale and legend history with the werewolf. It, too, has seen a revival of interest in contemporary culture through the writings of people such as Anne Rice, as well as films such as the early 20th century rendition of

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<sup>4</sup> See Charlotte F. Otten (1986) for comprehensive essays on werewolves.

"Dracula" (1931), and later films such as "The Daughters of Darkness" (1971), "The Hunger" (1983), "The Lost Boys" (1987), and "Bram Stoker's Dracula" (1992). The cinematic vampire's lure of immortality and eternal youth is always delicately compromised by a physical representation that is distorted and limited in its "human" manifestation.

The message of such horror films is one that favors normative behavior and a young and near-perfect body that tells the viewer it is better to be [excuse the pun] "dead than bled." (The pun is related to horror films' use of anti-Communist themes from the 1950s to 1980s, when one was rather dead than Red.) In an age of AIDS awareness, the ultimately deformed androgynous vampire is an abomination of categories--human/animal, male/female, alive/dead, creating/killing--living death with a voracious appetite.

In a bizarre turn, we may also look for a violation of cultural norms in some of the popular heroes of the 1970s and 1980s--often those same heroes who triumphed in horror films of those decades. It was a period that emphasized the American traditional value of physical fitness to a degree that the ultimate icon became a distortion of itself. Heroes such as Arnold Swarzenegger and Sylvester Stallone raced into various violent scenarios to rescue a multitude of "others" (from the Vietnamese "First Blood," 1982, and "Rambo: First Blood," 1985, to the "mutants" on Mars in "Total Recall," 1990). Their bulging bodies were icons of fitness that an exercise-obsessed 40-ish baby-boom population could see replicated on magazine covers and in their children's afternoon TV cartoon-heroes (e.g., He-Man and She-Ra). It seems to me that there has been a decided retreat in the 90s from these icons, these distorted exaggerations of human "normality." Was it because the emergence of female body-builders in the late 1980s and early 1990s confused too many cultural categories? It is no accident, I think, that Arnold Swarzenegger finally made his "acting" career in the late 1980s and early 1990s in quasi cyber-punk/horror films.

Just as the cyborg, the Sater, the Wolfman, and the Chicken Woman (of "Freaks," 1932) elicit physical and visceral loathing/discomfort in a contemporary self-identified "normal" American public, so, too, does the everyday person-on-the-street who is perceived as "disabled" because his or her existence is enabled by visible non-normative mechanical means.<sup>5</sup> And, just as the American public is repelled by the "distortion" of the characters in "The Howling[s]" (1981-1990), "Batman" (1989), "Batman Returns" (1992), or "Willy Wonka and the Chocolate Factory" (1971), so, too, are they repulsed by physical or behavioral deviation from the "norm." "Edward Scissorhands" (1990) could never be part of suburbia--at least not until there is a dramatic shift of contemporary American worldview, categories, and cultural norms.

The American public is distanced from its own aging and mortality just as it is from the frightening images of distortion in horror films. We have begun to acknowledge the fact

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<sup>5</sup> By "non-normative," I mean material physical aids that the culture sees as stigmatized. Some mechanical aids such as mobile phones and beepers or glasses and binoculars are not considered negatively in most contemporary urban American contexts.

that we cannot exercise ourselves into perfection. Images of horror in the 1990s in film have moved from the evil werewolf to portrayals of the monster as a misunderstood and predominantly human victim such as Jack Nicholson in "Wolf" (1994) or Robert DeNiro in "Mary Shelley's Frankenstein" (1994).

Paradoxically, as many in 1990s America have begun to pay lip service to a concept known as "diversity," they have done so in such a way as to keep "others" as "Others." As much as we would like to think that they have automatically accepted us as normal "disabled" human beings, we have only to look more closely to see evidences of earlier manifestations of the old horror tale of a monstrous "other" trying desperately to shape-shift, to find another skin--to be "normal." Leatherface in "The Texas Chainsaw Massacre" (1974)--who both is distorted and who distorts/disables--is a fictionalization of the very real Ed Gein, the "normal" recluse in Wisconsin who was eventually "unmasked" as a gruesome serial killer of women. His more recent relative, the perplexing killer in "The Silence of the Lambs" (1991), coveted the skins of women to make far more than a mask to achieve a transformation into his distorted "real" identity.

Cultural values change painfully slowly. The ADA might be somewhat of a help on the way to allowing disabilities to be seen as "normative" categories, but there is still a far distance to go. Legal change is slow when it is not preceded by cultural change, but instead seeks to effect it. Disability, when presented as "distortion," is still seen as horror in the 1990s, and it is both feared and judged. We need to contest this assumption if we do not wish to remain perceived as liminal beings. We must fight in cooperation with other "other" groups--gays/lesbians/transgendered people (certainly bisexuals, the last sexual tabu to fall in the flight for diversity); political and religious radicals; criminals; and those forced to the margins of race (e.g., Creoles), nationality, and ethnicity. Euro-American culture is a notoriously visual one--after all, "seeing is believing" ("The Company of Wolves," 1985).<sup>6</sup> We must convince the "normals" (as well as ourselves--both plural and singular) that we are all individuals who, in our (visual and non-visual) differences, defy cultural normative categories, just as do the grotesque creatures we encounter in the horror films of previous decades. Only if we do so, can we hope that our visibility (especially that of persons with "perceived" [dis]abilities) will cease to confound cultural categories, elicit fear, horror, and judgment from a society that is reluctant to expand its "normative" classifications to make room for us. It is already too late if we must wait for them to become us.

#### References

- Carroll, N. (1990). The philosophy of horror. New York, NY: Routledge and Keegan Paul.
- Carter, A. (1979). The bloody chamber. London, England: Penguin.

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<sup>6</sup> See Angela Carter's (1974) short story of the same title (pp. 110-118) from which she adapted the film script.

- Douglas, M. (1966). Purity and danger. London, England: Routledge and Keegan Paul.
- Otten, C. (1986). A lycunthropy reader. Syracuse, NY: Syracuse University Press.
- Turner, V. (1969). The ritual process. Ithaca, NY: Cornell University Press.
- Twitchell, J. (1985). Dreadful pleasures. New York, NY: Oxford University Press.

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## Social Stigma and Mobility Impairment in Ancient Greece

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In this paper, I look at some ancient Greek attitudes toward people with mobility impairments. Specifically, I ask if there was social stigma attached to people who walked with variant gaits, who relied on devices such as crutches to walk, or who did not walk at all. A standard definition of stigma is "the negative, prejudicial side of the majority's reactions to those who are different," especially those with "socially disqualifying attributes" (Katz, 1981, 1-2). In the modern, developed world, the stigma of physical disability is often characterized by pity (Katz, 1981; Shapiro, 1994). I look at mobility impairment in the ancient world from three angles: its frequency, its aesthetic value, and its status as a physical disability.

First, what was the variety of mobility impairment in a typical ancient Greek village? The profile of mobility impairment differed both in degree and in kind from the modern world. People in the ancient world did not survive severe spinal cord injuries, for example, except for the lowest of breaks. On the other hand, ancient Greece included people with mobility impairments that are not commonly seen today in the developed world, such as clubfoot and broken bones that have undergone profound morphological changes in the healing process. A simple accident such as a twisted ankle generally meant giving up use of that foot forever. Accidents of war, which was frequent and close-range, also accounted for permanent injury. Conditions that are much more than mobility impairments but can include mobility impairment nonetheless, such as multiple sclerosis and muscular dystrophy, also existed, though not-for better or worse-recognized as medical phenomena (von Staden, 1990). Furthermore, epidemic disease could result in limb loss for many members of an entire community (e.g., Hippocrates, 5th-2nd centuries B.C.E./1984, *Epidemics* passage 3.4).

The ease of acquiring an impairment of mobility is reflected in the Greek recognition of several ways it might happen, some rational to our way of thinking and some not. As an example of a concept that does not seem rational to 20th century thought, Aristotle postulates that males are born with dislocated limbs more often than females because males are stronger and hotter, and thrash around in the womb more (Aristotle, 4th century B.C.E./1979, *Generation of Animals* passage 775 a). More rational to the 20th century outlook is the idea that the human body, at any stage of its life, was always thought to be in precarious balance; and, in fact, those in perfect balance--those most conforming to the symmetrical ideal--were the most vulnerable (Plutarch, 1st-2nd centuries C.E./1967, passage 1090 c). The Greeks also realized that, if a person reached old age without a mobility impairment, he or she would acquire one then. Old age and mobility impairment were inextricably intertwined. Consider the riddle of the Sphinx, the solution to which depended on the recognition that all old men use canes, just as all babies crawl.

While it is impossible to determine whether people with mobility impairments were in the minority or the majority, we can conclude that mobility impairment was not the occasional exception in the Greek world. This does not rule out stigma, though. One must be merely in a *perceived* minority to be stigmatized.

The aesthetics of mobility impairment provide a clue in determining stigma. Mobility impairment was considered a cosmetic characteristic, sometimes a neutral one, as in the case of the god Hephaestus, who was identified by his limp and his epithet "Crook Foot." Mythology reflects reality: Less grandly, Anouph the Lamé is known to us only because he was identified on a tax roll (Grenfell & Bell, 1924, document #1917). Sometimes the cosmetic characteristic was mildly negative, mentioned in the same category with baldness and scars, and in this case, perhaps, could be considered a "socially disqualifying attribute," though not a profound one--for men. Upper-class women with this "cosmetic defect" seem to have had trouble fulfilling their socially-prescribed roles as wives and mothers. The historian Herodotus tells the tale of Labda the Lamé, daughter of a noble family from the city of Corinth, whom no noble man would marry (Herodotus, 5th century B.C.E./1982, passage 5.92). The degree of beauty would not be a major factor in arranging a marriage contract for the bulk of the Greek population, which was comprised of peasant farmers, not noble aristocrats. Nevertheless, mobility impairment was indeed a socially-disqualifying attribute for upper-class women.

Mobility impairment did not otherwise indicate inability. Physical disability was, to use a phrase from contemporary Disability Studies, "relational and not inherent in the individual" (Kiger, Hey, & Linn, 1994, p. 1). In other words, ability and disability were determined not by medical pronouncement, but by the community's understanding of people's roles--what they were supposed to do. The degree to which a person could perform these tasks determined the degree of his or her ability or disability. When ability and disability are thought to be "inherent in the individual," we reach a level of abstraction in which people are banned *a priori* from carrying out certain roles. For example, a 1928 social worker's collection of case studies includes the case of Elizabeth Morris, who "walks with the aid of one crutch and limps only slightly." Elizabeth Morris was not eligible to be a school clerk because of this "handicap" (Hathway, 1928, p. 66). The Greeks would not have known what to make of this. In the Greek records, we see people with what today would be called mobility impairments in a wide spectrum of economic activities. We learn about their mobility impairments only coincidentally, never because the physical variations were themselves noteworthy. Coppersmiths, tailors, tavern-keepers, students, farmers, and leather-workers are documented, as well as that crucial role of Greek men: soldiers. The military community contained men with a wide range of mobility impairments, including men who could not walk at all. Greeks did not waste manpower.

Mobility impairment, then, was not synonymous with disability. A 4th century court case illustrates this point (Lysias, 5th-4th centuries B.C.E./1988, speech 24). In Classical Athens, people who were incapable of earning a living were eligible for a small state pension. In this court case, a man's pension was threatened although he had been receiving it for years. This anonymous man relied on two crutches to walk, and could not

walk more than short distances. Yet to defend himself, he hired the speech-writer Lysias, who wove a triple defense: a father who had left him nothing, an aged mother whom he had to support, and the lack of children to support him when he reached old age. This, Lysias argued, is why he should have been able to keep his pension. His mobility impairment had little to do with the pension. The defendant could not simply appear and show the jurors his easily-visible condition. In fact, one of the accusations against him was that he was known to rely on horses because he could not walk, instead of using the cheaper Greek equivalent of the wheelchair, the donkey.

In summary, despite a large population of people with mobility impairments, mobility impairment was stigmatized, but the stigma was cosmetic defect, not disability. Men and women with mobility impairments could be considered cosmetically-flawed in the same way that bald people were considered unattractive. This had ramifications for upper-class women, whose physical appearance could restrict how nobly they might be married. Mobility impairment of any degree was not considered a disability and had no pity attached to it. Some people are struck by the lack of compassion (i.e., pity) that the Greeks showed towards "the physically disabled." In Greek thought, though, there were not two groups: The Greeks *were* "the physically disabled."

#### References

- Aristotle. (4th century B.C.E./1979). (A.L. Peck, Trans.) Loeb Classical Library (Vol. 14). Cambridge, MA: Harvard University Press.
- Grenfell, B.P., & Bell, H.I. (Eds.). (1924). The Oxyrhynchus papyri (Vol. 16). London, England: Egypt Exploration Society.
- Hathway, M. (1928). The young cripple and his job (Social Service Monograph 4). Chicago, IL: University of Chicago Press.
- Herodotus. (5th century B.C.E./1982). (A.D. Godley, Trans.) Loeb Classical Library (Vol. 3). Cambridge, MA: Harvard University Press.
- Hippocrates. (5th-2nd centuries B.C.E./1984). (W.H.S. Jones, Trans.) Loeb Classical Library (Vol. 1). Cambridge, MA: Harvard University Press.
- Katz, I. (1981). Stigma: A social psychological analysis. Hillsdale, NJ: L. Erlbaum Associates.
- Kiger, G., Hey, S., & Linn, J.G. (1994). Introduction. In G. Kiger, S. Hey, & J.G. Linn (Eds.), Disability studies: Definitions and diversity (pp. 1-4). Salem, OR: Society for Disability Studies and Willamette University.
- Lysias. (5th-4th centuries B.C.E./1988). (W.R.M. Lamb, Trans.) Loeb Classical Library. Cambridge, MA: Harvard University Press.

Plutarch. (1st-2nd centuries C.E./1967). *Moralia*. (B. Einarson & P.H. DeLacy, Trans.) Loeb Classical Library (Vol. 14). Cambridge, MA: Harvard University Press.

Shapiro, J. (1994). No pity: People with disabilities forging a new civil rights movement. New York, NY: Random House.

von Staden, H. (1990). Incurability and hopelessness: *The Hippocratic Corpus*. In P. Potter, G. Maloney, & J. Desautels (Eds.), La maladie et les maladies dans la collection hippocratique (pp. 75-112). Québec, Canada: Les Éditions du Sphinx.

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## Coping with Visible and Invisible Stigma: Neurofibromatosis 1

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This paper reports on issues related to stigma as experienced by individuals and families who have neurofibromatosis 1, a neurological genetic disorder, for many years misdiagnosed as "The Elephant Man's Disease." Neurofibromatosis 1 (NF1) is a common condition occurring in 1 out of 4,000 births; some 100,000 people in the United States are estimated to have the disorder. NF1 is inherited as an autosomal dominant trait occurring equally across sex, race, ethnic, and national boundaries, with one half of the cases being spontaneous mutations. The primary manifestations of NF1 are neurofibromas, tumors which develop in and along nerves and nerve sheaths. External neurofibromas may be cosmetically disfiguring and are associated with considerable stigma for affected persons. Internal neurofibromas may impinge on vital organs and impede mobility, and they may be malignant. Skeletal malformations and learning disorders are also commonly associated with NF1. Not only may the manifestations of NF1 be enormously varied, but the progression rate of the disorder varies dramatically among individuals. NF1's most damaging psychological feature is its unpredictability. NF1 was first identified and described clearly by Friedrich Daniel von Recklinghausen in 1882, but it became known to the general public only in recent years through "The Elephant Man" phenomenon (Ablon, 1995). For more details on NF1, see compendia by Rubenstein and Korf (1990) and Riccardi (1992).

The heterogeneity of presentation of NF1 creates a wide variety of possible symptoms ranging from the visible stigmata of tumors on the skin, skeletal abnormalities, and optic gliomas (eye tumors) to the invisible ones of learning disabilities and inability to reproduce without the danger of passing on the condition to one's children. While most persons who have skin tumors experience them chiefly, and sometimes only, on torso areas that can be hidden by dress, older persons and women past the age of child-bearing often have them on the face, neck, and hands. Skeletal abnormalities and eye tumors develop in early childhood and can be visible at a young age. While these objective physical symptoms of NF1 may be clearly apparent, the subjective experiencing of these symptoms and the social problems that may attend them vary. Consequences of learning disabilities are more subtle and tend to be manifest throughout the school and employment career. Feelings of stigma related to the dangers of childbirth and/or the choice not to have children are even less amenable to being objectively gauged.

Fifty-four adult subjects recruited from three NF1 Support Groups sponsored by the National Neurofibromatosis Foundation and the California Neurofibromatosis Network, and the caseloads of the Genetics Departments of two major metropolitan hospitals in Northern California were interviewed. Twenty-nine, or more than one half of the subjects, brought up issues and problems in their lives which clearly fall under the rubric of stigma, society's obvious and expressed negative evaluation of their physical appearance

or behavior. While many of these persons would be classified within the more extreme categories of visibility and sometimes severity, almost equal numbers would fall into the mildly and moderately visible categories. Clearly a great many persons with NF1 live with the specter of stigma as a daily companion.

### The Creation of Stigma

Accounts of early stigmatization reflect that stigma is engendered and perpetuated through a number of social sources--most commonly by the taunts of other children in school and in the neighborhood, by the family, by doctors and other medical personnel, and through the larger contexts of public opinion and values, media representations, and interpersonal social interactions.

### School Experiences--The Primary Childhood Context of Stigma

It is clear from the painful memories of many affected adults that children with NF1 frequently suffer through many years of sometimes excruciating teasing, taunts, and social assaults of various types and never tell their parents or other adults what they are experiencing. Many persons described how early physical symptoms constituted significant physical differences that other children noticed and for which they were censured, often resulting in their feelings of shame and social alienation. Said one man:

The kids would always make fun of me. Give me a bad time. Push me around. I was different. I couldn't keep up. I looked different. I had a bigger head, droopy eye. Obviously, I couldn't do what they do. Deformed, I guess. I don't like that word, but this was true.

And another:

In junior high and high school after my first surgery, after I was fourteen, some of my best friends knew I was having problems with tumors, and I was ridiculed, saying I was going to turn into a tumor, and things like that. Some of my closest friends said, "We can't go out with you anymore because we're afraid if we touch you we're going to turn into a tumor." That hurt. But I just thought, they don't understand. [Did you go home and tell your mom, or anyone?] Never did. I kept it all inside of me.

A number of women talked about painful memories of undressing in gym class and how their tumors were made visible to the world:

My worst experiences were when I had to shower at school. The tumor on my leg got larger and larger. And, in fact, when I was in high school it was enormous. It got to be this huge thing just hanging down, and that was the thing that people used to look at and comment about. The kids said, "What are those things on your legs?" And I'd say, "Well, you know, they're called von Recklinghausen, and

they're hereditary. You can't catch anything from me, and they're not going to hurt me or you."

Children who had to change schools several times described the additional burden of repeatedly having to make new sets of friends when the task was considerably more difficult for them than for an unmarked child. Three men talked about their special difficulties with sports; the fact that they were not able to engage in the typical round of sports activities was a source of shame to them. One woman described some of the social difficulties caused both by her physical symptoms and by the long absences from school due to spinal surgeries.

### Family as Generators of Stigma

One woman spoke bitterly of the creation of the stigma around her condition by parents who never put a name to it, but also told her "something bad was very wrong" with her.

My father had a flawed baby. They knew when I was born that I had the disease that I had. It was the dirty secret of the family. I mean they would talk to doctors about it, but it was a whispering disease. I was never told. I don't even think my sister knew.

Another spoke of how she felt her mother could have offset the assaults of society had she been more supportive:

My mother never let me know that I was still OK, and I was still lovable, and I was still pretty. I felt ugly and deformed inside, and I didn't have anybody telling me "That's not true." So, I would definitely tell my daughter or son that she or he was lovable and pretty and still loved.

### Medical Personnel as Generators of Stigma

At least a dozen adults spoke of behaviors by doctors and other medical personnel which they found to be stigmatizing. Not only did these behaviors reflect that doctors thought negatively of their condition, but they also bore a message that persons affected with NF1 should be ashamed of their condition. Said a severely affected man who has had numerous surgeries.

I've been a "genetic freak" for a long time to doctors. From the time I was six years old all the way through, I was more or less an exhibit for every doctor who wanted something to look at. I was a freak show, I guess. I'm that term, that's about it. I was a genetic wonder, a genetic oddity.

### American Cosmetic Values and Media Representation

Many persons brought up the importance of the mass media in influencing, shaping, or clearly demonstrating American cosmetic values. Mention of The Elephant Man, believed

for some eighty years to have had neurofibromatosis, was frequently made throughout the interviews. Many persons felt that the association with The Elephant Man has contributed to the stigma around NF1.

### Experiencing and Coping with Stigma in Everyday Life

Each person works out his or her own modes of coping or struggling with stigma. Many persons talked about their own problems in accepting the way they look, or in accepting the shame caused by the negative responses of others. Said one woman:

I went to a group therapy type of thing, but they didn't think I got too much out of the sessions, and, I guess, maybe I didn't. I mean, how often can you say that you feel bad because of the way you look and not being able to accept it. What I was saying at the sessions is I feel real angry at myself for not accepting myself when there are things that other people have that are worse than what I have. I can see, I can function, I can work. And yet this society is based on how we look.

I will close with one of many poignant statements that reflect the impact of societal stigma:

I can deal with the surgeries and the threat of deafening or blindness and paralysis. But, and it may seem vain, it's the disfigurement that bothers me. Society-wise that is the most inhibiting thing. If I have surgery once or twice every few years people don't shun me for that. But if you look like you have some horrible skin condition, people just can really be cruel. I've had this fantasy, if I could just have twenty-four hours where I didn't have NF. Just to feel what it's like! Even if no one else could see me, and I just saw myself! It's a strange fantasy. But just to know what I would look like without it. And I try not to think how different my life would be if I hadn't had this. I try not to go on about "what if" because, if I do that, I take away from my precious time now.

### References

- Ablon, J. (1995). "The Elephant Man" as "self" and "other": The psycho-social costs of a misdiagnosis. Social Science and Medicine, 40(11), 1481-1489.
- Riccardi, V. (1992). Neurofibromatosis: Phenotype, natural history, and pathogenesis (2nd ed.). Baltimore, MD: John Hopkins Press.
- Rubenstein, A., & Korf, B. (1990). Neurofibromatosis: A handbook for patients, families, and health care professionals. New York, NY: Thieme Medical Publishers Inc.

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## The Structure of Attitudes toward Persons Who Are Deaf: Emotions, Values, and Stereotypes

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There is an extensive literature on the attitudes of nondeaf people toward persons who are deaf. (For a review, see Shaver, Curtis, Jesunathadas, & Strong, 1987.) What this literature tells us is that attitudes toward deaf persons, like any intergroup attitudes, are complex (Messick & Mackie, 1989; Tajfel, 1982). According to the researcher's theoretical orientation, certain determinants of attitudes (e.g., affective, cognitive, behavioral intentions) would be emphasized over others. Recently, Zanna and associates have developed a theoretical approach to intergroup attitudes and a research strategy that address the complexities of the structure of intergroup attitudes (Esses, Haddock, & Zanna, 1993; Zanna, Haddock, & Esses, 1990; Zanna & Rempel, 1988). Their approach synthesizes the effects of values, stereotypes, and emotions in the formation of intergroup attitudes.

This study employs Zanna and associates' theoretical model and analytical approach to examine the influence of emotions, values, and stereotypes on nondeaf people's attitudes toward persons who are deaf. The study has three parts. The first tests the relative effects of values, stereotypes, and affect on attitudes toward deaf persons. The second compares these effects between attitudes toward persons who are deaf and attitudes toward persons who are homosexual to assess whether the structure of attitudes is different for different types of social groups. The third investigates the influence of individual-difference variables, specifically, measures of psychological insecurity and past experiences.

Attitudes held by hearing people toward persons who are deaf refer to "an individual's disposition[s] to respond favorably or unfavorably" to these group members (Ajzen, 1989, p. 241). One contemporary approach to the structure of intergroup attitudes recognizes their multicomponent character and attempts to integrate the influences of affect, values, and stereotypes on intergroup attitudes (Esses et al., 1993).

### Stereotypes and Attitudes

Walter Lippman (1922) coined the term "stereotype" to describe the cognitive schema a person uses to categorize knowledge, beliefs, and expectations about a social group. Many social psychological researchers point to the irrational basis of stereotyping (Brown, 1986). That is, some trait is defined as "typical" of a social group, and then that trait is assumed to apply to all members of the social group.

## Values and Attitudes

Milton Rokeach (1973) defined a "value" as "an enduring belief that a specific mode of conduct or end-state of existence is personally or socially preferable to an opposite or converse mode of conduct or end-state of existence" (p. 5). Attitudes are predicated upon values; so, if a person expresses an attitude, for example, toward persons who are deaf, the favorable or unfavorable expression depends on a perception of whether deaf persons facilitate or block some cherished value(s) held by the subject.

## Affect and Attitudes

Emotions are a powerful source of attitudes. In the study of intergroup attitudes, Allport (1954) noted that prejudice is most often a negative feeling toward an outgroup member that resists change even in the face of new, contradictory information. Emotions and ethnocentrism are related in that a respondent tends to evaluate positively ingroup members and to feel less positively toward members of another social group (Kleinpenning & Hagendoorn, 1993).

## Individual Differences versus Social Factors

There is a large literature on the relationship between individual prejudice and the expression of right-wing authoritarianism. The theory is that psychological insecurity is related to distrust and rigid thinking about outgroup members.

## **Method**

### Respondents

Undergraduate students (n=175) at a university in the Rocky Mountain region volunteered to participate in this study, which was part of a larger project on intergroup attitudes conducted in 1994.

### Instrument

Feeling thermometer. Each respondent initially was asked to indicate his or her overall evaluation of a "typical [person who is deaf]" on a feeling thermometer ranging from 0 "extremely unfavorable" to 100 "extremely favorable."

Stereotypes. Next, each respondent was instructed to "provide a description of typical members of [persons who are deaf]. Your description should consist of a list of characteristics or, if necessary, short phrases that you would use to describe typical members" (Esses et al., 1993). Then, each respondent was asked to evaluate each descriptor on a scale from -2 "very negative" to 2 "very positive." Lastly, each respondent indicated the percentage of [persons who are deaf] who possess each characteristic.

Emotions. Each respondent was instructed,

Please provide a list of the feelings you experience when you think about typical members of [persons who are deaf]. Provide as many feelings or emotions you believe are necessary to accurately convey your impression of the group and to describe members adequately.

Again, each respondent evaluated each feeling on a scale of -2 "very negative" to 2 "very positive." And, each respondent indicated the percentage of [persons who are deaf] who elicit each feeling expressed.

Values. Each respondent was asked to "indicate the values, customs, and traditions whose attainment is either facilitated or blocked by typical members of [persons who are deaf]." Then, each respondent rated the degree to which the typical [person who is deaf] blocks or facilitates each expressed value. The range was -2 "blocks a lot" to 2 "facilitates a lot." Lastly, each respondent assessed the percentage of [persons who are deaf] who block or facilitate each value mentioned.

For stereotypes, emotions, and values, a score was calculated to represent each dimension. Each valence score (values from -2 to 2) was multiplied by the corresponding percentage. The resulting values for each listed descriptor are summed. Then the sum was divided by the total number of descriptors listed. The process can be represented mathematically.

$$(P_{ig} \times V_{ig}) / n$$

Scores were calculated for stereotypes, emotions, and values.

Individual differences. Following Esses et al. (1993), the Right-Wing Authoritarianism scale was used to measure individual differences. An abbreviated version of this scale developed by Altemeyer (1988) was employed. Ten items were selected.

Past experiences. To assess the role of situational factors on intergroup attitudes, each respondent was asked two questions: (a) "Please describe the degree of contact/interactions you have had with [persons who are deaf]," and (b) "If you have had any contact with [persons who are deaf], on the whole, how would you characterize these experiences?" The first question was measured on a scale of 1 "none at all" to 7 "quite a lot." The second question was measured on a scale of -2 "very negative" to 2 "very positive." The two scores were multiplied.

Approximately five weeks after the instrument was administered to assess hearing respondents' attitudes toward persons who are deaf, the identical instrument was administered to the same respondents to assess their attitudes toward persons who are homosexual.

## Results

### Feeling Thermometer

The mean attitude score for persons who are deaf was 81.11 ( $SD=15.3$ ). For persons who are homosexual, the mean score was 29.22 ( $SD=25.5$ ).

### Content Analysis of Descriptors

The most common descriptors for persons who are deaf were: happy, alone, angry, and friendly. For homosexuals, the most common responses were: sick, weird, strong.

### Regression Analysis

Multiple regression results were generated with deaf persons and homosexuals as target-group members. For attitudes toward persons who are deaf, past experience and affect are statistically significant. For attitudes toward persons who are homosexual, affect, values, and stereotype are statistically significant.

## Discussion

This study examined a theoretical framework developed by Zanna and associates (1990) and applied it to specific intergroup attitudes. In a discussion of future research directions, Esses et al. (1993) queried, "whether different findings are systematically obtained for different types of social groups" (p. 160). The results of this study suggest that the structure of intergroup attitudes is different across target groups.

While respondents' attitudes toward persons who are deaf were generally positive, these findings could be context specific. That is, persons who are deaf are not viewed as a political, social, and economic threat to nondeaf persons. What would happen to attitudes if Deaf political activity became more prominent around, say, educational policies and practices?

Beyond the theoretical work examined here, there is also an applied component. If we want to modify attitudes toward persons who are deaf, what would be the best avenue? Given the theoretical framework developed here and the empirical findings, the answer seems to be affective appeals and contact. But, as Tajfel (1982) noted, it is not contact, *per se*, but interactions that are varied, frequent, and diverse that make it difficult for individuals to maintain negative stereotypes. This will enhance the development of positive attitudes.

## References

- Ajzen, I. (1989). Attitude structure and behavior. In A.R. Pratkanis, S.J. Breckler, & A.G. Greenwald (Eds.), Attitude structure and function (pp. 241-274). Hillsdale, NJ: Erlbaum.

- Allport, G. (1954). The nature of prejudice. New York, NY: Doubleday.
- Altemeyer, B. (1988). Enemies of freedom: Understanding right-wing authoritarianism. San Francisco, CA: Jossey-Bass.
- Brown, R. (1986). Social psychology. New York, NY: Free Press.
- Esses, V.M., Haddock, G., & Zanna, M.P. (1993). Values, stereotypes, and emotions as determinants of intergroup attitudes. In D.M. Mackie & D.L. Hamilton (Eds.), Affect, cognition and stereotyping: Interactive processes in group perception (pp. 137-166). New York, NY: Academic Press.
- Kleinpenning, G., & Hagendoorn, L. (1993). Forms of racism and the cumulative dimension of ethnic attitudes. Social Psychology Quarterly, 56(1), 21-36.
- Lippman, W. (1922). Public opinion. New York, NY: Harcourt Brace.
- Messick, D.M., & Mackie, D.M. (1989). Intergroup relations. Annual Review of Psychology, 40, 45-81.
- Rokeach, M. (1973). The nature of human values. New York, NY: Free Press.
- Shaver, J.P., Curtis, C.K., Jesunathadas, J., & Strong, C.J. (1987). The modification of attitudes toward persons with handicaps: A comprehensive integrative review of research (Project No. 023CH50160). Logan, UT: Utah State University, Bureau of Research Services.
- Tajfel, H. (1982). Social psychology of intergroup relations. Annual Review of Psychology, 33, 1-39.
- Zanna, M.P., Haddock, G., & Esses, V.M. (1990). On the nature of prejudice. Paper presented at the Nags Head Conference on Stereotypes and Intergroup Relations, Nags Head Conference Center, Kill Devil Hills, NC.
- Zanna, M.P., & Rempel, J.K. (1988). Attitudes: A new look at an old concept. In D. Bar-Tal & A. Kruglanski (Eds.), The social psychology of knowledge (pp. 315-334). New York, NY: Cambridge University Press.

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# An Inclusionist and Qualitative Approach to Understanding the Experience of Adolescents with Physical Disabilities

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This study explored stigmatization in the school and the social experience of adolescents with physical disabilities by analyzing qualitative descriptions of disability-related stigmatization. When asked about her experience, Melissa, a student with a mobility impairment, said that she feels as if she is "second" and that this feeling is carried with her even when she knows that she is with people who are not going to treat her "like shit." Narrative descriptions like these were systematically analyzed for thematic content and meaning relating to stigmatization and disability.

## Method

### Subjects

The sample was composed of 16 adolescent boys and girls ages 14-17 with a range of physical disabilities including diabetes, muscular dystrophy, spinal tumor, spina bifida, mild and severe asthma, kidney disease, cerebral palsy, hearing impairment, blindness, heart condition, and arthritis. Only respondents who had physical disabilities were interviewed. Those with primarily cognitive, emotional, and developmental disabilities were not included. The respondents, five boys and eleven girls, came from diverse racial, ethnic, and socioeconomic backgrounds, and they were educated in mainstream school settings.

### Data Collection

I developed an original interview guide which I used to conduct semi-structured individual clinical interviews. All interviews were taped and transcribed. The clinical research interviewing technique I used requires the interviewer to listen closely and respond to the interviewee's experience. I asked respondents to describe how they view themselves, how others such as parents, teachers, and friends view them. I invited them to comment on their views of disability and their status as persons with disabilities. After establishing whether the respondent thought of herself as having a disability, I asked her to tell me about times that she felt she was not treated well because of her disability or for some other reason. I asked students to tell me about events that involved their disability or someone else's disability. I asked, "How did you feel?" "What do you think?" One respondent described peers who ridiculed others and stared at her wheelchair as "rude." Probing further, I learned that she had felt insulted by a teacher who had expressed surprise that she dressed herself.

I used the guide to establish consistency in developing themes and topics of discussion, but the content of each interview varied greatly as I asked questions that followed the logic of their experience and my understanding of it. For instance, if in describing her day, a respondent said she likes gym, lunch, English, and Spanish, I might ask her to tell me about any of those activities, but I am most likely to ask about lunch, partly because I like to talk about food and eating, and partly because that is a more social time; and I had set out to learn about respondents' social experience. This method of data collection provided evidence of students' beliefs and feelings about disability and the messages they received from parents, peers, teachers, popular culture, and school curriculum. (Sample interview guides are available upon request.)

### My Role as Interviewer

My clinical and personal experiences guide my sensitivity to issues of disability and stigmatization. My clinical training concentrated on stigmatized groups, particularly sexually abused children and urban families in crisis. My experience as a person with a disability makes my interview approach unique because my history and identity as a person with a disability inform my knowledge of respondents' experience and influences how I conduct myself in their presence.<sup>1</sup> I also recognize that adolescents may speak about stigmatization experience in a way that is difficult for many adults to accept.

### Analysis

I used three methods to analyze the data: content coding (Miles & Huberman, 1984; Tolman, 1992), narrative summaries (Miller, 1991; Tolman, 1992), and reading for point of view (Brown, 1988; Faibisch, 1995; Tolman, 1992). These three methods are particularly appropriate for interpreting narratives that contain discussion of culturally-prohibited material, e.g., girls' sexual desire and stigmatization experience (Merriam, 1988; Tolman, 1992).

### Content Coding

I used content coding of interview transcripts to extract themes related to stigmatization experience (Strauss & Corbin, 1990). In a series of readings, the coder scans and parses for words, phrases, and their synonyms to generate categories for comparison across individual cases. Categories represent themes elicited during the interview. Based on my earlier literature review (Faibisch, 1992), I expected to find categories like rejection and paternalism. Other categories like ridicule and overprotection arose out of a description of time spent with friends at the mall. As events were described, I made note of the theme or category. The codes reflect the relationship between myself, my knowledge of disability literature, and the descriptions of experience offered by these respondents.

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<sup>1</sup> My disability is usually not apparent until I explain that I am legally blind. Also, my bias as interviewer and researcher will be accounted for by my use of reliability checks and the reading guide method of analysis.

This method does not use *a priori* codes. Themes emerged from the text as I saw words, phrases, and ideas that captured my attention and related to my understanding of stigmatization experience. I did this in a step by step fashion. First, I listened again to the interview tapes and noted words, phrases, and my own responses. I also made notes in order to recall non-verbal events, such as when an interviewee shook her head "no" in response to a question rather than speaking the word out loud. Second, I read each transcript noting events that the respondents reported. I then read each of the 16 transcripts for and noted their descriptions of beliefs and feelings about disability and stigmatization. Third, I read the beliefs and feelings set of transcripts and noted any themes that came up and related to disability and to social and educational experience, e.g., anger, view of self, medical aspects of respondents' disability. (Sample code lists are available upon request.) I then gathered these themes into clustered groupings by placing relevant responses and codes into thematic categories. For example, the dependence/independence cluster gathered descriptions about self-care, parent/teen relationships, and involvement in activities. (Sample clustered descriptions are available upon request.)

### Narrative Summaries

After coding the transcripts, I created narrative summaries. Content coding alone can remove context from interviews; I employed narrative summaries to restore that context (Miller, 1991). It helped me to follow the logic of stories begun, abandoned, and revisited over the course of the entire interview. A narrative summary reorganizes the narrative's terms and phrases into a logical order, lists key concepts drawn from both the content codes and the summary, and identifies potential themes across individuals so the researcher can interpret the reconstructed stories. For example, sprinkled throughout Ariana's interview were such phrases as "This school sucks," "I can't take shop," "My friend takes shop," "She is blind, too," "I'll give this school a bad rep." Putting these and other phrases together, I learned that Ariana was not allowed to take shop. She believes this is because she is blind, and she believes it is unfair. I constructed a narrative story of Ariana's exclusion from shop and then looked at other transcripts for more accounts of school-related exclusion.

### Reading for Point of View

The third method, reading for point of view, is an adaptation of the reading guide developed by Brown (1988). The reading guide is used to capture unspoken or covert communication and the relationship between respondent and researcher. The reading guide systematically depicts how the researcher's subjective knowledge and personal history interact with the respondent's descriptions. Meaning is sought in the structure and the content of the text. First, I read for my response to descriptions of stigmatization experience. Second, I focused on the interviewee's point of view as she described her experience.

Adolescents' personal descriptions of stigmatization are accompanied by indirectly expressed feelings of shame and devaluation. The reading guide offers a method by which

I can annotate tone of voice, tempo, volume, phrase repetition, and subject change which communicate meaning beyond the actual words spoken. For example, referring to her disability, one student repeated, "I don't think about it, I don't think about it, I don't think about it." When I asked others about their disability, they changed the subject, clearly preferring to discuss hair care or peers' inadequacies. Annotating these features helps the researcher to distill evidence that she can use to interpret nonverbal communication about stigmatization. When I read for my response, I might note that "I think that repeated protestations may suggest an unwillingness to believe that the disability affects her experience, feelings of anxiety, and that she wants me to see her as someone who has things besides her disability to think about." In contrast, when I read for my respondent's view, I might note, "she doesn't think about her disability."

Clinical interviewing and these analytical methods allow me to listen for indirect descriptions of stigmatization experience so that I can translate verbal communication and symbolic process into forthright, open discourse.

### Results

In general, respondents described stigmatization as a force that corrupts the social context of their education and that compromises their opportunities for social integration and educational inclusion. They told of being excluded from social and school activities such as field trips, being ridiculed and teased, teachers assuming they could not perform tasks they had actually performed in other settings, and finding their safety jeopardized. Through these methods of analysis, three significant forms of stigmatization emerged: 1) Insensitivity was described as experiences in which positive views of themselves and their abilities were challenged by another's misguided words, questions, or actions. Often this happened when an authority figure assumed that the respondent was less capable than her peers and generally displayed ignorance about the coping skills of people with disabilities. For example, Sheila reported that a teacher had wanted to exempt her from doing math problems at the blackboard and assumed that she was not entitled to walk from her seat to the board like other students. 2) Harassment was described in terms of repeated experiences that left respondents feeling intimidated, personally violated, denigrated, and under attack. The attacks could be physically violent as well as verbally and emotionally threatening. For example, Joe described encountering a group of boys who nearly pushed him down the school's stairs and called him "handyboy." 3) Discrimination occurred when respondents were treated in ways that were both unfair and different than their peers. The rules and policies of educational and other institutions were cited as factors leading to this unequal treatment. Respondents' descriptions of discrimination demonstrated a denial of rights and opportunities, social rejection, and educational exclusion. For example, Don described being offered less pay than others without disabilities and not being allowed to evacuate the building with peers during a bomb scare. He said this happened because he uses a wheelchair. All the respondents related stigmatizing treatment to the disability or to another stigmatizing mark.

## References

- Brown, L. (Ed.). (1988). A guide to reading narratives of conflict and choice for self and moral voice (Monograph I). Cambridge, MA: Harvard University Graduate School of Education, Center for the Study of Gender, Education, and Human Development.
- Faibisch, L.H. (1992). A literature review examining the effects of social attitudes on the education and psychological development of adolescents who are blind. Qualifying paper, Harvard University Graduate School of Education.
- Faibisch, L.H. (1995). Insensitivity, harassment, and discrimination: A hostile social, psychological, and educational climate for adolescents with physical disabilities. Unpublished doctoral dissertation. Harvard University Graduate School of Education, Cambridge, MA.
- Merriam, S. (1988). Case study and research in education: A qualitative approach. San Francisco, CA: Jossey-Bass.
- Miles, M., & Huberman, A. (1984). Qualitative data analysis: A sourcebook of new methods. Newbury Park, CA: Sage Publications.
- Miller, B. (1991). Adolescents' relationships with their friends. Dissertation, Harvard University Graduate School of Education.
- Strauss, A., & Corbin, J. (1990). Basics of qualitative research: Grounded theory procedures and techniques. Newbury Park, CA: Sage.
- Tolman, D. (1992). Voicing the body: A psychological study of adolescent girls' sexual desire. Unpublished doctoral dissertation, Harvard Graduate School of Education.

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## **New Representations of Disability in the News: The Americans with Disabilities Act Makes its Mark**

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The Americans with Disabilities Act represents a paradigm shift in the way U.S. society will understand and deal with disability in the future. Slowly, this new disability rights oriented perspective is pushing its way into public discourse, and this is reflected in news media. This content analysis, therefore, looks at how news coverage of the ADA in major U.S. newspapers and news magazines (n=524) compares with previous analyses of media portrayals of people with disabilities and their issues.

This study represents, in part, an extension of Clogston's (1989, 1990, 1991) work on representations of disability in the news media. He developed five media models which can be used in content analyses of news coverage of people with disabilities and disability issues. For analysis of the ADA coverage, however, this study developed three new models to add to Clogston's five.

The three new media models of representation are the business model, the legal model, and the consumer model. A story within the business model focused on the perceived hurtful effect of the Act on U.S. business concerns. Within the legal media model, the Americans with Disabilities Act and other laws are presented as legal tools to halt discrimination. In the consumer model, people with disabilities are shown to represent an untapped consumer group. These new models of representation of disability in the media more accurately reflect the newer themes found in news stories about the ADA. (See Table 1.)

**Table 1. Prevalence of Models in ADA Print Stories\***

<b>(n=524)</b>	<b>Prevalent</b>	<b>Evident</b>	<b>Not Evident</b>
Minority/Civil Rights Model	27.1%	30.3%	42.6%
Business Model	15.5	34.7	49.8
Legal Model	21.6	27.7	50.8
Consumer Model	15.1	22.3	62.6
Social Pathology Model	.4	6.1	93.5
Medical Model	0	5.3	94.7
Supercrip Model	0	3.4	96.6
Cultural Pluralism Model	.2	2.5	97.3

**\* Several models may be represented in one story.**

The findings of this study revealed the representations of the eight models in print stories about the ADA. Most of the stories contained elements of Clogston's minority/civil rights model or the three newer models. The more paternalistic themes, typical in many earlier news stories about disability, seemed to fall away in press coverage of the ADA. New narrative frames are making their way into stories about the ADA.

In addition, several questions from an in-depth British study of disability in factual programs (Cumberbatch & Negrine, 1992) were replicated in this content analysis. The comparative findings on these questions were found to be similar, even though the stories on the ADA are a specific type of news story, and the British study assessed all types of non-fiction programming mentioning disability. The civil rights narrative shone through once again in the ADA stories.

### References

- Clogston, J.S. (1991). Reporters' attitudes toward and newspaper coverage of persons with disabilities. Unpublished doctoral dissertation, Michigan State University.
- Clogston, J.S. (1990). Disability coverage in 16 newspapers. Louisville, KY: Advocado Press.
- Clogston, J.S. (1989, August). A theoretical framework for studying media portrayal of persons with disabilities. Paper presented at the Annual Meeting of the Association for Education in Journalism and Mass Communication, Washington, DC.
- Cumberbatch, G., & Negrine, R. (1992). Images of disability on television. London, England: Routledge.

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## Section III

### Educational Access

Educational access issues in the United States are compared to southern Africa and show us that we must be flexible in designing educational models to best meet the diverse needs of students. Susan Peters of Michigan State and Kuzvinetsa Peter Dzvimbo of Rand-Afrikaans University studied the idea of inclusive education in Michigan versus southern Africa. They found that the African social structure based on the extended family allowed for more flexibility and integration than the U.S. system, which is focused on segregation by age. Political factors also affect education issues. Both countries are trying to advance the educational rights of people with disabilities through changing laws. Their findings illustrate that perceived "weaknesses" of the African system are actually strengths because they provide flexibility and social support, and the U.S. focus on universal access needs must be evaluated for its impact on disenfranchised African-American youth, of whom a disproportionate number are labeled as learning disabled.

A crucial part of access to education is proper assistive technology. Mary Cortina of the National Center for Disability Services reports on a project designed to put more assistive technology in the classroom for young children, ages 5-10, in New York City's District 75. The results show that properly training the teachers to use technology in the classroom leads to comfort with the technology and better incorporation of the technology into curricula. In terms of computer use by the children, Cortina's findings suggest that students need more one-on-one computer assistance and simpler software. In addition, she found that software could be used to develop social skills in students with emotional disturbances, and software could be taught in a more structured way. In terms of augmentative communication devices, students need personal aids, use of non-electronic aids, and use of devices all day. The final goal of the project is to implement these changes in technology policies and practices district-wide.

Another way in which people with disabilities are denied access to educational experiences is lack of access to basic material about schools, colleges, universities, and graduate programs. Rhoda Olkin of the California School of Professional Psychology took on the task of assessing whether deaf persons can gather the information they need about graduate schools in clinical psychology. She worked from the assumption that deaf persons may be under-represented at APA-accredited psychology programs because of lack of information through TTY communication. Of the 220 programs in the United States, she found that 70 schools had no TTY or one that did not work. However, in 182 of the schools, the only way to obtain a TTY number was by first calling a general voice number for the school. Only six of the schools sent the TTY number with application materials. This shows that graduate schools are not making themselves fully accessible to deaf persons, thus throwing up obstacles to deaf persons becoming psychologists in the United States.

## Inclusive Education in Cross-National Perspective

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Kuzvinetsa Peter Dzvimbo, Ph.D.  
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### Introduction

This paper compares/contrasts the contexts in which educational opportunities for people with disabilities are initiated, developed, and implemented in two settings: professional development schools in mid-Michigan, and governmental schools in Southern Africa. The presenters explore cultural, social, and political factors which inhibit or enhance Inclusive Education for people with disabilities in these settings. While the population in both regions is almost exclusively students of color (African-American and Black South-African) with similar disabilities, the outcomes are very different, pointing away from a model of Inclusive Education toward multiple approaches with emphases on context and the need to recognize diversity in what has traditionally been perceived as a "homogenous" population of students.

### Cultural Factors

In the Southern African region as a whole, access to education for people with disabilities has its historical roots in attitudes toward disability. The words for disability in Shona and Ndebele (*chirema* and *isilima*) mean stupidity and inability to function. When educational opportunities were introduced (in the 1920's for people who are blind, and in the 1940's for people who are deaf), the services were mainly offered in residential institutions, which were viewed as essentially custodial. Vast distances meant segregation from family members. Few were lucky enough to gain entry, as few slots were available. When the idea of Inclusive Education was introduced, the disability group first targeted constituted blind individuals, as they were most prevalent in number. Still, this opportunity was reserved for the elite few whose parents had the economic means and aggressive attitude as well as a commitment to the importance of education.

In mid-Michigan and in the U.S. in general, people with disabilities are looked upon similarly as *chirema*, although Americans are "sophisticated" enough to avoid these terms outright. Disproportionate numbers of African-American students are labeled learning disabled and are serviced in general education schools, but for the most part in self-contained classrooms (Lipsky & Gartner, 1996). These students are indeed needy--often for reasons beyond the control of schools. They often come from "disadvantaged" homes, both economically and emotionally. U.S. school personnel struggle to create safe environments that develop appropriate expectations for students. In Southern Africa, schooling is a privilege that must be earned. In the U.S., it is a right that must be given.

As a result, student motivation is a significant concern in U.S. schools, involving concentrated efforts on the part of U.S. teachers. In Southern Africa, teacher concerns center on resources in support of those who gain access to education.

In sum, cultural factors play a very influential role in the purpose of education, access to education, and the instructional issues teachers face.

### Social Factors

Societal infrastructures determine many aspects of education for people with disabilities. In the South African region, four disability groups are recognized: mental impairment, physical handicap, blind, and deaf. In the U.S., there are at least fourteen disabilities recognized by law. This discrepancy is largely due to the presence/absence of trained personnel to diagnose and assess a disability. Students with learning disabilities and ADHD are largely "nonexistent" in Southern Africa because few are trained to diagnose these disabilities. By contrast, learning disability is the largest group of disabled students in the U.S. (Lipsky & Gartner, 1996).

Another social issue specifically involving Inclusive Education is the emphasis in the U.S. on socialization in classrooms. This concept is foreign to Southern Africans, as the entire society is built on the notion of extended family. The U.S. operates on the notion of the nuclear family. These contrary societal networks play out differently in educational terms. Specifically, on one occasion Peters observed a sixteen year old blind student in a first grade Southern African classroom. She commented that in the U.S. students were placed in age-appropriate classes. The response from the teacher was, "In our country, we ask the student which they would prefer."

Overall, the U.S. notion of socialization and its social infrastructure tend toward more segregation and inflexibility than the Southern African system.

### Political Factors

In general, the U.S. system of education tends to focus on litigation and legal mandates for educating people with disabilities. The Southern African region seems to be following suit with White Papers and the introduction of laws advancing the educational rights of people with disabilities. However, in both cases, political mandates will not work unless cultural norms and societal infrastructures are taken into account.

### Implications

Southern Africa and the U.S. could learn much from each other by critically analyzing the strengths and weaknesses of each system. Southern African "weaknesses" in terms of limited infrastructure and cultural predilections are actually their greatest strength—for example, the presence of extended social networks and the absence of a rigid infrastructure provide a platform for Inclusive Education to flourish. The U.S. "strength" in universal

access and diagnosis/intervention could benefit from (re)scrutinizing the goals and relevance of education to its disenfranchised African-American youth.

#### Reference

Lipsky, D.K., & Gartner, A. (1996). Inclusive education and school restructuring. In W. Stainback & S. Stainback (Eds.), Controversial issues confronting special education (pp. 3-15). Needham Heights, MA: Allyn & Bacon.

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# Technology Information and Education Systems: Project TIES

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This paper reports preliminary findings of a three-year research and demonstration project designed to: a) evaluate the programmatic use of assistive technology by young children (five to ten years old) with severe disabilities; b) identify barriers to the integration of assistive technology in classroom activities; and c) enhance District 75's ongoing technical assistance system for teachers and administrators. Findings suggest the following: 1) District 75 has successfully incorporated assistive technology in the classroom; and 2) there are still needs for more one-on-one assistance for students using the computer lab, for additional hardware adaptations and alternatives to the physical environment of the computer lab, for additional simpler software--especially that which emphasizes cause and effect, for more personalized augmentative communication devices, and for teachers of children with severe behavior problems to explore the use of non-electronic communication aids and techniques.

## Introduction

Research has shown that there is a wide array of technology available that can enhance the educational opportunities of children and adults with disabilities. However, studies have also documented that individuals with disabilities, service providers, and teachers often do not receive adequate information and training concerning technology (Dederer, Ellis, Thompson, Cunningham, Lam, & Chan, 1991; Romich, 1991). A report by the National Council on Disability, "Financing of Assistive Technology Devices and Services for Individuals with Disabilities," emphasized the following difficulties: 1) lack of standardized eligibility requirements across programs to determine needs; 2) inconsistent, fragmented information; and 3) lack of knowledge about individual rights to technology. These gaps in availability of technological resources and in their use by individuals for whom they were designed is especially critical because legislation, i.e., P.L. 102-119, the Individuals with Disabilities Act (IDEA), requires that assistive technology solutions be incorporated into the educational programs of students with disabilities.

Research has identified technology integration as an informational process involving four interrelated components: administrative decisions, human resources, material resources, and classroom instructional applications. The integration of technologies into special education is as much a managerial and organizational-developmental task as it is a technical issue (Livesay & Murray, 1992).

This report summarizes preliminary findings regarding the use and integration of adaptive technology in seven schools in New York City.

## Background

The Research and Training Institute (RTI) of the National Center for Disability Services, in collaboration with New York City's District 75/Citywide Programs, conducted a three-year project to identify factors that inhibit/promote the use of assistive technology in the classroom, inhibit/promote effective policy on assistive technology, and improve training and collaboration among teachers and service providers. District 75/Citywide Programs is a special education district created by the New York City Board of Education to service a population consisting of over 17,000 students with low incidence disabilities. It consists of over fifty schools and 250 sites. District 75 provides training services to teachers, administrators, parents, and students on the use of leading-edge assistive technology, along with resources and equipment.

## Method

The only criterion for participation in the study was that students were between the ages of five and ten. However, it was later decided to limit the participation of schools to those in Manhattan and Queens (for time and travel reasons only). A random selection of schools within these two areas was not possible because the District could not require schools to participate. Therefore, the Director and Training Coordinator of Technology Solutions (District 75) invited schools in Manhattan and Queens (with students that met the age criteria) to attend a meeting at which the project was presented. Representatives from seven schools attended the meeting, and all seven schools agreed to participate. A total of 234 students, 37 teachers, and 15 speech teachers participated in the study. Although the schools were not chosen at random, the children were typical of the students the District serves. Students were classified into disability categories based on their physical and cognitive functioning. The children in the project were classified into the following: autistic, emotionally disturbed, or severely emotionally disturbed, or as having severe physically-disabling conditions and other health impairments. The children's communication abilities ranged from non-symbolic to moderately disordered.

A variety of instruments were used to collect data, including the following: review of all IEPs, surveys of teachers, surveys of parents, structured interviews with unit coordinators and administrators, structured interviews with classroom teachers and speech therapists, observations of children using augmentative communication devices in a variety of settings, and observations by the project Technology Team<sup>1</sup> of children using computers either in their classrooms or in a computer lab.

The teacher surveys (n=37) were used to collect data regarding types of computer/technology training they had received from the District, their evaluation of the training, their comfort level with and knowledge about computers and assistive technology, their ability to integrate computer use within the classroom curricula, the

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<sup>1</sup> The project Technology Team consisted of a rehabilitation technology specialist, an occupational therapist/assistive technology specialist, and a speech language pathologist who specialized in augmentative communication.

support or lack of support given as they integrated technology, and their needs for the future. Interviews with unit coordinators and administrators (n=19) were designed to assemble data about the set-up of the classrooms and/or computer labs; attendance in computer lab; determinants of computer usage; decision-making concerning hardware/software purchases; and, finally, their perceptions of the barriers to using technology in the classroom.

Interviews with classroom teachers (n=27) and speech therapists (n=15) were conducted by the project speech language pathologist to gather detailed information regarding students' speech, use of augmentative devices, types of augmentative aids used, activities and times during which devices were used, vocabulary programmed, how devices were purchased, and how decisions were made as to which children would receive aids and which aids would be selected.

Computer observation forms were developed to gather data on the physical environment, the hardware and software in use, and the barriers to student use of hardware/software. These were classified in terms of how children responded to the software, if adaptations were needed for access/understanding, whether adaptations were provided, and how adaptations were utilized.

Observations of students using augmentative communication devices were conducted to record and verify information about the conditions under which devices were used, and to make recommendations to improve the selection and use of augmentative communication aids by teachers and students.

## Results

The District's goal was to provide assistive technology, i.e., computers, augmentative aids, and computer access devices, for its students and training for its teachers as they attempted to integrate technology in the classroom. How successful was the District in meeting these goals? Most of the teachers surveyed had received training, teachers were positive about the training, and they felt the training was of high quality and helped them to set goals for their students. As a result of the training, they felt more knowledgeable about and comfortable with computers, and better able to incorporate technology into their curricula. Their needs for the future were more training and more appropriate software to meet the needs of their students.

The computer room observations revealed that students used a variety of software, i.e., Kidpix, Living Books, Muppets on Stage, and Thinking Things. During most classes, students were able to choose from a menu the programs they wanted to use. For some students, especially those classified as autistic or emotionally disturbed, this proved to be distracting. Children classified as having severely disabling conditions with cognitive delays required a great deal of physical assistance to access the computers, and full assistance to operate the software. In general, many of the children, even if they could manipulate the software independently, did not appear to understand what the software required of them. Each school had its own methods for presenting computers (computer

lab versus computers in the classroom), selecting software, presenting software (free choice versus teacher control), deciding which classes would use computers (usually based on cognitive level of students), and determining who would be responsible for the purchase and distribution of technology.

Only a small percentage of students (17%) had functional speech. These students were provided with programmatic aids.<sup>2</sup> The most frequently cited reason for not furnishing an augmentative aid for a student was that he/she was developing functional speech.

### Discussion

This project attempted to document District 75's accomplishments and needs regarding the integration of assistive technology and to make recommendations as to how the District could maintain high quality services for its teachers and students. Recommendations were developed based on the data collected by surveys, interviews, and observations, and were designed to be specific to a school and its students. In general, computer presentation/use recommendations were: 1) to provide more one-on-one assistance for students as they use computers, especially in a lab setting; 2) to provide simpler software packages, emphasizing cause and effect, and other simple switch software; 3) to use software to promote social skills among students categorized as emotionally and severely emotionally disturbed; 4) to explore the use of additional hardware adaptations; 5) to explore physical alternatives within the computer lab, i.e., more accessible computer room furniture, the placement of a computer with CD-Rom in an alcove; and 6) to explore the presentation of software in a more structured manner.

The following recommendations were proposed concerning the use of augmentative communication systems: 1) to provide more personal aids for students; 2) to explore the use of non-electronic aids and techniques for students with behavior problems; 3) to use classroom aids throughout the course of the day; and 4) to explore modifications of classroom aids to meet the personal needs of students.

This project is in its third and final year. These suggestions have been presented and are being considered by the District and the participating schools. Project staff will collaborate with each school to make modifications (if necessary) and to implement the recommendations. The final project goal will be to evaluate how change in policies and practices is conducted at the level of the District and the individual school, and to assess the impact of these recommendations on the functioning of the student.

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<sup>2</sup> Programmatic aids are electronic and non-electronic augmentative communication aids that are owned by the District, shared by students, and programmed with vocabulary to allow participation in specific activities during specific times.

## References

- Dederer, T., Ellis, T., Thompson, R., Cunningham, J., Lam, D., & Chan, F. (1991). Utilization of assistive technology in state vocational rehabilitation: A needs assessment. Rehabilitation Education, 5, 265-292.
- Livesay, M.J., & Murray, P.E. (1992). Integration of instructional technology into special education: An organizational process model. Technology and Disability, 1(1), 7-18.
- Romich, B. A. (1991). Augmentative communication, 1991. Exceptional Parent, 21(1), 24-26.

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## **You Don't Call Me--and I Can't Call You: Graduate Schools of Clinical Psychology and TTY Phone Numbers**

**Rhoda Olkin, Ph.D.  
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Graduate psychology programs are required to accommodate "otherwise qualified" individuals with disabilities, including those who are Deaf.<sup>1</sup> Such accommodations are appropriate not only for Deaf students, but for applicants as well. For Deaf applicants, in particular, the early communication process with the school and program may have considerable impact on the potential applicant's decision to apply. The following assumptions might be made: (a) Deaf applicants are underrepresented in APA-accredited clinical and counseling psychology programs; (b) Any application processes that add an extra burden on a group of applicants will reduce the number of completed applications from that group (in this case, those who are Deaf).

The purpose of the present study was to ascertain how many APA-accredited graduate programs in clinical and counseling psychology had TTY (teletype machine, used for communication between Deaf and hearing persons or between Deaf people) phone numbers. A deceptively simple question, it required four methods of obtaining information and over two years to find answers to it.

This study was an offshoot of a serendipitous finding from a previous, larger study on the application process (from a disability perspective) to APA-accredited clinical/counseling programs. That study found that a paper search of application materials sent in response to routine inquiry yielded only six programs at five schools that had a TTY phone number listed. However, does not having a TTY number listed mean that a school or program does not have a TTY?

The present study examined this question by using four methods of obtaining TTY numbers for APA-accredited programs and the schools in which these programs were housed. It then examined what happened when each number was called.

### **Method**

Four methods of obtaining TTY numbers at the 220 schools with APA-accredited clinical/counseling psychology programs were used.

The first method was the above-mentioned paper search from application materials. The second method was to call voice information (area code plus 555-1212) and to request the

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<sup>1</sup> The term Deaf, with a capital "D," is used to denote those who are culturally deaf and whose primary language is ASL.

TTY listing for each program/school. The third method was to call TTY information (area code plus 855-1155) and to request the same information. The fourth method was to call, using voice, the school's main number and to request any TTY listings for the APA-accredited program(s), and, if lacking, for any other campus TTY listings.

Once a 4 x 220 (methods x school) table of all numbers obtained was formed, each TTY number identified was called using a TTY line. Results of such calls were tabulated according to whether a number was accurate, if a call was able to be completed solely through TTY, and what happened if voice was necessary to complete the call.

### Results

There was great variability across methods in how many TTY phone numbers were obtained. Total number of TTY phone listings obtained for each of the four methods were: 6 by method one (paper search); 47 by method two (voice information); 63 by method three (TTY information); and 182 by method four (calling school using voice).

None of the numbers obtained from any method were to the Psychology Department or the School of Education, much less to the APA-accredited clinical/counseling program. Most numbers were to Disabled Student Services, with the rest to a main operator number. Many programs (70) either did not have a TTY on campus or had one that did not work (e.g., not plugged in, no one knew how to use it, could not locate it, etc.).

What happens when one calls a TTY number? In most instances it was necessary to use voice. There were only about two dozen places that could be called successfully (i.e., without voice, TTY answered at other end). Most schools now rely on their state's relay service, though not all schools knew to make this referral.

Attempting to call via TTY clearly flustered some phone call receivers. In response to the (voice) inquiry about why the TTY was not working, many respondents said that it was not plugged in, the person who knew how to work it was out that day, no one knew how to work it, or there was no need for a TTY because no Deaf person ever called. Four people offered to turn up the volume on the regular phone! The process also frustrated us; it took an average of 2.25 transfers to obtain the TTY number by calling the school.

### Discussion

This study examined only one small aspect of the application process--the ability to call the school with questions, requests, or other communications. However, this part suggests that doors, or at least phone lines, are not fully open to Deaf applicants. Although it is now true (since the passage of the Americans with Disabilities Act, 1990) that each state has a relay service, this is not the same as direct applicant-program contact. An analogy might be that it is akin to getting email through a third party; the content remains, but the personality and flavor of the sender is missing. This impersonal quality is particularly troublesome because of the greater emphasis in the Deaf culture on personal contact and direct communication. Thus, lack of direct access to programs might constitute a

significant barrier to recruitment of Deaf applicants, coming at an initial step, before even considering other obstacles to increasing representation in psychology of people who are Deaf.

### Author Notes

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## Section IV

### Work Accommodation

We all understand the problem of unemployment in the disability community, but this is not just a U.S. phenomenon. Regina Pernice of Massey University in New Zealand studied employment commitment and its connection to mental health. She found that more people with disabilities than without wanted jobs or training. People with disabilities also said they had fewer alternatives to employment. However, over time, people with disabilities had a decreased interest in obtaining a job or training, but this lower employment commitment was accompanied by more emotional distress. Her results show that having alternatives to employment was linked to higher self esteem and lower distress scores. People with disabilities who wanted employment and did not get it and those who saw themselves as unable to work had poorer mental health. Pernice advocates that unemployed people who cannot find jobs should work in constructive alternatives, which will help their emotional health. And people who feel unable to work should receive supports to improve their mental health, which may improve their confidence to obtain work.

Many people with disabilities become disabled from their work, and Laura Trupin and Timothy Armstrong, both of the Disability Statistics Rehabilitation and Research and Training Center, explain how work disabilities intersect with unemployment and part-time work. The unemployment rate for people with work disabilities is about 10%, which is twice that of people without work disabilities. Age is a significant factor because, regardless of disability status, 18-24 year olds have the highest rate of unemployment. Part-time employment is more prevalent among people with work disabilities (25%), compared to people without (17%). Other factors that further increase frequency of part-time work for those with work disabilities are being male, being aged 55-64, being African American, having no high school diploma, or being divorced or separated. Trupin and Armstrong explain that the high incidence of unemployment and part-time work among people with work disabilities leaves them with several negative economic factors: low wages, no health insurance or poor insurance coverage, and ineligibility for unemployment insurance. For ethnic minorities or people with lower education, these factors add to already high unemployment rates. Trupin and Armstrong conclude that "people with work disabilities tend to have a less secure position in the labor market than the overall population" (p. 92).

Nancy Mudrick of Syracuse University further delineates the definition of a work disability and its impact on measuring work behavior and employment among people with disabilities. The definition of work disability comes from national surveys that ask about conditions that might limit kind or amount of work. Mudrick says the work disability construct is problematic because it focuses on performance, not on physical condition, in identifying disability. It may not apply to someone who can work despite a chronic disabling condition. It also does not distinguish work from occupation. Some conditions

may not prevent work but may prevent participation in a chosen occupation without accommodation. Mudrick says the Americans with Disabilities Act has helped to expand the definition of disability away from impairments and toward general work behavior. Mudrick suggests that the measurements must expand beyond looking at only the work limits, and should focus on the working environment and working circumstances to better understand accommodations, attitudes, and differences among occupations.

Since the passage of the Americans with Disabilities Act, NIDRR has provided technical assistance in helping people understand the ADA mandates in terms of the employment of people with disabilities. Raymond Glazier and Miriam Hertz of Abt Associates explain the results of this empowering initiative. The initiative has ten regional assistance centers, several national training projects, and several training materials development projects. From 1992 to 1995, the regional centers conducted 4,717 ADA training events and provided training to 215,780 participants across the country. The largest category of trainees were employers and business people. During the same time period, the centers assisted 400,408 people by answering ADA questions on its 1-800 line. Employers and businesses were once again the most frequent callers. The centers also distributed 2.3 million copies of ADA publications. Glazier and Hertz's findings illustrate that the word is getting out about employment accommodations, and businesses seem to be taking compliance seriously, as evidenced by their high participation in the NIDRR programs.

## Employment Commitment and Mental Health of Unemployed Persons with Disabilities

Regina Pernice, Ph.D.  
Massey University

As a Senior Lecturer at Massey University in the Department of Rehabilitation Studies in a small city in New Zealand called Palmerston North, it was a great pleasure for me to attend the 1995 Meeting of the Society for Disability Studies in Oakland, California. My presentation focused on a study of long-term unemployment.

In 1989 when I started the study, the number of unemployed people in the general population had risen to 13%, whereas the unemployment rate for people with disabilities was approximately 41%. In a survey commissioned by the Department of Labour, people with disabilities in New Zealand were found to want to work, with an estimated desired labour force participation rate of 89.5% for males and 74% for females (Stroombergen, Miller, & Jensen, 1991). This compared favourably with estimates of desire for labour force participation in the general population of 86.5% for males and 65.3% for females. In this study, participants were on unemployment benefits and, therefore, were registered with the New Zealand Employment Service. This implied that they were of working age and were actively looking for a job. Unemployment benefit is received when a person with a disability either has never had a job or has lost his/her job after an illness or accident, but he or she has been found fit to go back to work by a doctor.

This study investigated, both in 1989 and 1990, employment commitment and its relationship to mental health. Of particular interest were the questions: 1) What is the level of employment commitment and mental health of people with disabilities, and do they differ from those of able-bodied persons? 2) Does employment commitment and mental health change over a one-year period?

### Method

#### Sample

There were 25 people with disabilities and 52 people without disabilities participating. Their average length of unemployment in 1989 was 29 months; in 1990 this had increased to 41 months.

#### Employment Commitment

This was measured by five questions in a questionnaire, such as "Do you want a job?"

### In-Depth Self-Selection Interview

In a two-hour interview the questionnaire questions were reviewed and discussed. During the interview, participants made statements about their attitudes toward employment, such as: "I hate to be on the dole," or "I don't want a job just now. I am interested in training." These qualitative data were recorded, coded, analysed, and categorized according to procedures outlined by Strauss and Corbin (1990). Four employment attitude groups emerged: 1) wanting employment, 2) not able to work, 3) having alternatives to employment, and 4) interested in training. Then each person was presented with the list of statements made by 40 participants of a pilot study that had been grouped under the above four headings. Each participant in this study was asked to choose the group that would most accurately reflect his/her own attitudes. The group headings were excluded during this process. Therefore, the 77 participants of this study self-selected themselves into four employment commitment groups.

### Mental Health

Two validated instruments were used to measure mental health. The General Health Questionnaire (GHQ-12) (Banks, Clegg, Jackson, Kemp, Stafford, & Wall, 1980) measured distress and affective well-being. The Rosenberg Self-Esteem Scale (RSE) (Rosenberg, 1965) measured self-esteem.

## **Results**

### 1989 Percentages in Employment Commitment Groups

In 1989 more people with disabilities than persons without disabilities wanted jobs (32% vs. 21%) or training (24% vs. 17%). Fewer people with disabilities chose to portray themselves as having a satisfactory alternative to employment (12% vs. 31%).

### 1989 Mental Health (GHQ-12 and RSE)

There were no significant differences among the GHQ-12 and RSE scores of the four attitude groups among people with disabilities, in contrast to the able-bodied groups, who showed significant differences in both measures between those not able to work and those having alternatives.

Table 1. 1989 With Disabilities (n=25)

Employment Commitment Groups	Percent of total <sup>1</sup>	GHQ-12 <sup>2</sup>	RSE <sup>2</sup>
Wanting employment	32	18	40
Not able to work	32	17	38
Alternat. to employment	12	14	38
Interested in training	24	11	38

<sup>1</sup>X<sup>2</sup> (3, n=25) = 22, p<.001 with expected frequencies of 70, 10, 10, 10.

<sup>2</sup>Mean separation within columns by SNK. Unmarked columns have no significant difference.

Table 2. 1989 Without Disabilities (n=52)

Employment Commitment Groups	Percent of total <sup>1</sup>	GHQ-12 <sup>2</sup>	RSE <sup>2</sup>
Wanting employment	21	11 ab	39 ab
Not able to work	31	15 b	36 a
Alternat. to employment	31	9 a	41 b
Interested in training	17	12 ab	41 ab

<sup>1</sup>X<sup>2</sup> (3, n=52) = 65, p<.001, with expected frequencies 70, 10, 10, 10.

<sup>2</sup>Mean separation within columns by SNK. Means followed by the same letter are not significantly different at p<.05.

#### 1990 Percentages in Employment Commitment Groups

In 1990 the percentages of people with disabilities who wanted a job and of people who wanted training decreased (32% vs. 16%, and 24% vs. 4%, respectively), and the percentage of those who had an alternative to employment increased (12% vs. 40%).

Table 3. 1990 With Disabilities (n=25)

Employment Commitment Groups	Percent of total <sup>1</sup>	GHQ-12 <sup>2</sup>	RSE <sup>2</sup>
Wanting employment	16	19 b	39 ab
Not able to work	40	19 b	34 a
Alternat. to employment	40	8 a	41 b
Interested in training	4 (1 person)		

<sup>1</sup>X<sup>2</sup> (3, n=25) = 56, p<.001, with expected frequencies 70, 10, 10, 10.

<sup>2</sup>Mean separation within columns by SNK. Means followed by the same letter are not significantly different at p<.05.

#### 1990 Mental Health (GHQ and RSE)

The above change in choice of employment commitment groups was accompanied by significantly lower GHQ-12 and higher self-esteem (RSE) scores in those who had alternatives to employment and those who were interested in training, than in those who wanted a job and in those who were not able to work. The same trend both in change of choice in employment commitment groups and in level of GHQ-12 and RSE scores was observed in the unemployed without disabilities sample.

Table 4. 1990 Without Disabilities (n=52)

Employment Commitment Groups	Percent of total <sup>1</sup>	GHQ-12 <sup>2</sup>	RSE <sup>2</sup>
Wanting employment	15	15 b	37 a
Not able to work	31	16 b	35 a
Alternat. to employment	46	7 a	42 b
Interested in training	8	12 ab	42 ab

<sup>1</sup>X<sup>2</sup> (3, n=52) = 113, p<.001, with expected frequencies 70, 10, 10, 10.

<sup>2</sup>Mean separation within columns by SNK. Means followed by the same letter are not significantly different at p<.05.

## Summary of Results

### Employment Commitment

Unemployed people both with and without disabilities chose to self-select into four employment commitment groups. During one year, the percentage of people wanting employment and wanting training decreased. The percentages of people having alternatives to employment increased. The percentages of people who felt unable to work stayed the same.

### Mental Health

Having alternatives to employment was linked to positive mental health, that is, low distress scores and higher self-esteem. Poor mental health was evident in those who wanted employment (but did not get it) and those who considered themselves unable to work.

## Conclusion

People with low employment commitment self-selected themselves into two groups. One group had alternatives to employment with positive mental health; the other group felt unable to work and had very low mental health, that is, both high distress scores and low self-esteem. This pattern in employment commitment and mental health was similar in people with and without disabilities.

Why would the majority of people interviewed give up looking for a job? I interviewed all 77 people who had been out of work for nearly three years, and I found two very different reasons for this. Some had worked out satisfactory alternatives to formal employment. For example, one person had lost a leg in an accident and could not be reemployed in his old job. Given the unemployment levels, he gave up looking for a job and joined the local Disability Centre. He initiated the publication of a newspaper called "DisInformation." This paper is run by and published by people with disabilities on a voluntary basis to help inform other people with disabilities. These volunteers were active and self-reliant, and anecdotal evidence suggests that they had good mental health.

However, the employment commitment group who considered themselves not able to work, in addition to the common negative effects of being unemployed, expressed lack of confidence and lack of hope. Some of these people were quite young and had neither worked nor developed a work identity. They felt intimidated, overwhelmed, and unable to go into the job market. I interviewed some people with psychiatric disabilities, such as agoraphobia, depression, anxiety disorders, and eating disorders. The stresses of long-term unemployment may have pushed these people across the line between being able to cope and to hold a job, and having poor mental health.

Because these two groups of long-term unemployed were the majority, and only a minority wanted to work, it is clear that the New Zealand Employment Service needs to

change its approach. Given that there are fewer jobs than unemployed people, we as a society could consider it socially beneficial that some people with or without disabilities are well-adjusted and have constructive alternatives to a formal job. This may just require the extension of their income support rather than any other assistance programme. It is reasonable to expect people who are supported in this way to use their free time to be active citizens and to be helpful to their communities. Middle-aged and older people with a work history are probably better suited to do this and less susceptible than the young to the negative effects of a "welfare culture."

The main group which needs to be considered for appropriate government assistance is the group of those "not able to work" whose mental health has continued to deteriorate with long-term unemployment. Their immediate needs are for intensive professional counselling and therapy. With improved mental health, many in this group may have the confidence to seek employment in the future. Only then, could case management provide the appropriate assistance.

### References

- Banks, M.H., Clegg, C.W., Jackson, P.R., Kemp, N.J., Stafford, E.M., & Wall, T.D. (1980). The use of the General Health Questionnaire as an indicator of mental health in occupational studies. Journal of Occupational Psychology, 53, 187-194.
- Rosenberg, M. (1965). Society and the adolescent self-image. Princeton, NJ: Princeton University Press.
- Strauss, A., & Corbin, J. (1990). Basics of qualitative research: Grounded theory procedures and techniques. Newbury Park, CA: Sage Publications.
- Stroombergen, A.H., Miller, J., & Jensen, B. (1991). Estimates of the labour force and employment status of people with disabilities, 1990. Wellington, New Zealand: Business and Economic Research Ltd.

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## Disability, Unemployment, and Part-Time Work

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Disability Statistics Rehabilitation Research and Training Center

The need to monitor progress in employment access under the Americans with Disabilities Act (ADA) requires that we begin looking into the quality of the labor force experience of people with disabilities, beyond who is or is not in the labor force. This paper examines two aspects of this experience--unemployment and part-time work--comparing how people with and without work disability fare within a number of demographic and occupational groups. We present an analysis of the 1990-1991 Survey of Income and Program Participation (SIPP), a panel survey of approximately 60,000 participants who are interviewed every four months for two and a half years (U.S. Dept. of Commerce, 1991). Estimates represent the 1991 U.S. non-institutionalized population, aged 18 to 64.

### Labor Force Estimates

Employment status was ascertained for the week containing the 12th day of the month, and then averaged over the year. Part-time work was defined as fewer than 35 hours per week. The rate of involuntary part-time unemployment (i.e., due to slack work or the inability to find full-time employment) was calculated as the proportion of all weeks with a job in which a person was involuntarily employed fewer than 35 hours.

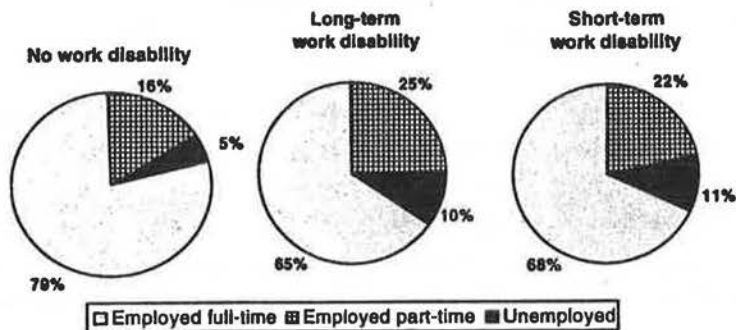
### Work Disability

In nearly every interview, respondents were asked if they had a physical, mental, or other health condition that limited the kind or amount of work they could do. Because this question had no time frame, there is noticeable fluctuation in responses over the course of the survey: six percent of the sample changed status during 1991. We focus here on participants whose responses were consistent during all 1991 interviews, i.e., people with long-term work disabilities, and those with no work disabilities.

### Unemployment

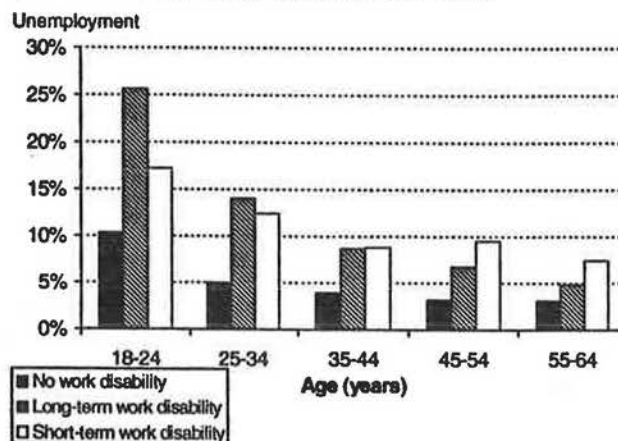
The unemployment rate for persons with long-term work disabilities was more than ten percent--about twice the rate of people who did not report a work disability (Figure 1). This pattern holds for men and for women, for Whites, Blacks, and Hispanics, for all marital status groups, and for most levels of education. Thus, in sectors of the population whose unemployment rates were already quite high, e.g., racial and ethnic minorities or high school drop-outs, unemployment rates among people with disabilities approached twenty percent. Among the most educated, however, the unemployment rates ranged between three and five percent, and did not differ significantly by disability status.

**Figure 1. Percent of Labor Force Employed Full-time, Part-time, and Unemployed, by Work Disability 1991 Status, Aged 18-64, SIPP**



Regardless of disability status, unemployment was highest among 18-24 year olds (Figure 2). However, it was more than 2.5 times as high in this age group for people with long-term disabilities than for those with no work disabilities. For 25-34 year olds, the unemployment rate was nearly three times higher for people with long-term work disabilities than for those without—fourteen percent and five percent, respectively. For people aged 35-44 and 45-54, the rates were about twice as high for those with work disabilities. Unemployment rates for 55-64 year olds, however, did not differ by work disability status. This may reflect a more secure position in the labor market among older workers with disabilities, or a higher proportion of labor force exits for this group than for 55-64 year olds without disabilities.

**Figure 2. Unemployment Rates by Age and Work Disability Status, SIPP 1991**



We divided the sample into six occupational groups: managerial and professional positions; technical, sales, and administrative positions; service sector occupations; skilled trades; laborer and operator jobs; and agricultural occupations. Both men and women with disabilities were more likely to be employed in occupations with high unemployment rates in 1991, indicating that higher unemployment rates among people with disabilities are somewhat attributable to the types of jobs they typically hold. However, some large differences by work disability status remained in occupation-specific employment rates. For example, men with work disabilities in service occupations had three times the unemployment rate of men without work disabilities in the service sector. Women with long-term disabilities in the managerial and professional occupations experienced four times more unemployment than their counterparts with no work disabilities.

### Part-Time Work

Part-time employment was more frequent among persons with a work disability; nearly 25 percent of those with a work disability were employed part-time, compared to 17 percent of persons with no work disability. For some segments of the population, including men, people aged 55-64, Blacks, those without a high school diploma, or people who were divorced or separated, the proportion of persons with work disabilities who worked part-time was more than twice that of persons without work disabilities.

Men with work disabilities were more likely to work part-time in all six occupational groups. More than 30 percent of men with long-term work disabilities who worked in the service sector worked part-time. For women, the differences by work disability status were much less pronounced, probably due to the higher rate of part-time work among women in general. However, in the managerial and professional occupations, nearly 40 percent of women with disabilities worked part-time, compared to 20 percent of women without disabilities.

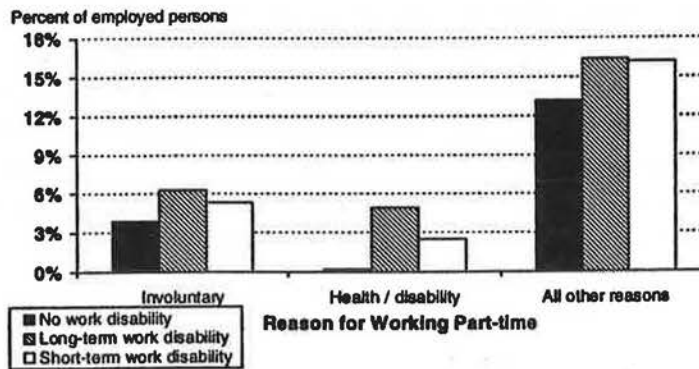
### Involuntary Part-Time Work

There were some differences by disability status in the reasons given for working part-time (Figure 3). About six percent of employed people with long-term work disabilities were involuntarily working part-time, compared to less than four percent of those without work disabilities. Twelve percent of workers without disabilities and fourteen percent of those with disabilities worked part-time for reasons unrelated to the labor market or to their own health or disability.

### Conclusion

High unemployment rates and high rates of both voluntary and involuntary part-time employment have negative implications for the overall economic well-being of persons with disabilities. Part-time jobs are likely to be low-wage and typically do not provide benefits, health insurance, or pensions, and part-time employees are often ineligible for unemployment insurance, due to minimum earnings requirements (Levitan & Conway, 1988). This is particularly problematic in the face of such high unemployment rates for

**Figure 3. Reason for Part-time Employment  
by Work Disability Status  
Percentage of All Employed Persons, SIPP 1991**



people with disabilities. The very high rates of unemployment in the younger age groups indicate that people with disabilities faced particular barriers to establishing a place for themselves in the labor market. For racial and ethnic minorities and for people who did not graduate from high school, the presence of a work disability served to compound already high unemployment rates. The experience of women with work disabilities in the managerial and professional occupations bears further investigation. Despite attaining high-status positions, they had particularly high rates of unemployment and part-time work relative to their peers without work disabilities.

In summary, most workers with long-term disabilities were either employed full-time or had chosen to work part-time for reasons other than their own disability. Nevertheless, higher rates of unemployment and involuntary part-time work indicate that people with work disabilities tend to have a less secure position in the labor market than the overall population.

### References

- Levitan, S.A., & Conway, E.A. (1988). Part-timers: Living on half-rations. *Challenge*, 31(3), 9-16.
- U.S. Department of Commerce, Bureau of the Census (1991). *Survey of Income and Program Participation (SIPP) 1990 Panel, Waves I - VII* [Computer files]. Washington, DC: U.S. Department of Commerce, Bureau of the Census [producer]. Ann Arbor, MI: Inter-university Consortium for Political and Social Research [distributor].

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## The Nature of Work Disability and Employment: An Overview of the Issues

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There is a wide range of meaning encompassed in the term *disability*. The lack of a uniform definition, and the difficulties associated with the various definitions currently in use have been commented upon by many authors (e.g., Albrecht, 1992; Brown, 1991; Haber, 1990, 1991; Reisine & Fifield, 1992). My intent is to describe how the definition of work disability has affected our ability to measure the work behavior and employment experiences of people with disabilities.

### Work Disability: A Basic Definition

Nearly all discussion of employment among people with disabilities, and virtually all empirical measurement of work behavior to date have used the concept *work disability*. As a result of the wide usage of this term, there is a large body of research and data built around this measure of disability. However, *work disability* as the major method for discussing disability among people of working age has limitations. These limitations are of increasing importance as both the disability rights movement and public policy in the area of income support seek to maximize the opportunities for continued paid work by people with disabilities.

The definition of work disability comes from the wording of a question that has been included in national surveys since 1966. Because most of the information about disability on a national level comes from these surveys, the wording of this question has had a key influence on how we discuss and study work disability in the United States. In fact, estimates of the size of the population with disabilities are often really estimates of the population with *work disability*. In these surveys, work disability is defined by asking the respondent whether he or she has *a mental or physical condition that limits the kind or amount of work a person can do, or which results in a person being unable to work*. All of the surveys use a format that includes the phrasing "limits the kind or amount" of work; some surveys additionally require that, in order to qualify the respondent as someone with a work disability, the condition be chronic or persistent. This is usually done by requiring that the limitation has had a duration of six months or more.

Even with a fairly consistent use of the term *work disability*, government surveys have obtained widely varying estimates of the population of people with disabilities. For example, the U.S. Census estimates that approximately 8.2% of working age people 16-64 are work disabled (U.S. Bureau of the Census, 1992), while the 1990 Current Population Survey (CPS) estimates the proportion at 9% (LaPlante, Miller, & Miller, 1992). The Survey of Income and Program Participation estimates that 11.5% are work disabled. These estimates are lower than the disability estimates obtained when information in

addition to the "kind and amount of work" answers are used to identify people with work disabilities. When receipt of Disability Insurance and Medicare are considered as well as the report of limitations in the kind or amount of work, the estimate of those with a work disability rises to 11.6% of the population age 16-67 (McNeil, 1993). If activity limitations are considered (Activities of Daily Living, Independent Activities of Daily Living, or other indicators of functional limitation), the estimate rises even higher to 17.9% of the population ages 15-64 (McNeil, 1993). One reason the estimates based on additional indicators are larger than the estimates produced by the work disability question is that not all people with a chronic condition or impairment report that it limits the kind or amount of work they can do. Haber (1990) points out that, in the 1978 Social Security Survey of Disability and Work, only 29% of those who reported an impairment defined themselves as work disabled.

The work disability definition is based on a framework published by Saad Nagi (1969) that conceptually separated the medical condition from its functional and disabling consequences. This framework has played a key role in support of the disability rights perspective of disability (as opposed to the medical model perspective). A model with three components--impairment, functional limitation, and disability--has evolved from Nagi's work. *Impairment* is defined as the chronic or permanent anatomical or physiological problem (i.e., health condition) that results from injury or illness (for example, paralysis or heart damage). *Functional limitations* are the restrictions or functional inability that result from an impairment (for example, the inability to climb stairs or to lift objects of more than 20 pounds). Finally, *disability* is defined as the consequence of functional limitation in terms of the activities of normal or expected roles. Although people have many different roles in their lives, it is the work role--and the ability to maintain the work role--that has been used most often to assess whether impairments and functional limitations are disabling. Someone who cannot maintain employment because of functional limitations is considered to be disabled. One implication of this model is that the determination of disability rests very much on the particular activities required by different roles--as well on the presence or absence of environmental barriers that support or impede (work) role performance. In this framework, two people with the same impairments and functional limitations can be rated differently in terms of disability. A college professor who experiences a loss of vision is not disabled, while a bus driver is. This outcome may be consistent with the Nagi framework, but it does not conform to "common usage." The professor who does not have vision is likely to describe himself as a person with a disability, even though he maintains his work role and productivity.

### Critique of the Work Disability Construct

While the work disability construct has been useful because it focuses on role performance, not medical condition, as a means of identifying disability, it is increasingly inadequate as the demand for information about the labor market experience of people with disabilities increases. This is because disability is only recorded if employment is limited or prevented by a chronic condition or impairment. Disability is *not* recorded if someone can work

without limitation despite the presence of a chronic condition or impairment. If an assistive device or employer accommodation results in the ability to work without limits to the kind or amount of work, then no disability may be deemed to be present. From one point of view, this may be an appropriate outcome--the presence of a disability is not noteworthy because it is not a relevant fact about the skills and value of the worker. From another point of view, it prevents us from knowing how many Americans have chronic health or other conditions--disabilities--and under what circumstances they seek, accept, and perform work in the labor force.

A second problem with the work disability construct is that it may not sufficiently distinguish work from occupation. That is, asked whether limited in the kind or amount of work they can perform, do respondents answer with reference to their usual occupation or kind of work--or work and occupations they could conceive of themselves as doing--or do they view this as asking about limitations to any kind of work? If you are a construction worker who works on high-rise buildings, it would not be unexpected if you report that a back injury limits the kind and amount of work you can do. However, do you report a work disability when the back injury has no impact on your work as a computer programmer, and you have never been a high-rise construction worker, and you never intend to become one? Do you report a work disability when you can do the work you wish to do with the aid of an accommodation--and when that accommodation is in place? The work disability construct may be very vulnerable to the attitudes, aspirations, life experiences, and opportunities of the respondents. Is it possible that a change in the distribution of occupations could affect the measured prevalence of work disability?

The Americans with Disabilities Act has provided additional reasons for dissatisfaction with the way work disability is defined and measured. The ADA identifies its target as people "with disabilities." These are people with *physical or mental impairments that substantially limit a major life activity*. This language is similar to the work disability definition in that it utilizes limitation in activity as an indication of disability. It differs in that the limitation may affect activities other than work. What is perhaps more significant is that the phrase "with disabilities" suggests that a disability is a characteristic, independent of the requirements of work. Because the ADA aims to ensure that people with chronic health conditions or impairments are not discriminated against in employment or public accommodation on the basis of their conditions, the "with disabilities" construction implicitly challenges the conventional use of the term work disability. That is, work disability has been used to identify someone whose impairments limit or prevent work. The term "with disabilities" suggests that among people who work, some are employees with disabilities, and others are employees without them. Identifying someone as a person with a disability does not simultaneously indicate anything about that individual's work abilities or limitations. Thus, the aim and language of the ADA shift the focus away from impairments as a path to disability (by limiting or preventing employment) and toward questions about the work behavior of people with disabilities, questions also asked for other labor force groups (e.g., women or Hispanics).

## Topics for the Measurement of Work by People with Disabilities

With the data currently available from government surveys, we can estimate how many people report that they are prevented from working or are limited in the kind or amount of work because of a physical or mental condition. However, there is a great deal we do not know. For example, we often do not know how long the disability has lasted or when it began. We do not know whether a disability has always limited or prevented employment, or whether the limitation in employment followed the onset of the disability by several years. Government surveys assume that, once someone has reported a disability, his or her status is relatively unchanging. Yet, this assumption may not be valid. Additionally, because the data are gathered as a cross-section, we also do not know whether the employment patterns of people with disabilities are relatively unchanging over time, fluctuating, or intermittent. We know little about the work environment and working circumstances of people with disabilities. In this era of the ADA, no major survey is structured to ascertain what proportion of workers are working with a disability. What proportion of workers with disabilities require modifications or workplace accommodations to maintain productivity, and what proportion do not? How much effort is required to secure employment? How long is the job search, how many resumés or applications are sent out, how many interviews take place, what other efforts are expended to secure employment? What is the work environment like for people with disabilities? Is it hostile, accessible, welcoming, tolerant? How much job mobility is experienced by people with disabilities? Is there a "glass ceiling"? Are there differences by occupation or by industry? In summary, we will find it difficult to truly understand the labor force experience of people with disabilities if we do not also attend to the ways we define, measure, and think about disability and employment.

## References

- Albrecht, G.L. (1992). The disability business. Newbury Park, CA: Sage Publications.
- Brown, S.C. (1991). Conceptualizing and defining disability. In S. Thompson-Hoffman & I. F. Storck (Eds.), Disability in the United States: A portrait from national data (pp. 1-14). New York, NY: Springer Publishing Company.
- Haber, L.D. (1990). Issues in the definition of disability and the use of disability survey data. In D.B. Levine, M. Zitter, & L. Ingram (Eds.), Disability statistics: An assessment: Report of a workshop: National Research Council (Appendix B, pp. 35-51). Washington, DC: National Academy Press.
- Haber, L.D. (1991). Operating definitions of disability: Survey and administrative measures. In S. Thompson-Hoffman & I. F. Storck, (Eds.), Disability in the United States: A portrait from national data (pp. 228-241). New York, NY: Springer Publishing Company.

- LaPlante, M.P., Miller, S., & Miller, K. (1992). People with work disability in the U.S. Disability Statistics Abstract, No. 4, National Institute on Disability and Rehabilitation Research. Washington, DC: U.S. Department of Education.
- McNeil, J.M. (1993). Americans with disabilities: 1991-92, U.S. Bureau of the Census, Current Population Reports (P70-33). Washington, DC: U.S. Government Printing Office.
- Nagi, S.Z. (1969). Disability and rehabilitation: Legal, clinical, and self-concepts and measurement. Columbus, OH: Ohio State University Press.
- Reisine, S., & Fifield, J. (1992). Expanding the definition of disability: Implications for planning, policy, and research. The Milbank Quarterly, 70(3), 491-508.
- U.S. Bureau of the Census. (1992). 1990 Census of population and housing, summary social, economic, and housing characteristics, United States, report 1990 (CPH-5-1). Washington, DC: U.S. Department of Commerce.

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## The NIDRR ADA Technical Assistance Initiative

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### NIDRR's ADA Mission

Since its establishment in 1978, the National Institute on Disability and Rehabilitation Research (NIDRR, formerly the National Institute on Handicapped Research) has supported research to improve the employment status and promote the independence of persons with disabilities. Public Law 101-336, the Americans with Disabilities Act (ADA), was enacted on July 26, 1990, to prohibit discrimination against individuals with disabilities in employment, public accommodation, transportation, State and local government services, and telecommunications. Because of NIDRR's track record of success in supporting information dissemination and technical assistance on issues related to disability, and because of its information base of knowledge resulting from NIDRR-supported research and demonstration efforts in this field, Congress provided additional funds to NIDRR to support an ADA technical assistance initiative.

### Paradigm of the NIDRR ADA Technical Assistance Initiative

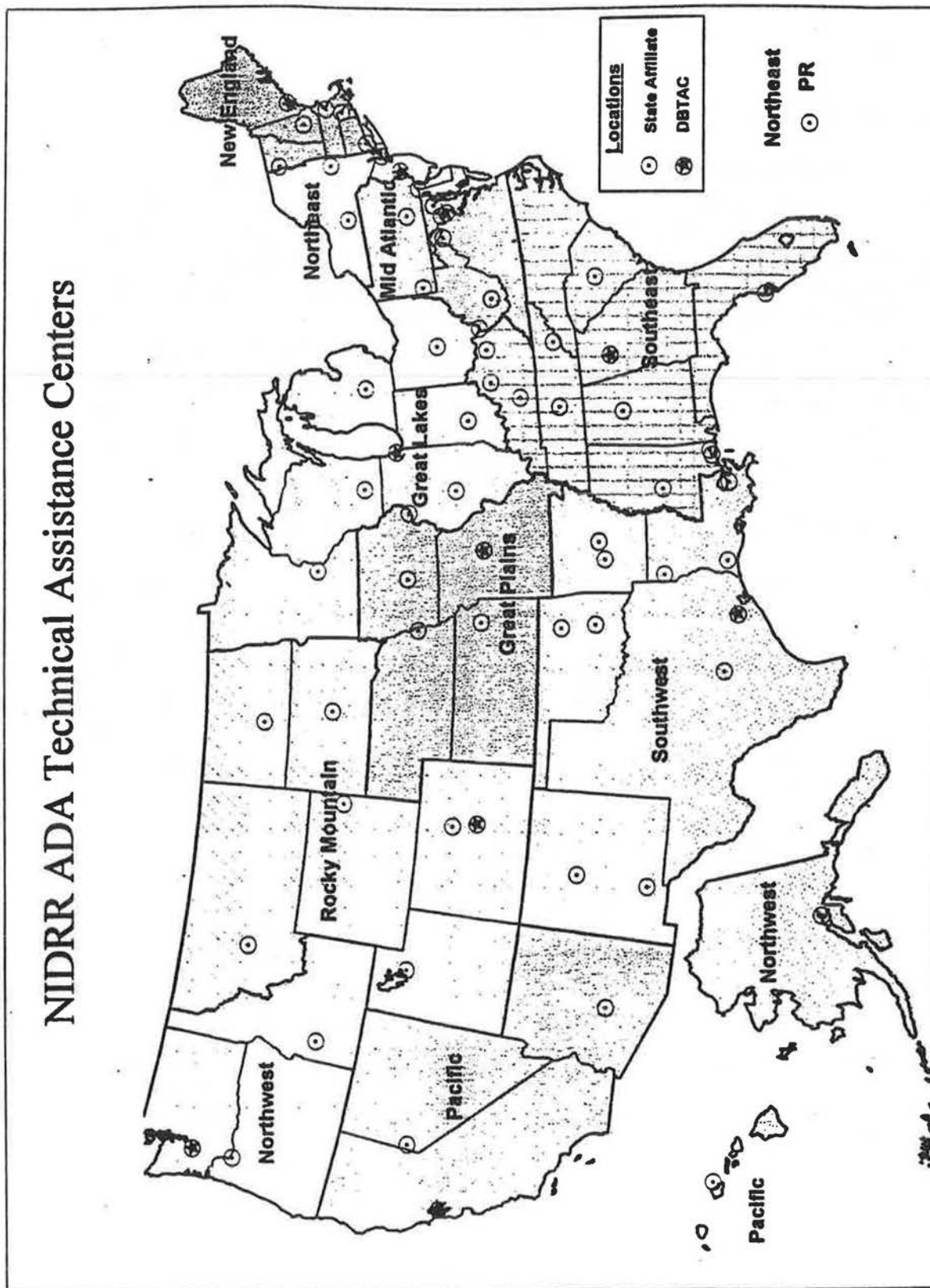
On May 21, 1991, NIDRR published in the *Federal Register* its Proposed Priorities for Fiscal Years 1991-92 for a "program of activities to support the implementation of the Americans with Disabilities Act (ADA) of 1990." Priorities for three types of related projects were proposed, the integrated whole to constitute what later became known as the NIDRR ADA Technical Assistance Initiative, which originally included ten regional Disability and Business Technical Assistance Centers, two National Training Projects, and three now-completed Material Development Projects, as well as a Technical Assistance Coordinator (TAC) contractor.

### Disability and Business Technical Assistance Centers (DBTACs)

The ten regional Disability and Business Technical Assistance Centers focus on providing, within their respective regions, information and technical assistance to employers and other covered entities, as well as to persons with disabilities, in order to facilitate appropriate implementation of the ADA, successful employment outcomes for individuals with disabilities, and greater accessibility in public accommodations. In addition, the DBTACs are developing information resources, data bases, reference guides, and expert consultant pools that will serve as resources for implementation of the technical assistance programs. There is one DBTAC for each of the ten Department of Education Administrative Regions.

Figure 1:

U.S. Map Showing NIDRR Regions, DBTAC Locations, and State Contact Locations



### National Training Projects (NTPs)

The National Training Projects conduct training in order to enhance the capacity of persons with disabilities and their organizations to facilitate the implementation of the ADA. The first two NTPs were each funded through a three-year grant (both completed in Fiscal Year 1994). One NTP focused on peer training of independent living center staff, associates, and volunteers. The other focused on developing a peer and family training network in which individuals with disabilities or their parents or other family members provided training to their peers throughout the country. There are now five NTPs with three-year funding. These provide training to family organizations, school districts, independent living centers, state and local ADA coordinators and policymakers, and to Hispanic people with limited English proficiency.

### Materials Development Projects (MDPs)

The three Materials Development Projects developed and tested technical assistance and training materials and programs for use by the DBTACs and NTPs. Two of the MDPs focused primarily on employment issues, developing training programs, materials, and resources, or on repackaging existing materials. The other MDP's focus was on accessibility and public accommodations, e.g., developing or identifying and adapting self-administered survey guides.

### Technical Assistance Coordinator (TAC)

The Technical Assistance Coordinator project was a three-year contract (extended for a fourth year) awarded to Abt Associates Inc. in an open competitive RFP process. Abt is an employee-owned social research firm with corporate headquarters in Cambridge, Massachusetts. While the TAC does not provide ADA services directly, Abt is responsible for facilitating, coordinating, monitoring, and assessing the performance of the grantees whose activities comprise the NIDRR ADA Technical Assistance Initiative.

### ADA Training Activities<sup>1</sup>

The ten regional NIDRR Disability and Business Technical Assistance Centers (DBTACs) and the various NIDRR National Training Projects (NTPs) together conducted 4,717 ADA training events over the 40-month period from June 1992 through September 1995: 565 in the last quarter of federal Fiscal Year 1992; 1,065 in Fiscal Year 1993; 1,458 in Fiscal Year 1994; and 1,629 in Fiscal Year 1995. These sessions, held all over the country, provided primary ADA training to a total of 215,780 participants from all walks of life and from various concerned constituencies: 30,759 in the last quarter of federal Fiscal Year 1992; 63,351 in Fiscal Year 1993; 56,800 in Fiscal Year 1994; and 64,870 in Fiscal Year 1995. The largest number of trainees resided in the South U.S. Census region. And the

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<sup>1</sup> All numbers have been updated to include tallies for federal Fiscal Year 1995, which covers the period 1 October 1994 - 30 September 1995.

largest proportion of people who received training, as measured by percentage of U.S. Census region populations, were residents of the Midwest Census region. In all four years, Employers/Business Establishments and Organizations comprised the largest category of trainees.

#### ADA Technical Assistance

Over the same 40-month period referenced above, the ten NIDRR DBTACs combined provided 400,408 instances of ADA technical assistance to persons with ADA rights and to covered entities with ADA obligations: 40,313 in the last quarter of federal Fiscal Year 1992; 79,964 in Fiscal Year 1993; 127,736 in Fiscal Year 1994; and 152,395 in Fiscal Year 1995. The national toll-free ADA Information and Referral line (1-800-949-4ADA) served more than 247,100 callers with a total of about 16,685 hours of usage during the 40 months: nearly 20,000 callers and 1,263 hours in the last quarter of federal Fiscal Year 1992; over 61,000 callers and 4,373 hours in Fiscal Year 1993; more than 75,700 callers and 5,227 hours in Fiscal Year 1994; and over 90,400 callers and 5,822 hours in Fiscal Year 1995.

Consistently across the four years, Employers/Business Establishments and Organizations were the largest category of technical assistance recipients.

#### ADA Materials Dissemination

Over the 40-month period reported herein, the ten regional NIDRR DBTACs altogether distributed more than 2.3 million copies of ADA publications, a goodly number in alternative formats accessible to persons who are blind or are non-English readers: 188,842 in the last quarter of federal Fiscal Year 1992; 539,511 in Fiscal Year 1993; 698,040 in Fiscal Year 1994; and 901,878 in Fiscal Year 1995. There was a noticeable shift from an early emphasis on general ADA information to publications on more specific topics.

#### Time Trends

After January 26, 1993, all new facilities designed and constructed for first occupancy had to be accessible, and it became legal to file lawsuits regarding new construction and alterations against businesses with ten or fewer employees and gross receipts of \$500,000 or less. During the accompanying calendar quarter that spanned January through March 1993:

- Training to representatives of business establishments, public entities, and voluntary organizations and service providers each reached its highest volume.
- Training to all types of audiences combined and training to individuals with disabilities or their organizations both attained their second highest volume.

- Training to voluntary organizations and service providers reached its highest percentage of training to all types of audiences combined, and training to public entities reached its second highest percentage.
- Technical assistance to public entities reached its highest percentage of technical assistance to all types of entities combined.

On July 26, 1994, employment requirements went into effect for employers with 15-24 employees. During the accompanying calendar quarter that spanned July through September 1994:

- Training to the general public reached its highest percentage of training to all types of audiences combined and its second highest volume.
- Technical assistance to business entities attained its second highest volume.

#### References

- Glazier, R.E., Jr. (Ed.). (1993, April). The first year (FY-1992) of the NIDRR ADA Technical Assistance Initiative: Facilitating implementation of the Americans with Disabilities Act of 1990 (Report for the National Institute on Disability and Rehabilitation Research, Department of Education Contract No. HN91041001). Cambridge, MA: Abt Associates Inc.
- Glazier, R.E., Jr. (Ed.). (1994, February). The second year (FY-1993) of the NIDRR ADA Technical Assistance Initiative: Promoting implementation of the Americans with Disabilities Act of 1990 (Report for the National Institute on Disability and Rehabilitation Research, Department of Education Contract No. HN91041001). Cambridge, MA: Abt Associates Inc.
- Glazier, R. (Ed.). (1995, February). The Third Year (FY-1994) of the NIDRR ADA Technical Assistance Initiative: Advancing Implementation of the Americans with Disabilities Act of 1990 (Report for the National Institute on Disability and Rehabilitation Research, Department of Education Contract No. HN91041001). Cambridge, MA: Abt Associates Inc.
- Glazier, R. (Ed.). (1996, February). The Fourth Year (FY-1995) of the NIDRR ADA Technical Assistance Initiative: Fostering Implementation of the Americans with Disabilities Act of 1990 (Report for the National Institute on Disability and Rehabilitation Research, Department of Education Contract No. HN91041001). Cambridge, MA: Abt Associates Inc.

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## Section V

### Intersecting Health Issues

Too often research looks at disabling conditions in isolation. The following research studies avoid that trap by looking at the intersection of a disability with other health factors. Gary Linn, Marion Anema, Christine Sharpe, Van Cain, and Sandra Hodess of Tennessee State look at the intersection of gender, HIV infection, mental health, and self perceptions about health. Based on information from 103 HIV-infected women, the authors found that self-appraisal of health links HIV and depression. Their perceptions about their health may lead to psychological distress. Other resources in their lives, such as family support or gathering information about AIDS, may help to mitigate the negative self perception somewhat, but it does not completely counteract the depression. Linn et al.'s findings suggest that lessening symptoms of HIV not only treats the physical illness, but may enhance self perception of health and lessen psychological symptoms such as depression. Their findings also show that women with HIV have better health self perception when they have strong family and community supports. The study concludes that optimism is an important component in the treatment of HIV infection.

Firoozeh Molaparakast of Seton Hall University and James Walkup of Rutgers also illustrate this link between chronic illness and depression. Their study looked at the relationships between arthritis, depression, and disability among 317 rheumatology patients. They found that the presence of depression may cause increased disability even when symptoms are low. They also found that sometimes the needs of patients go unmet and that they endure distress without any help. The authors hypothesize that the social withdrawal component of depression may cause some individuals not to ask for help. Therefore, physicians need to be aware of mental health factors among chronically ill patients and to dispense psychosocial support to them, if necessary.

Michael Dunn of the VA Medical Center in Palo Alto reports on the intersection of difficult behaviors and rehabilitation, and advocates for the proper training of rehabilitation professionals for these situations. Dunn had 309 undergraduate and graduate students in disability-related coursework evaluate behavioral situations in terms of difficulty. He then compared these results to findings among rehabilitation staff. Dunn found that students showed more discomfort than staff with difficult behavioral situations. Undergraduates expressed more discomfort with problematic sexual situations, such as a patient's sexual advances, and graduate students related more discomfort with staff situations, such as being belittled by another staff member in front of a patient. The students' previous experience with disability had little impact on their discomfort level. Dunn proposes that training programs for rehabilitation students better integrate training about uncomfortable situations into the educational process.

Promoting health among people with disabilities is an crucial factor in assisting them with full participation in U.S. society. Susan Kinne, Mary Rose, Donald Patrick, and Mary Richardson of the Center for Disability Policy and Research studied the numerous benefits of exercise among people with disabilities. They based their study on research that shows that 35% of adults with disabilities do no physical activity during leisure time. Their findings from their first 60 respondents suggest that exercise level does not vary by disability type, health status, or any demographic category. Kinne et al. found six primary barriers to exercise: tiredness, impairment, inconvenient facilities, lack of money, embarrassment, and little time. These results suggest that people with disabilities face not only motivational barriers to exercise, but, more prominently, they face external barriers, such as financial or architectural ones. They confirm that health promotion must be differently tailored for people with disabilities.

Finally, Amy Ai of the University of Michigan explores the implications of alternative medicine, also known as complementary medicine, for people with disabilities and chronic illnesses. The new NIH Office of Alternative Medicine has been evaluating alternative medicine in order to better integrate it into current U.S. health care practices. Ai's study of numerous uses of complementary medicine for disabling conditions illustrates that this newer biopsychosocial model of health care can work well in today's different environment for chronic illness and disability. Disability can affect "the individual's quality of life, self-concept and body image, emotional balance, coping strategies, and environmental adjustment. It imposes a wide range of impacts at the individual, familial, and societal levels, involving multiple factors: psychosocial, environmental, nutritional, physiological, and genetic" (p. 134). This method of complementary medicine contrasts with the biomedical model that focuses on specific diseases. For example, complementary medicine would not treat a condition with a drug alone, but through modification of lifestyle, attitudinal changes, and social support enhancement.

## Perceived Health, HIV Symptoms, and Psychological Distress in Women

J. Gary Linn, Ph.D.  
Marion G. Anema, R.N., Ph.D.  
Christine P. Sharpe, R.N., Ph.D.  
Van A. Cain, A.B.D.  
Sandra Hodess, R.N., M.S.  
Tennessee State University

The objective of this study was to test several hypotheses that predict depression and perceived health in women infected with HIV. This analysis addressed the following question: What is the role of subjective self-appraisal of health in the relationship between HIV disease and mental distress?

### Hypothesis

The following propositions were evaluated:

1. HIV-illness related depression is precipitated more by self-appraisal of the individual's health than by symptoms of the disease per se.
2. Perceived health (self-appraisal) is contingent upon both symptoms of HIV disease and resources.
3. Inadequate resources lead to a "negative" health appraisal which, in turn, contributes to greater depression.

The concepts and their hypothesized relationships are shown in Figure 1.

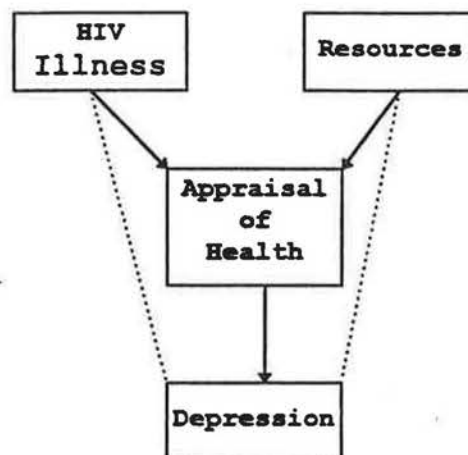


Figure 1: Hypothesized structure of HIV illness-related depression

## Method

This analysis was based on data obtained from 103 HIV-infected women (age 18 or older) who sought support, counseling, and maintenance services from one of four selected HIV care and referral centers in the mid-South.

The respondents were predominantly Black (74% Black vs. 26% White) and young (mean age=32) with limited education (mean years of education=11.7) and income (mean income=\$10,000). Therefore, they were similar to the HIV-infected female population in the United States, which has been described as predominantly poor and minority. Sixty-two percent of the women said that they have one or more children under the age of 18 living with them. Child care responsibilities are likely to drain time and energy away from self-care. Their most frequently given reasons for having a positive HIV test were "single heterosexual partner," "intravenous drug use," or "multiple heterosexual partners." With respect to stage of illness, 67% of the study participants indicated that they were HIV positive, 22% said that they had AIDS Related Complex, and 11% reported that they had been diagnosed as having AIDS. All interviewees were assessed by their physicians with regard to their HIV status.

## Results

Tests of the proposed structure of HIV-illness related depression are presented in Tables 1 and 2. In order to test the study hypotheses, stepwise multivariate regression analyses were performed for each hypothesized dependent variable in the model. The regressions assume uncorrelated error terms and that causal effects are unidirectional (i.e., a recursive model). Before the analyses, data were inspected for univariate and bivariate outliers as well as for normality of distributions.

## Discussion

Self-appraisal of health evidently serves as a link between HIV disease and depression, a major dimension of mental distress. Thus, as proposed (Figure 1), perceived health status may fulfill a psychological distress-moderating, or distress-aggravating function for this group of infected adult females. The data suggest that the moderating capacity of self-appraisal is somewhat contingent on the adequacy of resources available to the individual client. However, as we observed in Table 2 (step 2), resources contribute only a modest, though significant, amount to the explanation of the health appraisal (variance, or  $R^2$ ) when the self-assessment is under the pressure of HIV illness. Interpretation of these data implies that, even under the most favorable conditions--namely, when women are "high" on control of all relevant resources--the resources are not completely adequate for counteracting the deleterious effect HIV disease may have on the individual's mental health status, or her level of depression.

These findings have several implications for the care of women with HIV disease. To increase the likelihood of a positive self-perception of health, clinical attention

Table 1. Regression of Depression on Appraisal of Health (step 1), HIV symptoms (step 2), and resources (step 3).

Independent Variables	Dependent Variable: Depression		
	Step 1 beta	Step 2 beta	Step 3 beta
Appraisal of Health	-.48*	-.50*	-.52*
HIV Symptoms			
Hearing Loss	.22*	.25*	
Night Sweats	.08	.05	
Rashes	.02	.05	
Nasal Congestion	.02	.05	
Vomiting	.18*	.19*	
Swollen Glands	.02	.09	
Weight Loss	.11	.20*	
Diarrhea	.14*	.14*	
Headaches	.12*	.14*	
Numbness	.06	.13*	
Sore Throat	.11	.23*	
Muscle Weakness	.19*	.16*	
Heart Burn	.25*	.29*	
Non-productive Cough	.03	.11	
Vision Problems	.15*	.23*	
Shortness of Breath	.11	.05	
Fever	.03	.13*	
Difficulty Swallowing	.02	.10	
Chills	.09	.08	
Resources			
Attend Church		-.14*	
Seek Information about AIDS		.12*	
Relatives Nearby		.10	
Friends Nearby		-.12*	
Race		.04	
Education		-.28*	
Income		.06	
Explained Variance (R <sup>2</sup> )	.23*	.39*	.50*

\*  $p \leq .05$

Table 2. Regression of Depression on HIV symptoms (step 1), and resources (step 2).

Independent Variables	Dependent Variable: Depression	
	Step 1 beta	Step 2 beta
<b>HIV Symptoms</b>		
Hearing Loss	-.16*	-.24*
Night Sweats	-.14*	-.18*
Rashes	-.02	-.05
Nasal Congestion	-.05	-.12*
Vomiting	-.04	-.04
Swollen Glands	-.13*	-.06
Weight Loss	-.09	-.00
Diarrhea	-.10	-.09
Headaches	-.01	-.07
Numbness	-.21*	-.13*
Sore Throat	-.01	-.05
Muscle Weakness	-.20*	-.24*
Heart Burn	-.12*	-.25*
Non-productive Cough	-.01	-.08
Vision Problems	-.15*	-.15*
Shortness of Breath	-.13	-.21*
Fever	-.20*	-.27*
Difficulty Swallowing	-.08	-.33*
Chills	-.13*	-.39*
<b>Resources</b>		
Attend Church		-.08
Seek Information about AIDS		-.01
Relatives Nearby		.29*
Friends Nearby		-.01
Race		.02
Education		-.12*
Income		.00
Explained Variance (R <sup>2</sup> )	.26*	.40*

\*  $p \leq .05$

should be focused on the type and number of HIV symptoms experienced by the person as well as on the adequacy of her personal and social resources. The antiviral drug AZT and other pharmaceuticals and treatment strategies that lessen the physical torments of HIV-related illness and symptoms should also be considered important for maintaining, or improving, psychological functioning among those infected with HIV.

Social workers and other care providers should help HIV-infected women strengthen and maintain family and community support networks. Our results show the importance for positive health appraisal of having more adult family members nearby (Table 2, step 2), and the importance for less depression of having greater numbers of friends close by and frequently attending church (Table 1, step 3). Many women in this study may not be able to address their own special health care needs and, consequently, feel more positive about their own health until they receive assistance with child care from kin, friends, and/or church members.

Furthermore, there should be clinical interventions that provide female clients with information about the probable course of their HIV disease that is realistic, but that still allows them to maintain optimism. This strategy will improve the chances for a positive health appraisal, while decreasing anxiety and depression. However, given the limited education of these respondents (mean years of education=11.7) and many other women and men with HIV, complex medical information about the disease probably needs to be interpreted on a one-to-one basis.

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## Patients with Chronic Illness and Depressive Symptoms: Their Disability and Site of Care

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Many reports indicate that depressive symptoms/disorders are elevated among individuals with chronic illness (Taube, Goldman, Burns, & Kessler, 1988; Wells, Golding, & Burnam, 1988), and comorbid depressive symptoms are associated with additional disability over and above that attributable to the medical illness (Von Korff, Ormel, Katon, & Lin, 1992). Psychological distress has also been found to influence rates of physician visits among chronic patients (Katz & Yelin, 1993). But these combined conditions are unevenly accommodated by the current service delivery system. Despite the clinical significance of comorbid depression, most studies suggest that nonpsychiatric physicians often fail to recognize and/or treat these comorbid depressive symptoms (Schulberg & Burns, 1988). To address this need for further information on combined conditions, this study reports on relations found among arthritis symptoms, depression, and disability in a community sample of patients under the care of a rheumatologist, and on medical and mental health services used. We hypothesized that the presence of comorbid depressive symptoms is associated with increased disability, even after controlling for the effect of disease severity.

### Sample and Methods

The data were derived from a more comprehensive series of state-wide surveys, conducted in 1985-1986, that was concerned with the assessment of patients' needs and the psychosocial factors which influence the course of disease and treatment of patients with arthritis in Pennsylvania.<sup>1</sup> A geographically-proportionate, random sample of rheumatologists was asked to refer twelve arthritis patients in different diagnostic categories. A total of 317 patients was referred to the study, and 277 of them were interviewed over the telephone, yielding a response rate of 87%.

### Measures

As dependent variables, we used three measures of disability indicating varying aspects of functioning: difficulty in performing daily activities (a modified Activities of Daily Living [ADL] scale calculated from the average of 14 items), the number of days restricted to perform normal daily activities (DRA), and the number of days stayed in bed (DIB) for

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<sup>1</sup> The authors would like to thank the Principal Investigators of the study at the University of Pittsburgh: Drs. Edmund Ricci, Caroline Kaufmann, and Anne Medsger.

a half-day or more because of arthritis in the past month. The last two measures were six-point ordinal scales in which higher rating indicated more disability.

The health-related measures consisted of self-assessed general physical health status (ranging from excellent to poor), the other complicating medical problems (sum of ten items on other chronic health problems besides arthritis), and the disease severity (sum of ratings over seven common arthritis symptoms). Median split procedure was used to dichotomize the sample into mild and severe subsamples. Ordinal measures of service utilization were the number of nights stayed in a hospital because of arthritis in the past year, the number of times calling a doctor, and the number of times visiting a doctor for treatment of arthritis in the past month.

The Center for Epidemiological Studies Depression Scale (CES-D) was used to measure psychological distress (Radloff, 1977). Since this 20-item scale is developed as a global measure of psychological distress for general community samples, some investigators have suggested that including the somatic items in the scale may overestimate the underlying associations in chronically-ill populations. Based on the current suggestions (Blalock, DeVellis, Brown, & Wallston, 1989; Pincus & Callahan, 1993), we excluded three somatic items from the scale and constructed a modified CESD. Considering the number of items dropped, we selected the cut-off point of 13 and rated scores above 13 as high depression. Measures for the kinds of help sought/received in dealing with emotional problems were informal help index, formal help index, and use of psychotropic drugs.

## Results

A large proportion of the sample were female (76%) and married (63%). Age ranged from 15 to 86 years, with a mean of 57 years. Most of the patients were high school graduates with an annual income of less than \$20,000. About 70% were either unemployed, disabled, or retired; and 20% were not working because of arthritis.

The mean score on ADL was relatively modest (1.76). Over 60% of the patients, however, reported high or moderate disability. About 56% reported no days of restricted activity in the past month, while over 26% reported such restrictions almost every day. The mean of 2.09 indicates that the average patient had two or three DRA each month. About 78% of the patients reported no days in bed during the past month, and only 9% reported staying in bed every day.

The modified CESD, after dropping three somatic items, had a mean of 8.84. Approximately 28% of patients were classified as highly depressed, as opposed to 30% when the full scale CESD was used. About 71% of the patients reported receiving no help in dealing with emotional problems. The reported use of these supports, and help-seeking efforts in dealing with psychological problems seem much lower than levels of reported psychological distress.

A t-test was used to assess the significance of the difference between the means of disability indices for low and high depressed patients, controlling for symptoms severity. The

differences in the means indicated that those categorized as highly depressed scored significantly higher on all measures of disability. The association remained significant among those with mild symptoms only for DRA, suggesting that, for this measure, the presence of depression may increase the likelihood of experiencing more disability even under conditions in which disease symptoms/impacts are not substantial. ADL is a more discrete measure of physical disabilities and is not sensitive in detecting psychopathologically-related disabilities. DRA seems to be a more global measure for assessing disability, irrespective of physical and non-physical causal factors.

To assess how all predicting variables hang together, multiple regression analyses were performed. Analyses were conducted separately on each disability measure for the total sample, and for mild and severe symptoms subsamples. In each regression model, variables were entered in blocks according to our theoretical model. Sociodemographic variables were entered first, followed by health and utilization variables, and then by depression scale score, CESD-M.

The summary of hierarchical regression of ADL on the three blocks of independent variables showed that education, marital status, work status, general health, disease severity, and pain were associated with ADL, yielding statistically significant coefficients. Health and demographic variables jointly accounted for 43% of the adjusted variance in ADL. CESD, however, did not have a significant direct effect on ADL. The models performed weaker for the mild symptom subsample, and stronger for the severe symptom subsample.

The summary of hierarchical regressions of DRA (Table 1) showed that work and marital status, symptoms severity, days in bed, and calling a doctor were positively associated with DRA. Adding CESD (model 3) showed that CESD had a significant direct effect on DRA and moderately mediated the effects of other variables. Unlike what was found in ADL models, here we found support for the hypothesis that comorbid depressive symptoms create additional disability, as measured by DRA. All variables jointly accounted for 43% of the adjusted variance in DRA. The results for both the mild and severe subsamples were similar to the total sample.

When we regressed DIB on the blocks of independent variables, we found that, similar to ADL, CESD did not have a significant effect for total sample or for mild and severe subsamples.

### Conclusion

Our findings support the growing argument on the propriety of using the CESD to assess depression in those with medical illnesses. We removed the contaminating items that may elevate scores because they index physical rather than psychological symptoms, and found that this procedure changes the composition of the high depressed group, though not much. Whether this small change is important enough to warrant continuing this practice is a question to be answered in the future as more studies accumulate.

**Table 1. Hierarchical Regression of DAYS OF RESTRICTED ACTIVITIES on Independent Variables**

Predictors	1	2	3
Age	-.16**	-.05	-.05
Sex	-.09	.03	.04
Marital Status	.06	.10*	.12**
Education	-.13*	-.08	-.08
Work Status	.31***	.15**	.14**
General Health		.04	.01
Symptoms Severity		.14*	.13*
Other Diagnoses		.05	.05
Pain		-.01	-.01
ADL		.10	.10
Days in Bed		.36***	.36***
Nights-Hospital		.04	.03
Calling-Doctor		.13**	.11*
Visiting Doctor		.01	-.01
Psychotropic Drugs		-.03	-.03
Psycho-Support		.07	.08
CESD-M			.20***
Multiple R	.38	.66	.68
R Square	.15	.43	.46
R Square Change	.15	.28	.03
Adj. R Square	.13	.39	.43

\*  $p < .05$

\*\*  $p < .01$

\*\*\*  $p < .001$

The difference we found among our measures of disability when it comes to co-occurring depression warns providers against possible mistakes. When checking for disability, questions about ADL are not sufficient. Without specific DRA questions, significant disability may be missed. The cause of restricted activities cannot be exclusively located in disease activity; it can also be a sign of psychosocial distress. ADL is a more discrete measure of physical disabilities that is not sensitive in detecting psychopathologically-related disabilities, while DRA seems to be a more global measure for assessing disability irrespective of different physical and non-physical causal factors.

Finally, we reported some unmet needs. Considerable distress is apparently endured without much help, whether formal or informal, from others. We do not know if these individuals do not ask for help, perhaps reflecting the social withdrawal often found in depression, or if they are not diagnosed/treated/referred by primary care physicians who may assume that depression is a natural consequence or response to disease symptoms and loss of physical functions. Whatever the cause, it is a source of dismay. Non-psychiatric physicians need to be aware of the significance for functioning of the mental health status of chronically-ill patients, and they must dispense psychosocial support to those in need.

#### References

- Blalock, S., DeVellis, R., Brown, G., & Wallston, K. (1989). Validity of the Center for Epidemiological Studies Depression Scale in arthritis populations. Arthritis and Rheumatism, 32(8), 991-997.
- Katz, P., & Yelin, E. (1993). Prevalence and correlates of depressive symptoms among persons with rheumatoid arthritis. Journal of Rheumatology, 20(5), 790-796.
- Pincus, T., & Callahan, L. (1993). Depression scales in rheumatoid arthritis: Criterion contamination in interpretation of patient responses. Patient Education and Counseling, 20(2-3), 133-143.
- Radloff, L.S. (1977). The CES-D Scale: A self report depression scale for research in the general population. Applied Psychological Measurement, 1, 385-401.
- Schulberg, H., & Burns, B. (1988). Mental disorders in primary care: Epidemiologic, diagnostic, and treatment directions. General Hospital Psychiatry, 10(2), 79-87.
- Taube, C., Goldman, H., Burns, B., & Kessler, L. (1988). High users of outpatient mental health services: Definitions and characteristics. American Journal of Psychiatry, 145(1), 19-24.
- Von Korff, M., Ormel, J., Katon, W., & Lin, E. (1992). Disability and depression among high utilizers of health care: A longitudinal analysis. Archives of General Psychiatry, 49(2), 91-100.

Wells, K., Golding, J., & Burnam, M. (1988). Psychiatric disorder in a sample of the general population with and without chronic medical conditions. American Journal of Psychiatry, 145(8), 976-981.

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## Use of the Rehabilitation Situations Inventory to Measure Students' Perceptions of Difficult Behavioral Situations in Rehabilitation

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One of the major strengths of rehabilitation is the milieu in which it occurs. Peer interaction and accurate feedback from staff is necessary for good physical, emotional, and social adaptation to newly-acquired disabilities. Experienced staff have the behavioral skills and comfort with disability to provide such feedback, but students in rehabilitation may not yet have either. Increased comfort is expected to be acquired by mere contact, but the emotional consequences of coping with a new disability may create difficult social interactions between patient and student, so that contact without training may have the opposite effect. Part of professional education in nursing, physical and occupational therapy, social work and psychology ought to involve specific training in dealing with difficult behavioral situations that may occur in rehabilitation. The question is: For which situations should students be trained?

The Rehabilitation Situations Inventory (RSI) was developed to provide a measure of comfort with difficult behavioral situations and an inventory of which situations are the most difficult (Dunn, Umlauf, & Mermis, 1992). It is expected to be used not only to assess which situations should be emphasized in training, but also as an outcome measure for such training (Dunn, 1994; Dunn, Lloyd, & Umlauf, 1991; Dunn, Lloyd, Umlauf, & Sommer, 1992). The current paper will report on the results of administering the RSI to a sample of rehabilitation students. Questions to be answered are: 1) Do rehabilitation students, compared to experienced professionals, have greater levels of discomfort in rehabilitation situations? 2) Which situations do the students find to be most difficult to manage? 3) Are there differences in disciplines in terms of the difficult situations?

Subjects for this study were 309 undergraduate and graduate students from seven different locations. They were from four undergraduate courses in the psychology or sociology of disability, two psychology graduate programs, and an occupational therapy graduate program. One third of the students were physical therapy students, one third were psychology students, and the remainder were sociology, occupational therapy, and nursing students. Half were graduate students, two-thirds were female, two-thirds were between the ages of 21 and 30, and two-thirds had some experience with disability. Results from prior studies from 101 staff with more than five years experience in rehabilitation were used as comparison with the students. Sixty percent of these staff were nurses, and 25% were physical therapists or occupational therapists. Eighty percent were female; 33% were between 30-39 years of age, and 40% were between 40-49; 60% had six to ten years of rehabilitation experience.

The instrument used, the RSI, consists of 30 items which describe behavioral situations that rehabilitation staff have reported to be troublesome. Instructions were: "Some

situations that staff encounter in a rehabilitation setting are difficult to handle, awkward, or embarrassing. Please evaluate how difficult you would find each of the following situations and circle the number which corresponds to the difficulty on a scale of 1 to 5, with 5 being the most difficult." Total score is obtained by calculating the mean over all thirty items, with higher scores indicating more discomfort. The RSI has been used with over 400 staff at eight rehabilitation facilities, and it shows good test-retest reliability over a two-week period and high internal consistency (Dunn & Mermis, 1992). Subscales have been developed which involve the following general areas: Aggression, Motivation/Adherence, Sexual Situations, Depression, Staff/Staff Interactions, and Families. The subscales have been shown to be internally consistent, reliable, and distinct, although moderately correlated with each other (Dunn, 1996). Example items of the subscales are:

Motivation/Adherence	Patient refuses to use a splint even though it prevents damage.
Sexual Situations	During a transfer patient repeatedly kisses you on the neck.
Aggression	Patient who is vulgar, abusive, and offensive to you.
Depression	Patient says, "I'm old. I'd rather be dead than injured."
Staff/Staff Interactions	Being put down by another staff member in front of a patient.
Families	Spouse says, "Will he walk out of here?"

The instrument was administered in a number of ways. For the psychology and sociology of disability classes, all students filled out the inventory as part of their class. One third of the psychology graduate students and all of the occupational therapy students filled out the inventory before a workshop on clinical intervention with people with disabilities. The other psychology graduate students received the form in their mailboxes with a letter requesting their assistance. Fifty-nine out of 250 returned the inventory.

In comparison with the experienced staff, students showed more discomfort in the overall score and on all the scales, although discomfort in sexual situations was the greatest difference. Examining characteristics of the students in terms of the overall score, it was found that experience with disability was nonsignificant, but that males, psychology graduate students, and 31-40 year olds reported less discomfort.

A comparison of the students on the six scales using multivariate statistics and student characteristics as independent variables revealed a number of significant effects. For the various schools there were large differences. In general, the undergraduates expressed

more discomfort with sexual situations, and the graduate students reported more discomfort in staff interactions. These two types of situations, however, were the most discomfort-producing ones. When the students were classified as having or not having experience with disability, those students who had experience with disability reported less discomfort with the sexual situations, but there were no differences in the other scales. For the gender variable, the males reported less discomfort only on the aggression and sexual situations. For the age variable, the 21-30 year olds reported more discomfort than the older students in sexual situations, while the 31-40 year olds reported less discomfort in the family and motivation situations.

If one is designing a training course to help rehabilitation students learn how to interact therapeutically with people with disabilities, one must take into account a number of factors. It would be best to administer the RSI to the class before training begins and to use the data from the class. If this is not possible, one should take into account the demographic characteristics of the class in order to design the training program. On the basis of the current results, graduate students should spend proportionately more time on staff/staff interactions; those students with no experience with disability should spend more time on sexual situations; females should spend proportionately more time on aggression and sexual situations. It is expected that these results can be used in professional education and training in order to enable students to be more effective and comfortable in dealing with people with disabilities.

#### References

- Dunn, M. (1994). Managing difficult behavioural situations in rehabilitation settings. Toronto, Canada: Lyndhurst Spinal Centre.
- Dunn, M. (1996). Subscale development of the Rehabilitation Situations Inventory. Rehabilitation Psychology, 41, 255-264.
- Dunn, M., Lloyd, E.E., & Umlauf, R. (1991, September). Training staff for difficult behavioral situations in SCI centers: A workshop. Paper presented at the Annual Meeting of the American Association of SCI Psychologists and Social Workers, Las Vegas, NV.
- Dunn, M., Lloyd, E.E., Umlauf, R., & Sommer, N. (1992, September). Working with difficult behavioral situations in SCI centers: A workshop. Paper presented at the Annual Meeting of the American Association of SCI Nurses, Las Vegas, NV.
- Dunn, M., & Mermis, B. (1992). Test-retest reliability of the Rehabilitation Situations Inventory. Archives of Physical Medicine and Rehabilitation, 73, 989.
- Dunn, M., Umlauf, R., & Mermis, B. (1992). The Rehabilitation Situations Inventory: Staff perception of difficult behavioral situations in rehabilitation. Archives of Physical Medicine and Rehabilitation, 73, 316-319.

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## Participation in Exercise by People with Disabilities

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If we wish people with disabilities to participate fully in American society, it is critical that they are supported in maintaining health and function. The Center for Disability Policy and Research has been funded by the Chronic Disease Section of the Centers for Disease Control (CDC) to investigate ways to promote the health of people with disabilities.

After conversations with people who have various physical and cognitive disabilities, we concluded that exercise and physical activity should be our focus. Exercise and physical activity are important preventive activities for everyone, and inactivity is a known risk factor for chronic disease. But more immediately, people with disabilities may benefit from physical activity because it can prevent or reduce many debilitating secondary conditions, such as loss of functional capacity, depression, obesity, and social isolation. From the scanty population data available, we infer that inactivity among people with disabilities is a problem, as it is in the general population. Healthy People 2000 estimated that 35% of adults with disabilities do no leisure-time physical activity.

There are various barriers that keep people from exercising. We define exercise as purposive physical exertion beyond that needed for the activities of daily life. We examined the importance of these barriers and their relationship to exercise in a group of people with mobility impairments. The data we will present were collected as an adjunct to a study that examined physical and psychological outcomes of participation in a community exercise program.

The participants in this project are people who use a walking aid such as a wheelchair, cane, crutches, or brace. We recruited participants through advertisements in local papers, through disability support groups, and through a community activity center whose programming is primarily for people with disabilities. Participants were briefly screened, then asked to fill out a questionnaire. They received \$20 for mailing the questionnaire back to us. Here, we are reporting on the first 60 respondents; we expect to collect data from a total of 150 people with mobility impairments.

This initial sample is relatively well-educated and well-off. Table 1 gives demographic characteristics of the sample. Participants report varied disabilities, including multiple sclerosis, post-polio syndrome, spina bifida, orthopedic impairments of back and lower extremities, spinal cord injury, traumatic brain injury, cerebral palsy, and arthritis. Type of disability was not related to any of the variables of interest, so we will not report it.

Table 1  
Demographics of study sample

Percent male	47%
Average age	47 years, range 17-69
Percent with some college education	88%
Percent with household income over \$25,000	50%
Percent living with others	85%
Percent with permanent disability	91%
Percent receiving SSI	60%
Average Sickness Impact Profile (SIP) score (above 20 indicates substantial impairment)	23.7

We asked participants about several different kinds of exercise: aerobic, range of motion, and strength training. We are reporting here only on aerobic exercise, since that is the kind of exercise most clearly linked to cardiovascular health, and that for which recommendations are most clear. We asked, "Over the past 7 days, how often did you do exercises that increase your heart rate and/or your breathing rate, or make you sweat (e.g., rowing, swimming, wheelchair racing, etc.)?" We also asked about duration: more than or less than 20 minutes per session, since that was the recommended minimum at that time for a bout of aerobic exercise during the preceding week. We combined responses to create a single exercise variable: people who did no aerobic exercise (35%); people who did at least one session (39%); and people who exercised at least three times a week for at least 20 minutes per session (25%), meeting the old CDC standard for aerobic intensity and frequency. We found that this level of exercise did not vary by type of disability, by self-reported health status, or by any standard demographic variable (age, sex, education, marital status, income).

We asked about barriers to health-promoting behaviors, including exercise, using a set of questions developed by Heather Becker and her colleagues for use with people with disabilities (Becker, Stuifbergen, & Sands, 1991). The questions listed 18 barriers that had been identified by focus groups and, for each, asked how much this kept the respondent from taking care of his or her health. The mean rankings and standard deviations for the six greatest barriers are shown in Table 2. The ranking is based on the average score for each barrier. The score ranges from 1, for "never a problem," (2 = "sometimes," 3 = "often") to 4, "routinely a problem," so a higher average score indicates that the barrier is more important.

**Table 2**  
**Rankings and Scores for Barriers to Exercise**

1.	Too tired	(2.44, sd 0.88)
2.	Impairment	(2.43, sd 1.09)
3.	Lack of convenient facilities	(2.28, sd 1.00)
4.	Lack of money	(2.23, sd 1.14)
5.	Embarrassed about appearance	(1.91, sd 1.10)
6.	Lack of time	(1.88, sd 0.96)

The 18 barriers can be grouped as mainly external to the individual, or as involving individual motivation. Examples of external barriers are "lack of convenient facilities," "lack of transportation," "lack of money," "lack of support from family and friends," and "impairment" (11 items total). Motivational barriers include "too tired," "not interested," "feeling what I do doesn't help," and "embarrassment about my appearance" (7 items total). We calculated an external barrier score, a motivational barrier score, and a total barrier score for each person, using Becker's groupings of barriers. We compared barrier scores to participant characteristics, to see if any particular groups encountered more barriers. There were no significant relationships between demographics and external, motivational, or total barriers.

We also compared barrier scores to reported levels of exercise for our participants to see whether those with more barriers exercised less (Table 3). We found that, very consistently, those who exercised more reported lower barrier scores, but the relationship was not statistically significant.

**Table 3**  
**Barrier Scores and Reported Levels of Exercise**

	Those doing no aerobic exercise (n=18)	Those doing any exercise (n=22)	Those doing 3x/wk, 20 min (n=14)
External barrier score (s.d.) (n.s.)	20.6 (6.07)	20.3 (4.63)	19.5 (4.05)
Motivational barrier (s.d.) (p=.081)	10.8 (3.83)	9.5 (2.77)	8.4 (1.65)
Total barrier score (s.d.) (n.s.)	35.4 (9.55)	33.4 (7.28)	31.6 (5.11)

As we accumulate a larger sample, we suspect that we will see a stronger relationship emerging. We note that the rankings and average scores for barriers were different for a sample of people without disabilities to whom Becker gave the questions. Across the list, barrier scores were lower for people without disabilities.

### Conclusions

Our focus in this paper is the barriers that people feel they encounter in taking care of their health, specifically in relation to exercise. Motivational barriers have been the traditional target of health promotion--getting people to take responsibility for their health. For this sample of people with disabilities, however, external barriers were more prominent than motivational barriers. When we adjusted for different numbers of items in the two scales, average external barrier score was 1.87, the average motivational barrier score was only 1.54, and the average total barrier score was 1.97. The absolute magnitude of barriers was not large, which is encouraging. But these data suggest that, if we wish to make it easier for people with disabilities to promote their own health, we need to concentrate on reducing barriers such as transportation, access, cost, and time. This is hardly a revolutionary finding, but it reinforces our sense that the health promotion needs of people with disabilities are different from those of the nondisabled population in some particulars.

We recognize the limitations of these preliminary data, which are cross-sectional and reflect a small sample that is not demographically representative of all persons with mobility impairments. As we recruit more participants, we will repeat the analyses. In a larger study of which this questionnaire is a part, we will be able to follow our exercise class participants and a group of non-participant controls over a period of six months to observe the longitudinal relationship between barriers and exercise.

### Reference

Becker, H., Stuifbergen, A.K., & Sands, D. (1991). Development of a scale to measure barriers to health promotion among persons with disabilities. American Journal of Health Promotion, 5(6), 449-454.

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## The Emergence of Complementary Medicine: Implications for Health Care and Disability

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In the United States, complementary medicine and alternative medicine are defined through a social process as those practices that do not form part of the dominant system for managing health and disease (Definitions Group, 1995). This definition includes any medical practice or intervention that a) does not have sufficient documentation; b) is not taught in medical schools; and c) is not generally reimbursable for third-party insurance billing. It has been classified into the following fields: mind/body interventions, bioelectromagnetic applications, alternative systems of medical practice, manual healing models, pharmacological and biological treatments, herbal medicine, and diet and nutrition in the prevention of chronic disease (National Institutes of Health, Office of Alternative Medicine, 1994; Spencer, 1994). This chapter indicates some current events related to the emergence of complementary medicine and its potential for health care and disability.

In recent years, the health care crisis has led to public acceptance of complementary medicine in the U.S. Echoing this, in 1991 the U.S. Congress mandated establishing the Office of Alternative Medicine (OAM), within the Office of the Director, National Institutes of Health (NIH). The following factors lay behind this action: a) a dramatic increase in health care expenditure and difficulties in access to the care; b) public dissatisfaction with narrowly defined disease care and with its ineffectiveness in treating chronic conditions and disabilities; c) increasing public interest in low-cost or easily accessible health techniques outside mainstream medical care; d) some current scientific research indicating the effectiveness of alternative therapies; e) health maintenance organizations' and insurance companies' response to consumer demands, and their gradually increasing coverage for disease prevention and alternative treatment; and f) growing numbers of concerned professionals at academic medical institutions involved in complementary treatment.

### Alternative Approaches to Health Issues

In modern society, chronic illnesses have become major categories in line with morbidity, mortality, and social disability. Chronic illness or disability has considerable impact on the psychosocial aspects of individuals' lives and families. Because disease-specific care is built around removable, biological abnormalities, it tends to overlook other needs of people in coping with life transitions. The biomedical care of disease and disability does not mean a reconstruction of overall health. This contrast became especially apparent at mid-century as chronic illness replaced communicable diseases as the leading cause of death.

For these chronic conditions, adults from all demographic groups in the U.S. are currently seeking help from alternative therapies. An investigation of unconventional cancer treatments by the Office of Technology Assessment, a research arm of the Congress, found that many thousands of patients use complementary therapies, and many thousands more intend to do so (Moskowitz, 1992). As reported in a nationwide survey, 34% of respondents were pursuing unconventional therapies for chronic medical conditions (Eisenberg, Kessler, Foster, Norlock, Calkins, & Delbanco, 1993). The amount spent on unconventional medicine was equivalent to that spent by Americans for all hospitalizations.

As the authors noted, the sample underrepresented the number of alternative users among people with poor health, who had a considerably higher rate of use than those who reported better health (52% vs. 33%) (Eisenberg et al., 1993). To find out the pattern of such help-seeking in an older and sicker population, Steve Bolling, a thoracic surgeon, and I conducted a survey study of patients who underwent their first coronary bypass artery bypass graft surgery in 1993 at the Medical Center of the University of Michigan. Using the same 16 categories as in Eisenberg's study, we found that 85% of these patients sought alternative approaches for their health issues during the year following surgery. Likewise, a survey of people at the University Cancer Center showed that half of their patients were pursuing alternative therapies.

These reports have added to our understanding of how complementary medicine plays a significant role in health care today. A number of reasons people need alternative approaches include: a) perceived remedy of suffering; b) easy access; c) lower cost; d) fewer perceived side-effects; e) better attention or care; and f) better control over or more choice for one's body and illness. The health problems that push consumers to alternative services range widely from chronic pain, arthritis, cancer, musculoskeletal disorders, and chronic renal failure, to addictive disorders, anxiety, depression, and other psychological ills, and to AIDS. Many of these conditions are likely to cause chronic disability.

#### Some Treatment Effect on Disability-Related Chronic Conditions

Some current studies have shown the effects of alternative therapies. Low back pain has been regarded as "the leading cause of disability and morbidity in middle-aged persons," experienced by 75% of all Americans in their lifetime. Research has revealed convincing evidence for the efficacy of chiropractic treatment on this condition. It was empirically documented that manipulation is safer and cheaper than surgery (Manga, Angus, Papadopoulos, & Swain, 1993). A three and half year study indicated that a combination of biofeedback with simple pelvic muscle exercises reversed urinary incontinence, a major cause of isolation and depression among older women. It is a disorder suffered by 10 million older Americans, and a primary reason for nursing home admissions (National Institutes of Health, Office of Alternative Medicine, 1993). Heart attack is listed as one of the top death-producing diseases in the U.S. Dean Ornish has devised a reversal program for advanced coronary heart disease through lifestyle modification. In 1993, analysis of the one-year data exhibited impressive results--a 15% difference between the treatment group and a control group who received mainstream biomedical treatment. The

Positron Emission Tomography (PET) also demonstrated revascularized myocardium (Colgate, 1993).

In current documentation (Institute for Health Policy, 1993), substance abuse was described as placing "a major burden on the nation's health care system" (p. 8). Chemical dependency has a greater impact on deaths, illnesses, and disabilities than any other preventable health condition in the U.S. At least one-fourth of the two million annual deaths are attributable to addiction. In 1974, Michael Smith, a psychiatrist, employed a non-chemical tool to replace methadone treatment in a large-scale outpatient program at the Lincoln Hospital. The program used auricular acupuncture to control withdrawal symptoms and craving and to alleviate psychological disorders that are commonly seen in addiction treatment settings. In his testimony before the Selective Committee on Narcotics of the U.S. House of Representatives, Smith (1989) reported that 8,000 crack patients, many of whom were severe criminal justice clients, had graduated from the Lincoln program. Seventy-six percent of mothers at the Lincoln Clinic delivered non-toxic infants. The average birthweight for babies with more than ten maternal treatments was 6 lb., 10 oz. This approach has saved more than three million dollars each year for the city by reducing costs to fund boarder babies and subsequent foster care.

#### Impact on Health Care and Welfare Policy

The NIH Office of Alternative Medicine was created to facilitate the investigation of alternative medicine, including acupuncture and Oriental medicine, homeopathic medicine, and physical manipulation therapies; to support research training of alternative medicine practitioners, and to increase the understanding of alternative medical knowledge among physicians and scientists. The ultimate goal is to integrate validated alternative practices into health care (Moskowitz, 1993). So far, the office has funded ten research centers to evaluate alternative treatment for many chronic health conditions, and is developing a network for reporting research information (National Institutes of Health, Office of Alternative Medicine, 1996).

The above events will contribute to creating new opportunities for disability communities and for changes to the cost crisis in conventional health care. Aging and care for the poor are the two major health policy and welfare policy areas. The two programs account for the largest single source of payments for personal health care and social disability. Medicare has grown from \$5 billion in 1965 to \$110 billion within three decades (Castro, 1991). The growing crisis facing aging-related disability is all too clear now: One of three persons may develop cancer; one of five will fall victim to heart disease; and AIDs and other ailments will increasingly claim lives.

Medicaid costs have also increased markedly, from \$2.3 billion in 1967 to 69 times as much in 1990. Medicaid covers 250,000 nursing home patients (half of all), with an annual cost of \$34,000 for each. It also takes responsibility for the 158,000 crack babies born every year (\$1.8 billion a year), and the 35,000 people who have AIDS (Castro, 1991). Despite its being one of the fastest-growing spending programs in the U.S., Medicaid barely covers 40% of the poor at present. One of the greatest costs for Medicare and Medicaid is

inpatient hospital care, which contributes little to the quality of life for chronic patients. By seriously evaluating and promoting complementary treatment, care of aged people and those who are poor can be improved, while social dependency and social costs may be reduced.

### Changing Health Care Model and Broadening Opportunity

The challenge of complementary medicine is to the entire conventional health system. A holistic view of health advocates a new biopsychosocial model of health care versus the current model, which is based on the biomedical concept that specific agents cause particular diseases. This model has contributed to the successful control of certain types of diseases that were once prominent, such as tuberculosis, pneumonia, and other infectious diseases. The contemporary landscape of chronic illness and disability is quite different. It can strike the individual's quality of life, self-concept and body image, emotional balance, coping strategies, and environmental adjustment. It imposes a wide range of impacts at the individual, familial, and societal levels, involving multiple factors: psychosocial, environmental, nutritional, physiological, and genetic. This type of problem cannot be explained by a single invasive agent and, thus, needs an explication of alternative models, including contributors and interventions at multiple levels.

Wayne Jonas (1994), the OAM director, has presented a systems view of disease etiology and the perspective that alternative health care models take in approaching illness and treatment. In contrast to the conventional "specific cause model," his "contributory cause model" attempts to intervene at multiple levels and to understand illness in a pattern of impact from multiple etiologies on the global individual. In this model, causal relationship become less important than the balance of the whole being. Depression, for instance, should be treated not only by anti-depression drugs but also through modification of energy, life-style, and attitude, and by other training as well as social support and empowerment.

For centuries conventional and unconventional therapies have followed separate paths in their approaches to the same end--the improvement of human health. What is new today is an emerging need for integrating the two sides. Their cooperation may give rise to a mutual contribution with respect to the evolution of theories and practices and to a new model of health care. As Moskowitz (1993), the Principle Deputy Director for Science Policy and Technology Transfer at NIH, suggests, if some complementary medical practices are "validated and incorporated into routine health care, it is likely that significant savings of public funds will result." Through adequate evaluation, some unconventional modalities will find a proper place within mainstream care and may well bear significant implications for development of better care and rehabilitation for chronic conditions and disability.

### References

Castro, J. (1991). Condition: Critical. Time, 138(18), 34-40.

- Colgate, A.M. (1993). A preliminary inquiry into insurance coverage of alternative medicine. Bethesda, MD: NIH Office of Alternative Medicine. (Available from OAM/NIH, 9000 Rockville Pike, Building 31, Room 5B-38, Mail Stop 2182, Bethesda, MD 20892)
- Definitions Group. (1995, April). The Conference on Complementary & Alternative Medicine Research Methodology. Sponsored by the NIH Office of Alternative Medicine, Bethesda, MD.
- Eisenberg, D.M., Kessler, R.C., Foster, C., Norlock, F.E., Calkins, D.R. & Delbanco, T.L. (1993). Unconventional medicine in the United States. New England Journal of Medicine, 328(4), 246-252.
- Institute for Health Policy, Brandeis University. (1993). Substance abuse: The nation's number one health problem, key indicators for policy. Princeton, NJ: The Robert Wood Johnson Foundation.
- Jonas, W.B. (1994, September). Balancing quality research in acupuncture: Matching methodology with goals and materials. Paper presented at the meeting of the Society for Acupuncture Research, Washington, DC.
- Manga, P., Angus, D., Papadopoulos, C., & Swain, W. (1993). The effectiveness and cost effectiveness of chiropractic management of low-back pain. Ottawa, Canada: Pran Manga & Associates Inc.
- Moskowitz, J. (1992a). Address to the Advisory Panel on Unconventional Medical Practices, June, 17 1992. Unpublished paper. (Available from OAM/NIH, 9000 Rockville Pike, Building 31, Room 5B-38, Mail Stop 2182, Bethesda, MD 20892)
- Moskowitz, J. (1993). Statement before the Senate Appropriations Subcommittee on labor, health and human services, education and related agencies, June 24, 1993. Bethesda, MD: NIH Office of Legislative Policy and Analysis. (Available from OAM/NIH, 9000 Rockville Pike, Building 31, Room 5B-38, Mail Stop 2182, Bethesda, MD 20892)
- National Institutes of Health, Office of Alternative Medicine. (1993). Alternative Medicine, 1(2), 2.
- National Institutes of Health, Office of Alternative Medicine (OAM). (1994). Functional description.
- National Institutes of Health, Office of Alternative Medicine (OAM). (1996). Complementary and Alternative Medicine at the NIH, 3(1), 2.

Smith, M.O. (1989). The Lincoln Hospital drug abuse program. Testimony presented to the Select Committee on Narcotics at the House of Representatives. Bronx, NY: Lincoln Hospital Acupuncture Clinic. (Available from Lincoln Hospital Acupuncture Clinic, 349 E. 140th Street, Bronx, NY 10454)

Spencer, J. (1994). Exploratory centers for alternative medicine research. NIH Guide, 23(15), 2-12.

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### Author Notes

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## Section VI

### Understanding Cultural Attitudes

The access of people with disabilities to society can be affected by the attitudes of people both with and without disabilities, as well as general cultural attitudes. Adele S. Benzaken of Alfredo da Matta Institute, and Susan Bernet, Gary Linn, Sandra Hodess, and Barbara Brown from Tennessee State University illustrate how attitudes affect women with AIDS in Brazil, which has the second highest incidence of HIV/AIDS in the Americas. The authors studied beliefs about AIDS among female prostitutes in an effort to understand how to target prevention programs better. Their findings show that Brazilian prostitutes understand AIDS and its risk, and many have changed their behaviors by forcing partners to wear condoms. However, the majority of the prostitutes said they often found themselves in situations in which they could not protect themselves from the virus, such as when a male client refused to use a condom. These findings will be applied to current AIDS education efforts among prostitutes in metropolitan Manaus.

Cultural attitudes also inform the language and paradigms used to describe disability. David Pfeiffer of Suffolk University critiques the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) based on that assumption. He calls the paradigm of the ICIDH flawed and finds medicalization, eugenics, pathos, and ableism imbedded within its language. The underlying logic of the ICIDH is defective, he says, because it blames the victim rather than understanding that "society, not the disability, produces the handicap" (p. 146). The ICIDH is imbued with the concept of normality, which is tied to the specific values of Western, white, middle class, males. Pfeiffer explains that disability should not be associated with health, but with a political movement that seeks to end discrimination and exclusion.

The implications of societal attitudes toward genetics and the dwarf community led Ruth Ricker of Little People of America to propose a study of the social and ethical issues in genetic screening. In 1995, Little People of America started an information dissemination and discussion program on genetic screening issues. The concern lies in the surge in genetic screening in recent years and the implications of the Human Genome Project for the dwarf and short stature community. The medical model informs these genetic screening issues too often, and the disability rights orientation is rejected. This, Ricker says, leads to the continued devaluation of people with disabilities in society. If the disability community does not address the genetic screening issue, "we will lose the ground we have begun to gain with passage of the ADA and other statutes" (p. 153). She advocates that the dwarf community and the disability community at large must give parents up-to-date, realistic information, so they can make decisions with all the information at hand.

## **AIDS-Related Beliefs and Preventive Behaviors in a Group of Brazilian Prostitutes**

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J. Gary Linn, Ph.D.  
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Barbara E. Brown, R.N., Ph.D.  
Tennessee State University**

After the United States, the highest incidence of HIV/AIDS in the Americas is found in Brazil (Centers for Disease Control, 1994). Recently, the Pan American Health Organization (1994) reported that the proportion of cases attributable to heterosexual contact in this South American nation is increasing rapidly. The role that female prostitutes and their contacts play in the transmission of the infection is a significant issue for the public health community. The purpose of this analysis was to explore the beliefs and risk-related behavior of prostitutes in Manaus, a city of approximately 1.5 million inhabitants located in the Amazon basin. Recent literature suggests that sexual behavior related to risk is affected by cultural practices and social conditions. Research reported by the Women and AIDS program found that these factors, together with women's economic dependency, affect a woman's ability to negotiate safer sex practices. Their studies of Brazilian women clearly indicate that condom use and sexual practices are largely determined by men. Cultural norms give priority to male pleasure and control. Attempts to discuss or negotiate these issues can threaten family stability or physical safety (Gupta & Weiss, 1993).

There is a generally accepted double standard in Brazil that allows married men to choose other sex partners, including prostitutes. Young men commonly visit prostitutes both before and after marriage. Condom use may be infrequent, especially in rural areas (Flowers, 1988). Anal intercourse is considered a part of normal heterosexual practice by 40-50% of Brazilian adults (Parker, 1988). This combination of high-risk sexual behavior and the almost institutionalized existence of prostitution is of concern in HIV transmission.

There is a perception in Brazil that AIDS is a homosexual disease or that it is a problem found only in Sao Paulo or Rio de Janeiro (Benzaken, 1994). At one time, the epidemic was concentrated in these southeastern urban areas, but Brazil is a vast country with migration from rural to urban areas and to frontier regions. AIDS has spread throughout the country, but public awareness has lagged.

Brazil has undertaken a public awareness campaign, and most Brazilians are probably aware of AIDS and how HIV infection is spread. Condom use has been promoted

(Benzaken, 1994). In their 1994 review of studies on HIV prevention, Choi and Coates (1994) found evidence that educational programs increase use of condoms by commercial sex workers. However, prostitutes were found to use condoms less frequently in personal relationships.

In other studies of prostitutes, risk-related behavior was affected by education, but inaccurate beliefs coexisted. Even when risks were known, clients' demands for anal intercourse or their refusal to use condoms meant that economic considerations might override concern about infection. Women who insisted on condom use with clients did not use them with their husbands or boyfriends (Wirawan, Fajans, & Ford, 1993; McKeganey & Bernard, 1992). Clearly, an understanding of sexual attitudes and beliefs is important in identifying approaches to HIV risk reduction.

### The Sample

As part of an HIV/AIDS prevention program targeting sex workers in the city of Manaus, Amazonas, Brazil, 101 female prostitutes were interviewed in the summer and fall of 1993 by members of the AMAVIDA HIV outreach group about their AIDS-related beliefs and practices. The women were mostly young (67% were less than 31), poorly educated (90% had fewer than nine years of schooling), Catholic (88% reported being Roman Catholic), migrants (53% originated in some place outside of Manaus), and mothers (80% said that they had at least one child). The vast majority of the interviewees (85%) identified themselves as street prostitutes; while the remainder (15%) were employed in brothels. About one-fifth of the interviewees had other paid employment, but in all cases it was in unskilled or semi-skilled occupations (cleaners, street vendors, waitresses, shop workers, manicurists, or domestics).

### An Early Intervention

In the spring of 1993 the sex workers who were employed in brothels had been given HIV prevention education and condoms by members of the AMAVIDA organization. At that time, the brothel owners instituted a policy that required all male patrons to use condoms. None of the women who identified themselves as street prostitutes had received any systematic AIDS education prior to the interview.

### Findings

AIDS awareness and the perceived risk of contracting HIV/AIDS were relatively high among both types of female sex workers. Seventy-four percent of the street prostitutes and a similar proportion of the women employed in brothels reported that AIDS was a problem in Manaus, while sixty-two percent of those who met their clients on the street and fifty-eight percent of those who worked in a house of prostitution said that they were very worried about getting AIDS.

Virtually all of the sex workers employed in brothels, and almost all (86%) of the women who met their clients on the street, indicated that they had changed their sexual behavior

in order to reduce the risk of contracting HIV (see Figure 1). The most frequently mentioned behavior changes for both groups were: 1) using condoms for vaginal sex; 2) using condoms for oral sex; 3) using condoms for anal sex; and 4) reduced use of alcohol. Nevertheless, over two-thirds of the street prostitutes and one-half of the sex workers in brothels said that they found themselves in situations in which they could not protect themselves from the AIDS virus (see Figure 2). For both types of prostitutes, the most common situation was the refusal of a male client to use a condom. This was followed by not having a condom available, or not having money to purchase a condom. Although there are relatively few (n=15) sex workers from brothels in the sample, the data suggest that condom utilization policies established by brothel owners may not be enforced and/or have low rates of compliance.

Findings from this study informed a program that ultimately provided AIDS education to female sex workers throughout metropolitan Manaus.

### References

- Benzaken, A. (1994, June). Projeto Companheiras. A report issued by the Alfredo Da Matta Institute. (Available from Alfredo Da Matta Institute, Manaus, Brazil)
- Centers for Disease Control. (1994, July). AIDS Monthly Statistics. Atlanta, GA: Centers for Disease Control.
- Choi, K., & Coates, T.J. (1994). Prevention of HIV infection. AIDS 1994, 8, 1371-1389.
- Flowers, N.M. (1988). The spread of AIDS in rural Brazil. In R. Kulstad (Ed.), AIDS 1988: AAAS Symposia Papers. Papers presented at a symposium held by the American Association for the Advancement of Science in February 1988 (pp. 225-247). (Available from the American Association for the Advancement of Science, 1424 K Street, NW, Suite 700, Washington, DC 20005)
- Gupta, R.G., & Weiss, E. (1993). Women's lives and sex: Implications for AIDS prevention. Culture, Medicine and Psychiatry, 17, 399-412.
- McKeganey, N., & Bernard, M. (1992). Selling sex: Female street prostitution and HIV risk behavior in Glasgow. AIDS Care, 4, 395-406.
- Pan American Health Organization. (1994). AIDS in Latin America and the Caribbean: Current situation. Epidemiological Bulletin of the Pan American Health Organization, 15(1), 1-8.

Have you changed your sexual behavior in order to reduce your risk of getting AIDS

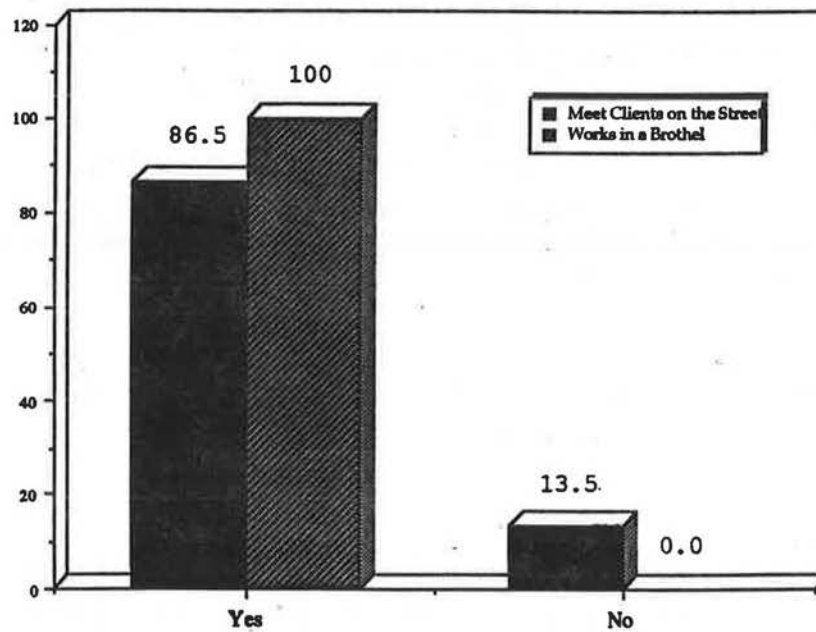


Fig. 1

Have you found yourself in situations in which you cannot protect yourself from the AIDS virus?

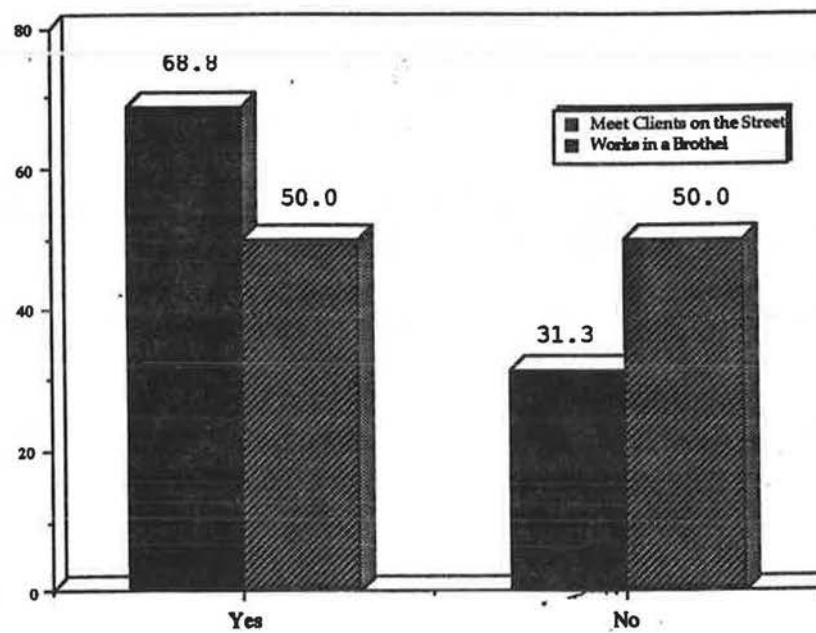


Fig. 2

- Parker, R.G. (1988). Sexual culture and AIDS education in urban Brazil. In R. Kulstad (Ed.), AIDS 1988: AAAS Symposia Papers. Papers presented at a symposium held by the American Association for the Advancement of Science in February 1988 (pp. 342-365). (Available from The American Association for the Advancement of Science, 1424 K Street, NW, Suite 700, Washington, DC 20005)
- Wirawan, D.N., Fajans, P., & Ford, K. (1993). AIDS and STDs: Risk behavior patterns among female sex workers in Bali, Indonesia. AIDS Care, 5, 289-303.

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## Major Problems with the ICIDH

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The purpose of this paper is to set forth some rather severe criticisms of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH). The ICIDH is an impressive document and the result of a considerable amount of hard work. However, it embodies the language and the perspectives of twenty years ago (Albrecht, 1992; Chamie, 1990; Heerkens, Brandsma, & van Ravensberg, 1993; Whiteneck, Charlifue, Gerhart, Overholser, & Richardson, 1992). There must be changes in its language and in its paradigm.

My argument has six concerns: (1) the underlying paradigm of the ICIDH is flawed; (2) the medicalization of disability is a problem; (3) the language of the ICIDH implies eugenics; (4) the ICIDH presumes a type of normality that is not normal; (5) there are problems of logic; and (6) the ICIDH contains handicapist language.

1. The Paradigm. The ICIDH is based upon a paradigm (the medical model) which embodies the sick role. In the sick role, a person is expected to obey the physician's orders to get well. While in the sick role, the person is released from social obligations. Decisions are made for, not by, the person in the sick role. Disability, however, is not sickness.

I became disabled from a disease, polio, but I am no longer sick. There are persons with disabilities who have chronic conditions, but there is a difference between a chronic condition and a disability. The medical model is not the proper paradigm for disability.

2. Medicalization. The ICIDH medicalizes disability. It discusses how its use helps identify social and vocational problems, but these problems are not medical ones. Being disabled does not mean that one is not healthy. There is a real difference between poor health and disability, which the ICIDH does not recognize. Making (or keeping) disability as a medical or health problem is not a solution.

The problem with the medicalization of disability is that it gives control to medical professionals, and this control is supported by the rest of society. A person with a disability is required to have his/her "doctor's" permission to do many things that a person without a disability undertakes with no one thinking of requiring a doctor's permission.

Perhaps in a very primitive society, the shaman is entitled to control the lives of others, but we are not in a primitive society. Perhaps in an authoritarian society, medical personnel could make controlling decisions, but we are not in an authoritarian society. The real danger with the medicalization of disability is the proclivity of medical personnel

to make decisions about the quality of life of persons with a disability. This proclivity connects directly to my next concern.

3. Eugenics. The ICIDH encourages thinking about the quality of life of persons with disabilities, which leads us to eugenics. Perhaps you think this is too strong a charge. Let me quote: "ICIDH concepts and definitions have been . . . used to determine various types of demographic indicators of Healthy Life Expectancy (impairment-free, disability-free, or handicap-free life expectancy)" (Wood, 1980, p. 3). In this quote, healthy is defined as not having an impairment, a disability, or a handicap.

The threat is very real. Every day, decisions are made by medical professionals based upon a judgment of the quality of life of people with disabilities. They use health-related quality of life measures. I have used several of their scales to measure my quality of life. For example, in the Disability/Distress Index, I ended in the Rosser disability category VII. The next lowest category (category VIII) contains people who are unconscious.

Other scales assign 1.00 to good health and 0.00 to death. In the Health Utilities Index (Mark I), I scored 0.53, which means I am half way between being healthy and being dead. In the Health Utilities Index (Mark II), I received 0.13 for the multiattribute value function and 0.63 for the multiattribute utility function. On the Quality of Well-Being Scale, I scored 0.48. I lost points because I use a wheelchair, thus indicating the "experts" view of wheelchair users.

In its present form, the ICIDH is dangerous to persons with disabilities (not just wheelchair users) as are all attempts to measure our quality of life (Kaplan, 1994; Nussbaum & Sen, 1993; Romney, Brown, & Fry, 1994). It is eugenics, and it should be recognized as such (Brock, 1993; Evans, 1994; Goode, 1994; Parmenter, 1994).

4. Normality. One of the major assumptions of the ICIDH is that there is a normal way to do things. Social norms do exist, I admit, but they are only usual ways of carrying out an activity. They are not ideal goals that we must attain, and deviations from the norms are not to be viewed as bad, limiting, or in any way disabling.

5. Logic. The ICIDH has flaws in its logic. The diagram found in Wood (1980, p. 30) illustrates the relationship between impairment, disability, and handicap. The arrows imply causality which does not exist (Heerkens et al., 1993, pp. 14-17). Society, not the disability, produces the handicap. It is clearly blaming the victim.

Through this process the victim is blamed. Too frequently in past history and in our society today, this process happens. We could explain racial discrimination in this manner:

### Impairment

### Disability

### Handicap

skin color, features ----->	irresponsible	
	low IQ ----->	discrimination
	smelly	
	shiftless	
	lazy	

We could go on and make diagrams explaining religious, ethnic, age, gender, or any type of discrimination.

6. Handicapist Language. A few quotes: "On the other hand, disabilities reflect failures in accomplishments so that a gradation in performance is to be anticipated" (Wood, 1980, p. 14). "Disabilities are not threshold phenomena; they reflect failures in accomplishments" (Wood, 1980, p. 38). "An individual with reduced competence in any of these dimensions of existence is, *ipso facto*, disadvantaged in relation to his peers" (Wood, 1980, p. 38). The dimensions are: orientation, immediate physical needs, mobility, occupying time, social relationships, and socioeconomic activity. Nelson Rockefeller was a billionaire, was elected to be governor of the State of New York, and was chosen to be Vice President of the United States. He had a learning disability. Documents had to be read to him. He also had to have someone clean his house, take care of his children, cook his meals, drive his car, and do other things. We can say a similar thing about Franklin Roosevelt except that he had no trouble reading and writing, only with mobility. You can protest that Rockefeller and Roosevelt had this assistance because they were wealthy, but we do not know if they could have done all or none of these things. My point is that assuming ipso facto that someone with a disability is disadvantaged is handicapist.

### Conclusion

The paradigm of the medical model which underlies the ICIDH produces the medicalization of disability, which then permits medical personnel to make decisions about the lives of people with disabilities which are not medical decisions. Measuring the quality of life of people with disabilities using their impairments leads to eugenics. People judged to have a poor quality of life are denied resources beyond health services. They then become candidates for euthanasia.

The ICIDH is also based upon the concept of normality. However, this concept is that of Western, white, middle class, male values. In addition, there are logical problems. The most far reaching is the direction of causality from impairment all the way to handicap. The causality of the diagram (Wood, 1980, p. 30) puts the blame for the discrimination on the person with a disability. It must change.

The terminology of the ICIDH is handicapist. It devalues the person with a disability, describing disability in negative and pejorative terms. The ultimate consequence of the use of the ICIDH is to oppress people with disabilities. We are blamed for the discrimination we encounter, and we are told that we are inadequate. Our natural

reaction is to internalize the shame and the blame. We then behave in a subservient manner. If we protest, then we are described as not accepting "reality." We are "counselled" to follow the sick role and become well. However, not being sick, we will never become "well." We forever remain in the dependent role, and the need for the ICIDH is clearly established.

Disability is not a health question, but rather it is a political one. It consists of discrimination and exclusion in the same way that race, color, gender, religion, and other characteristics result in discrimination and oppression. The ICIDH features pathos and dependence. These two invoke pity. It leads to the need for supervision. But disability is not like that.

Disability is a natural experience. Everyone will become a person with a disability. Perhaps only for a few moments before death from a massive heart attack, but most people will spend a large amount of time as a person with a disability. People with disabilities have a right to be different and a right to be treated equally. Therefore, the WHO must revise the ICIDH. The language must be modified. The paradigm must change.

#### References

- Albrecht, G. (1992). The disability business. Newbury Park, CA: Sage Publications, Inc.
- Brock, D. (1993). Quality of life measures in health care and medical ethics. In M.C. Nussbaum & A. Sen (Eds.), The quality of life (pp. 95-132). Oxford, England: Clarendon Press.
- Chamie, M. (1990). The status and use of the International Classification of Impairments, Disabilities and Handicaps (ICIDH). World Health Statistics Quarterly, 43(4), 273-80.
- Evans, D.R. (1994). Enhancing quality of life in the population at large. Social Indicators Research, 33(1-3), 47-88.
- Goode, D. (Ed.). (1994). Quality of life for persons with disabilities: International perspectives and issues. Cambridge, MA: Brookline Books.
- Heerkens, Y.F., Brandsma, J.W., & van Ravensberg, C.D. (1993). A survey of criticism about the classification of impairments and the classification of disabilities of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH). Amersfoort, The Netherlands: WHO Collaborating Center for the ICIDH.
- Kaplan, R.M. (1994). Using quality of life information to set priorities in health policy. Social Indicators Research, 33(1-3), 121-163.

- Nussbaum, M.C., & Sen, A. (Eds.). (1993). The quality of life. Oxford, England: Clarendon Press.
- Parmenter, T.R. (1994). Quality of life as a concept and measurable entity. Social Indicators Research, 33(1-3), 9-46.
- Romney, D.M., Brown, R.I., & Fry, P.S. (Eds.). (1994). Improving the quality of life of people with and without disabilities. Social Indicators Research, 33(1-3), 1-272.
- Whiteneck, G.G., Charlifue, S.W., Gerhart, K.A., Overholser, D., & Richardson, G.N. (1992). Quantifying handicap: A new measure of long-term rehabilitation outcomes. Archives of Physical Medicine and Rehabilitation, 73, 519-526.
- Wood, P. (1980). International Classification of Impairments, Disabilities, and Handicaps: A manual of classification relating to the consequences of disease. Geneva, Switzerland: World Health Organization.

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**Do We Really Want This?**  
**Little People of America, Inc., Comes to Terms with Genetic Testing**  
**(a Project to Study the Ethical and Social Implications**  
**of Genetic Screening for the Dwarf and Short Stature Community)**

Ruth E. Ricker, B.S.  
Little People of America, Inc.

Little People of America, Inc. (LPA) is a genetic support group with over 5,000 members, primarily individuals with dwarfism and their families. For 35 years it has been led by adults with various forms of short stature. The membership is diverse in background, profession, and disability. However, there is a common feeling of self-acceptance, pride, and community that has been compared to more traditional disability groups and the deaf community. The concept of a dwarf community is illustrated in part by the dozens of dwarf children from all over the world adopted by LPA members. However, the perspective on the idea of community would be different for the 90% of people with short stature who are not involved in LPA, as membership in LPA denotes a self-selection or identification process. Some short statured people are involved in the larger disability community and not in LPA. Dwarfs and other persons of short stature vary as to whether they identify themselves as having disabilities. This seems to be evolving. In the younger people who have been able to benefit from disability rights legislation, there is more comfort and identity as people with disabilities.

It seems that the dwarf community, and possibly other genetic support group communities, differ from the wider disability arena in their perspectives on the medical field. We tend to have positive, on-going relationships with the geneticists who work with our families (short and average-sized parents). Some of the leading geneticists serve as a sort of primary care specialists for dwarf children whom they see in their clinics, monitoring when and if intervention by other specialists is warranted (neurology, orthopedics, etc.) This is a concept I have found hard to explain to some friends in the disability community who cannot fathom such warm friendships with the medical community, especially geneticists. We are also collaborating on joint projects to establish better and more effective medical services.

In the last year, the gene mutations for the most common types of dwarfism have been discovered. Until now, LPA's general membership, like the general U.S. population, has had limited knowledge about the Human Genome Project and its potential ramifications.

Many dwarf couples have used ultrasound prenatally in attempts to detect fetuses with fatal (in infancy) dwarfing conditions (which occur up to 25% of the time depending on specific diagnosis, when both parents are dwarfs). However, this technology was not reliable, in that there were a number of false positive and false negative results. Due to skeletal design, most dwarf women have high risk pregnancies necessitating C-section deliveries, adding to the seriousness of family planning decisions. Many short statured

couples have just gained the ability to screen prenatally through amniocentesis, due to the gene mutation(s) being known.

On the other hand, average-sized parents who happen to bear dwarf children by chance have not had any prenatal information before the final weeks of pregnancy, and, only then, when it was guessed from an ultrasound being done for other reasons. Many of these couples have been told horrifying and incorrect things about their fetus/baby in terms of whether or not it had a dwarfing condition, the specific diagnosis, and the severity of health concerns. This will change in the relatively near future with knowledge of the gene mutations.

Most LPA members have been unaware of the potential screening for (non-fatal "regular" or otherwise "healthy") dwarf fetuses by average-sized individuals, and that, potentially by the end of the century, a pregnant woman could walk into a medical provider's office and go through a checklist of the 100 most common "birth defects" for the ones she would choose to screen out, or her insurance provider might present her with a list of conditions they would not cover in a child she chose to carry to term.

We instituted an information dissemination and discussion program on genetic screening issues for the membership in January 1995. We are providing information about the Human Genome Project, the status of the genetic mutations and tests known for dwarf diagnoses, and articles exploring the various perspectives on the ethical and social implications, potential risks, and benefits to individuals and to our community. The literature being provided includes articles by several bioethicists, disability policy writers, and our own members. We are broaching the possibility with the membership that, within one or two generations, we could see dramatically fewer dwarf children being born to average-sized parents and pressure on parents of all sizes to screen for and to prevent the birth of "healthy" dwarf babies, as is being done to reduce spina bifida and Down Syndrome. To some of our members, based on their life experiences or their own philosophies, this possibility is one with which they are comfortable. There are individuals in the wider disability community who feel similarly, that they would not want to bring a child into the world to experience health-wise and socially what they have "suffered." The disability rights perspective maintains that these persons with disabilities have subscribed to their own oppression. This would apply to persons who want their children to avoid the discrimination they have encountered, but perhaps not the physical pain and health concerns.

We held forums at several regional meetings in the spring of 1995. The process will culminate in a national forum at the annual conference in July 1995 and a national position statement. The first position statement was issued in July 1994 at the press conference where the finding of the achondroplasia gene was announced. (Achondroplasia is the most common type of dwarfism.)

Dwarfism is not all that different from other disabilities and genetic conditions in general regarding these issues. We have historically been viewed through the medical model of disability. In that light we are concerned about health policies which emphasize

victimization and suffering and devalue human variation. Eugenic public health policies, such as widespread prenatal testing, also avoid discussion of the point that a majority of disabilities are not "birth defects," so that prenatal screening may not generate major cost savings.

Many disability rights advocates involved in the genetics ethics debate see it as a black and white issue for the disability community as a whole. Their perspective is understandable. They indicate that we have to stand firm and say that genetic screening, prenatal diagnosis, and related technologies should not be allowed, period, for any disability, paralleling the view of those bioethicists who feel screening for gender should not be allowed. This disability rights perspective against all prenatal screening holds that we need to be concerned with the impact on the larger community over time, even if that involves personal pain for individuals with dwarfism or other disabilities who will not have the option of prenatal screening for those instances when most people might consider the process justifiable, such as for a condition which is predictably fatal in infancy.

One more factor to be weighed in--Is there a chance we could get prenatal screening for disability outlawed in the U.S. anyway? If not, perhaps, we should shift our energies.

The overwhelming concern in the disability community should be that, if we allow the continued devaluation of persons with disabilities, we will lose the ground we have begun to gain with passage of the ADA and other statutes. How far is the widespread acceptance of the principles and practice of prenatal screening from the eugenics concepts of euthanasia and assisted suicide? These are all natural extensions of the devaluation of certain groups in society, including dwarfs and others with genetic and/or disabling conditions.

The screening for Down Syndrome and spina bifida has become so routine, even though these are not consistently, seriously disabling conditions. Yet, to say that plays into the line of thought that it is OK to put disabilities on a scale or continuum; these disabilities are acceptable, and those are justifiably screened. We should not allow ourselves to become so divided over these specifics that we lose on the big issue. Because Down Syndrome and spina bifida are not even fatal conditions, it is easy to imagine that dwarfism would be screened for routinely with the same pressures placed on mothers, especially under rationed health care and other futuristic scenarios, that they already have placed on them to be tested for Down Syndrome and spina bifida.

Average-sized parents of young dwarf children have indicated that the prospect of prenatal screening scares them . . . thinking of what they might have done if they had been presented with the decision to make during their pregnancy, with the same or less or worse information than they were given when their child was diagnosed in infancy. Once these parents received current, realistic information and talked with other parents and individuals of short stature, it was fine, a whole different ballgame. This is what is scary . . . women and their families making life and death decisions without enough information.

**Little People of America:  
Position Statement on Genetic Discoveries in Dwarfism (1996)**

The short statured community and society in general have become increasingly aware of the eugenics movements (efforts to improve human qualities by selection of certain traits) in medical history in the U.S. and abroad, and the traditional desire of parents to create perfect, healthy children. Along with other persons affected by genetic disorders, we are not only concerned as to how our health needs will be met under dramatically changing health care systems, but how the use of genetic technologies will affect our quality of life, medically, as well as socially. What will be the impact of the identification of the genes causing dwarfism, not only on our personal lives and our needs, but on how society views us as individuals?

The gene for achondroplasia, the most common type of dwarfism, was discovered in 1994. Achondroplasia is caused by a gene mutation that is the same in 98% of the cases. The mutation, affecting growth, especially in the long bones, occurs early in fetal development in one out of every twenty thousand births. Since the achondroplasia gene discovery, genes for many other forms of dwarfism have been located and identified, including those for spondylepispheal dysplasia, diastrophic dwarfism, and pseudoachondroplasia. These discoveries occurred much more rapidly than either the members of Little People of America (LPA) or the medical community had anticipated. Suddenly and unexpectedly, LPA was placed right in the middle of the medical, social, and ethical debate surrounding the brave new world of genetic technology. At that time, formal discussions and education on genetic issues had not yet begun within LPA. Most of us, like most of society, had limited knowledge about the Human Genome Project and the social and ethical implications associated with the possible applications of genetic technology. On one hand, the breakthrough may be used to help achondroplastic couples to identify a fetus with "double dominant" or homozygous achondroplasia, a fatal condition that occurs in 25% of births to those couples. It is also possible that the tests for genes causing short stature will become part of the increasingly routine and controversial genetic screening given to all expectant mothers.

LPA's discussion of these possibilities brought forth a strong emotional reaction. Some members were excited about the developments that led to the understanding of the cause of their conditions, along with the possibility of not having to endure a pregnancy resulting in the infant's death. Others reacted with fear that the knowledge from genetic tests such as these will be used to terminate affected pregnancies and therefore take the opportunity for life away from children such as ourselves and our children. The common thread throughout the discussions was that we as short statured individuals are productive members of society who must inform the world that, though we face challenges, most of them are environmental (as with people with other disabilities), and we value the opportunity to contribute a unique perspective to the diversity of our society.

LPA is revitalizing its public education campaign so that people of all sizes, including potential parents and health care professionals, will be properly informed of the realities

of life with short stature. LPA is made up of over five thousand individuals with more than a hundred types of dwarfism, their families, a medical advisory board, and other friends and professionals. We are teachers, artists, lawyers, doctors, accountants, welders, plumbers, engineers, and actors. We represent every nationality, ethnic group, religion, and sexual orientation. Many of us have secondary disabilities as well. We are single and married, with families with spouses, parents, and children who are average-sized and dwarfed, biological, and adopted. For LPA members there is a common feeling of self-acceptance, pride, community, and culture. Since 1957, LPA has provided peer support and social and educational opportunities to thousands of individuals with dwarfism and their families. We have been educating society and the medical community about the truths of life with short stature and working to dispel commonly held myths. With the discovery of various genes and mutations causing dwarfism, our educational and advocacy efforts have become ever more important in the face of a rapidly changing genetic frontier.

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## Section VII

### Unheard Voices

Many of the needs of various subsets of the disability community go unmet because their concerns go unheard or just plain ignored. However, disability scholars are beginning to focus attention on the specific issues of ethnicity and gender and people with disabilities.

Elaine Makas refines her attitudinal scale for the American Indian/Alaska Native population. Her revision points up significant differences that must be understood in assessing attitudes toward American Indians with disabilities. First, the term "disability" means something different in the Native American community than in the "majority" culture; disability is associated with functional loss rather than medical condition. Secondly, American Indian/Alaska Native cultures emphasize interdependence over the independence model of the U.S. society at large. In addition, the independent "majority" culture is seen as overly competitive by the Indian community. Thirdly, Native American respondents said they have a more positive sense of self, so a disability does not cause shame, but is seen as the will of God. However, not all these differences found by Makas resulted from cultural diversity. Instead, respondents said that poverty, unemployment, limited health care, and environmental barriers also caused large differences between the "majority" culture and native cultures. Finally, Makas says the calm and polite manner in which statements are made in American Indian/Alaska Native cultures could affect the ability of native people with disabilities to receive proper disability services. Those from the "majority" culture may decide to give services only to those people who express their needs loudly and adamantly; therefore, the voices of American Indians and Alaska Natives with disabilities often go unheard.

Lance Egley reports on a project conducted by the World Institute on Disability's PAS Research and Training Center to assess the most culturally-appropriate methods for providing personal assistance services (PAS) to American Indian populations. Egley highlights some of the practical and policy barriers that interfere with the provision of PAS to people on tribal lands. He makes many valuable recommendations to increase the availability, accessibility, and desirability of such services. Paramount among these suggestions are the necessity for respecting American Indian people, their values, and their traditions; and the importance of seeking the active involvement of potential recipients of these services in all phases of program planning and implementation.

Llewellyn Cornelius of the University of Maryland at Baltimore shows how African Americans and Latinos with disabilities may have health care needs that are somewhat different from those in the "majority" culture. Cornelius examines how race/ethnicity affects continuity of care. In general, he found that persons with disabilities, compared to persons without disabilities, have lower continuity of care with their regular doctor. The findings, however, indicate that insurance coverage and perceived health, rather than

race or ethnicity, are correlated with low continuity of care. So the status of being a disabled person, rather than race/ethnicity, was the biggest predictor of poor health care services.

Baqar Husaini of Tennessee State University also found predictors other than race in a study of chronic depression. The findings show that elderly whites and elderly blacks have similar predictors of depression. Gender, however, did show differences. For women, depression rises because of chronic medical problems rather than stressful life events. For men, chronic depression is predicted by stressful life events, not medical condition. Husaini says the findings suggest that depression in elderly males is more sociogenic, whereas, for females, depression is related to both medical and social factors. The program suggested from this study is one that emphasizes stress reduction, illness prevention, and increased social interaction for elderly people to better prevent depression.

Ann Cupolo, Marlene Strong, and Linda Barker of Berkeley Planning Associates found that women with disabilities face additional gender-related barriers to key services. Guided by participatory action research (PAR), the researchers included women with disabilities as an advisory board to monitor all aspects of the project. The project identified nine barriers to social services for women with disabilities: violence against women with disabilities, neglect of adoption opportunities for women with disabilities, AFDC eligibility problems, child custody issues, inaccessible child care, need for aging services, inaccessible reproductive health services, inaccessible substance abuse services, and non-inclusive programs for girls with disabilities. A common stereotype that results in several of the barriers is an incorrect societal belief that women with disabilities are asexual and cannot be mothers. Another stereotype causes barriers to substance abuse programs and reproductive health issues for teens: that girls with disabilities are naive and childlike. In addition, minority women with disabilities and women with hidden disabilities are often not considered in policies for women with disabilities.

Lara Michelle Brown of UCLA continues this theme by showing how AIDS policy discriminates against women. She says a major social construction that informs AIDS policy is that people with AIDS are victims (children or hemophiliacs) or social deviants (homosexuals, drug abusers, prostitutes). Women are included in this construct when they are seen as a "vector of transmission" through pregnancy, sexual practices, or drug abuse. Otherwise, women are excluded from AIDS policy. This exclusion can be seen in AZT drug trials in 1992, which included only 4% women. The result is that women are given AZT prescriptions even though the FDA is unclear on specific side effects for women. Brown clearly delineates how social constructions affect policymaking process and may render a whole gender group voiceless in the process.

## The People Speak, but No-one Listens

Elaine Makas, Ph.D.

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In 1994-1995 I developed a measure of attitudes toward people with disabilities based on standards set by American Indians and Alaska Natives who have disabilities. This attitudinal measure was constructed on the same underlying principle that I have used to develop other scales: that the standards by which attitudes are measured must be set by the people toward whom these attitudes are targeted. This concept, which I call the MIDS (or Modified Issues in Disability Scale) technique, is described more fully in Makas (1994c). It has resulted, thus far, in four attitudinal measures: the (original) MIDS (Makas, 1985; 1991); the revised MIDS (MIDS-R) (Makas, 1993; 1994b); the African-American/Caribbean Black Version of the MIDS (MIDS-AA/CB) (Makas, 1994a; 1996); and the American Indian/Alaska Native Version of the MIDS (MIDS-AI/AN) (Makas, 1995).

This chapter summarizes a comparative study, done as a by-product of the development and validation of the MIDS-AI/AN, to identify potential ethnic cultural differences related to attitudes toward disability and toward people with disabilities. For the purposes of this comparison, American Indian/Alaska Native cultural values were considered to be those expressed by three groups who participated in the development of the MIDS-AI/AN: a) the American Indian judges<sup>1</sup>--57 American Indians and Alaska Natives with disabilities; b) the American Indian "good attitudes" respondents--55 nondisabled people who were selected by the American Indian judges as individuals with particularly positive attitudes toward people who have disabilities;<sup>2</sup> and c) the American Indian students--46 American Indian students at two Southwestern universities. "General population" values were considered to be those expressed by three comparable groups: a) the general population judges--44 ethnically-diverse<sup>3</sup> people with disabilities who participated in the development of the MIDS-R (Makas, 1994b); b) the general population "good attitudes" respondents--the 45 nondisabled participants in the validation of the MIDS-R who had been selected by these general population judges as individuals with particularly positive attitudes toward

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<sup>1</sup> Even though this group includes several Alaska Natives and a number of people who prefer to be called "Native Americans" or "Indigenous People," the group will be referred to here collectively as "American Indians" (with apologies to those preferring other terms).

<sup>2</sup> It is important to note that approximately half of the individuals in this "good attitudes" group are not American Indians themselves. As a result, their responses do not necessarily reflect Indian values. However, since they were individually selected by the American Indian judges as persons with good attitudes, it is reasonable to assume that their attitudes and behaviors are culturally acceptable to Indian people.

<sup>3</sup> The general population groups approximated the ethnic composition of the U.S. To represent this balance, each general population group included one American Indian.

people with disabilities; and c) the general population students--55 ethnically-diverse students from two Southwestern universities who participated in the validation of the MIDS-AI/AN.

All groups responded to the same 100 statements related to disability. The two groups of judges responded in a way which they felt represented "the most positive attitudes toward people with disabilities," while the two "good attitudes" groups and the two student groups responded to the items honestly.

With the obvious exception of ethnicity, these three paired groups were demographically similar. The two "good attitudes" groups, for example, were approximately the same age, reported similar amounts of contact, and had equally (and disproportionately) high numbers of females. The two student groups were also demographically equivalent. The American Indian/Alaska Native judges, however, tended to be older than their "general population" counterparts (averaging 46.4 years old and 39.1 years old, respectively). This was due, undoubtedly, to the fact that a number of American Indian/Alaska Native elders were specifically recommended to the researcher as potential judges.

Forty-five of the statements in the item pool were selected for comparative analysis. They included all items which met the criteria for inclusion in the MIDS-AI/AN and/or the MIDS-R (i.e., high consensus among the judges and high variance among the student respondents). These 45 items were placed into general categories (e.g., education, parenting/childcare) by the researcher and distributed to nine "interpreters" along with the relevant statistics for each of the six respondent groups (i.e., percentages of consensus among judges, and mean scores among "good attitudes" people and among students). The nine interpreters were American Indians/Alaska Natives with disabilities; all but one had participated as judges in the development of the MIDS-AI/AN. They included five men and four women from diverse tribal affiliations and geographic locations. The interpreters were asked to review the data and to offer explanations, based on their own views and on those of others within their communities, for the differences between the three "American Indian" groups and the three "general population" groups.

The following are the most frequently-mentioned interpretations of differences between the responses of the "American Indian" groups and the "general population" groups. Although not all interpreters agreed on all issues, there was considerable consistency in the interpretations that were offered.

One important issue that was raised by the interpreters was that American Indian and Alaska Native participants may have been basing their responses on a different definition of "disability" than that used by those in the "general population." All but one interpreter agreed that "disability" represents a functional loss rather than a medical condition. One interpreter said that a man who had lost his right arm would not be considered to have a disability unless he were unable now to do the things with his left arm that he had previously done with his right arm. He added that this man would be considered to "have a disability" by many within the general population even if the medical condition had no functional impact on his life. This might explain the rather large differences between the

responses of the American Indian judges/"good attitudes" people and the general population judges/"good attitudes" people on two items: "A physical disability changes a person's life completely and causes her/him to think differently about everything"; and "There is no clear distinction between 'having a disability' and 'not having a disability.'"

One cultural factor which most interpreters noted was an American Indian/Alaska Native emphasis on interdependence, in contrast to a general population focus on independence. Several interpreters suggested that the rural nature and small size of many Native communities necessitates such interreliance. One interpreter said, for example, that he had difficulty with the wording of one item--"A person who has a disability might be better off if he/she chose friends who do not have disabilities"--since it states that one chooses one's friends. He suggested that, within a traditional Indian community, "You don't choose friends. You get friends." This same concept was expressed clearly by another of the interpreters. She said, "You have to associate with the people around you, whether they have disabilities or not."

The value placed on interdependence was also used to explain other responses. All but one interpreter stressed the incompatibility between the "majority culture" notion of competition and the American Indian concept of interdependence. Several noted, for example, that everyone has a role within an interdependent community, and that the role depends, in large part, on the person's functional abilities. The allocation of a special role, however, does not imply that the role is less critical. One interpreter gave a vivid example. He said that elders are not expected to do certain tasks (because of their age), but they are respected for the roles that they now fill (because of their age). Such an interpretation is directly related to several of the education and employment items--for example, the American Indian judges' greater agreement with the statement: "Certain jobs should be set aside for blind persons so that they don't have to compete directly with persons who do not have disabilities."

Nearly all of the interpreters noted that the phrase "our competitive society" in one item was very inappropriate and might have been confusing to some respondents because it applies primarily to the "majority culture." Two interpreters suggested that, because the judges knew that the researcher was not Indian, they may have thought the statement referred to a willingness to fit into her society. Other interpreters noted that the item was offensive; it implies that there is only one society, a competitive (i.e., "majority culture") one, to which all persons are expected to adapt. (These comments strongly support the inclusion of people from the target group in all phases of research--in this case, in the development of the items as well as in the setting of standards in response to the items.)

Another important difference between the American Indian groups and the general population groups that some interpreters attributed to the value placed on interdependence relates to expressions of kindness and offers of assistance. Several said, for example, that they accept unnecessary assistance because a refusal might be seen as a rejection of friendship and an insult to the community.

Most interpreters reacted quite strongly to the item--"Most people who have disabilities are not ashamed of their disabilities"--even though the differences between the responses given by the American Indian groups and the general population groups were not large. Several interpreters felt that American Indian/Alaska Native cultures, to a greater extent than the "majority culture," teach people to value themselves. One interpreter stated, for example, that a person must respect his/her body because it is "God-given." Another, relaying information from several elders, said that, if a person has a disability, it is because that is "the path you have chosen to live." There was considerable consensus that being ashamed of one's body was an insult to the Creator.

A similar feeling of noninterference with God's will was evident in comments made by some of the interpreters in response to another item--"It is more humane to allow a child with a severe disability to die at birth than for her/him to live as a person with a severe disability." One interpreter noted that this statement implies choice; she said that such issues are decided solely by God.<sup>4</sup>

The issue on which the interpreters showed the greatest agreement was that many of the differences found between the American Indian groups and the general population groups were the result of experiential, rather than cultural, differences: greater environmental barriers, more extensive poverty, considerably higher unemployment, and less access to health care. Each interpreter pointed out at least one instance in which the differences simply acknowledged economic realities. The lower consensus among the American Indian judges than among the general population judges on full educational mainstreaming, for example, may have been the result of less financial support for local schools in Indian communities than in "majority culture" communities. A parent who wants his/her child to go a special school may simply recognize the fact that the local school may not have the financial resources to provide needed access. This "rejection" of full mainstreaming within the "regular school system" should not be misunderstood as a rejection of the mainstreaming concept.

Environmental realities were also cited as the reason for other differences that may be erroneously classified as philosophical differences. For example, in response to one item--"Since a physical disability interferes with certain activities, the disability is foremost in the mind of a person with a disability practically all the time"--most interpreters noted that physical access is virtually non-existent on many reservations, and, therefore, a disability is much more apparent than it would be in a more accessible environment. One interpreter suggested that this may account for the difference in responses to another item--"People who have disabilities are generally no more anxious or tense than people who do not have disabilities." He said that he, himself, gets frustrated whenever he goes back to his reservation because it is so difficult for him to get around in such a "rural, rural area."

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<sup>4</sup> The use of the term "God" may have been a gesture of kindness by several of the interpreters, who may have felt that the researcher might be unfamiliar with non-"majority culture" concepts of creation and spirituality.

Perhaps the most important difference found as a result of these analyses was not in the responses given to specific items, but, rather, in the manner in which these responses were given. The American Indian judges, students, and "good attitudes" people showed a reluctance to respond strongly to any of the items. Because those within the equivalent general population groups showed no similar tendency, it would be easy for someone from the "majority culture" to conclude that American Indians/Alaska Natives do not care as much about the issues being addressed, or that they are passive. Taking this one step further, it is possible to imagine that Native people may not be receiving the services that they want and need, simply because those who control the distribution of these resources do not recognize a need unless it is stated adamantly, as is the custom within the "majority culture." As one interpreter said, "You tell them what you need. There's no need to be rude about it." Unfortunately, many service providers are so overwhelmed with requests that they rely on the "majority culture" practice in which "the squeaky wheel gets the oil." The solution to the dilemma probably rests somewhere between the two extremes (which, as seen above, is itself a very American Indian/Alaska Native concept): Perhaps service providers can be taught that serious needs can be expressed in a very calm and polite manner, and American Indians/Alaska Natives can be cautioned that some people within the general population equate the severity of need with the volume of voice and the physical adamancy with which it is expressed.

#### References

- Makas, E. (1985). The MIDS (Modified Issues in Disability Scale). Washington, DC: The George Washington University.
- Makas, E. (1991). In the MIDST: Modified Issues in Disability Scale testing. In G. Kiger & S. Hey (Eds.), The social organization of disability experiences (pp. 109-114). Salem, OR: The Society for Disability Studies and Willamette University.
- Makas, E. (1993). The MIDS (Modified Issues in Disability Scale, Transitional Version). Lewiston, ME: Lewiston-Auburn College of the University of Southern Maine.
- Makas, E. (1994a). The MIDS-AA (Modified Issues in Disability Scale, African-American Version). Lewiston, ME: Lewiston-Auburn College of the University of Southern Maine.
- Makas, E. (1994b). MIDS-life changes: The updating of the Modified Issues in Disability Scale. In E. Makas & L. Schlesinger (Eds.), Insights and outlooks: Current trends in disability studies (pp. 129-137). Portland, ME: The Society for Disability Studies and The Edmund S. Muskie Institute of Public Affairs.
- Makas, E. (1994c). The Modified Issues in Disability Scale (the MIDS): Growing pains and showing gains at age seven. In G. Kiger, S.C. Hey, & J.G. Linn (Eds.), Disability studies: Definitions and diversity (pp. 15-21). Salem, OR: The Society for Disability Studies and Willamette University.

Makas, E. (1995). The development of the MIDS-AI/AN: The American Indian/Alaska Native Version of the Modified Issues in Disability Scale. Flagstaff, AZ: Northern Arizona University, American Indian Rehabilitation Research and Training Center.

Makas, E. (1996). Respecting cultural differences in disability research: Attitudes toward disability and people with disabilities among African-Americans. In E. Makas & L. Schlesinger (Eds.), End results and starting points: Expanding the field of disability studies (pp. 57-62). Portland, ME: The Society for Disability Studies and The Edmund S. Muskie Institute of Public Affairs.

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## Personal Assistance Services for American Indians with Disabilities

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Personal Assistance Services (PAS) for people with disabilities have been increasingly available in the U.S. for more than a decade, but they are little known to American Indians with disabilities, especially those who live in rural areas. At the same time, American Indians have higher rates of disability than the general population. The proportion of American Indians with Activities of Daily Living/Independent Activities of Daily Living limitations (6.7%), the people most likely to use PAS, is 25% greater than in the general population (5.4%) (Adler, 1990). Among American Indians, the proportion of people with functional limitations is over 20%, and the proportion with work disabilities is almost three times higher than the general population. The proportion with disabilities by some definition is one third, even reaching 75% among American Indian people age 65 and older (Altman, 1990).

In 1994 the World Institute on Disability's PAS Research and Training Center (RTC) began research to determine what approaches to PAS would best serve American Indians with disabilities. Interviews were conducted with dozens of American Indians who know about disability services, direct service providers in the Navajo Nation, 16 American Indians with disabilities, and 2 family members of American Indians with disabilities. These interviews were conducted at the 1994 PAS and Independent Living Conference in Colorado, by telephone, and during a visit to the Navajo Nation. Further interviews with American Indian PAS consumer experts and American Indians with disabilities are planned.

Diverse cultural relationships to disability and to PAS exist among the 542 American Indian tribes in the U.S., which are comprised of nearly two million American Indians and Eskimos (Bureau of the Census, 1991). For many features, PAS requires cultural competence with the particular tribe. To approach this diversity, information was sought from cross-tribal sources. Informal interviews revealed many cultural features, some of which are common to many tribes.

Honoring Cultural Values. Adapting PAS for American Indians requires recognition of basic values honoring family and group interdependence, privacy, and spirituality. Preliminary returns from a survey of American Indians with disabilities show that most American Indians obtain PAS primarily from unpaid family members. While family providers are also common among Caucasian people and have most of the same advantages and disadvantages, the value placed on family providers is more intense among American Indians. Indians have more extended family contacts and more desire to obtain assistance from extended family members who preserve cultural traditions.

American Indians also emphasize group, clan, or tribe. At Chinle, Arizona, and Shiprock, New Mexico, Navajo providers wanted group interviews. Julie Clay (1992) says values about interdependence mean American Indians interpret "independent living" to reflect "enhancement of an individual's ability to fulfill his or her role within the family and tribe" (p. 48) more than the Independent Living Movement's definition of having control over one's own life based on choice of service options that minimize reliance on others. Indian interpretations allow more family and tribal input on how PAS is provided. Interviews confirmed Clay's statement. Treva Roanhorse (personal communication, April 1994), Section 130 Director of the Navajo Nation, says that consumer control is important to Indians, but only in the context of other issues: holistic approaches and family involvement.

Indians also honor nature and spiritual values. Maria Estes (personal communication, April 1994) of the Lower Brule Sioux describes the role of spirituality:

Probably the most crucial aspect of cultural difference is our spirituality. How disability is taken depends on the family. Traditional people consider birth of a disabled child to be a message from God. The family feels obligated to help the child. Often the child may be seen as a positive event. If a family is not spiritual, they may feel shame about having a disabled child, especially concerning mental retardation or developmental disability.

Carol Locust (personal communication, May 1994), a Cherokee from the Native American RTC, ties spirituality to health. To American Indians, ill health means disharmony among mind, body, feelings, and spirit, or between the individual and society. Clay (1992) notes that disability, in itself, does not indicate disharmony. Among more traditional American Indian people, disability has meaning in the natural order. One interviewee stated about her child who has a developmental disability, "I don't know why this happened, but the creator must have had a purpose." Sometimes a child with a disability is even considered, in the Dakota word, "wakan" or spiritual. They are supposed to be very intuitive and see the future (Estes, personal communication, April 1994). However, a person's reactions to disability and how the person responds to the environment through a disability may indicate disharmony if the responses do not fit well. Carol Locust (1985) notes, "In the Indian belief, it is each person's responsibility to keep this protective shield [wellness] strong and beautiful, not only for his own well-being but for the well-being of the tribe" (p. 17). The ultimate measure of the spiritual value of PAS would lie in its ability to assist the person with a disability to improve relationships and reactions to events.

Practical Implications of Values. Values about timing may conflict with those of agency providers. Indian values about doing things "in time" on a natural time scale may conflict with agency providers' clock scale "on time" values. In one case, PAS was discontinued to a client with no phone who was away on family business when the paid assistant showed up. Language is also a critical cultural element. For many tribes, a portion of the population cannot be served unless service is in traditional language.

For tribal members the principle alternatives to unpaid, family PAS are entering an institution or moving to an urban area that has services. Either option usually destroys family bonds and tribal identity. Urban PAS programs present barriers of no transportation, unfamiliar culture, high cost, and use by differing age groups, even for urban Indians.

Practical Barriers to Paid PAS. PAS for American Indian people with disabilities are often not available, not desirable, and not accessible, and they do not meet the total need. When services exist, many attendants fail to provide agreed-upon services. Because of poverty, low wages and benefits, unreliable transportation, and widespread alcoholism, it is difficult to find reliable attendants on tribal lands. Rural conditions may prohibit transporting attendants during winter, so that, practically speaking, nearby neighbors and relatives are the only possible source of paid PAS.

While most people with disabilities lack sufficient private funds to pay for their own PAS, American Indians with disabilities are even poorer. In addition, most tribes have few resources to support members with or without disabilities. Having any paid PAS is atypical for Indian Nations. A visit to the Navajo Nation did reveal several PAS programs, but they were insufficient to meet the need. Accessible, non-medical transport and respite services were high priority needs. Furthermore, additional services, such as hauling wood, fuel, or water, may be required in rural, remote areas.

Policy Barriers. Existing policies limit adapting publicly-funded PAS for American Indians by prohibiting family providers. Federal Medicaid PAS funds fail to reach American Indian Nations because states administer them on an optional basis. Rural states, where most Indian reservations are located, are most likely to opt out of federal programs, leaving Indian Nations with no federal funds for which they can apply. Practical limitations make regular Medicaid health dollars the only available federal PAS money to tribes. Thus, both the Red Lake Nation (Chippewa) and the Lower Rosebud Sioux are developing medically-oriented PAS programs.

Multiple, overlapping jurisdictions deter improvements because of the difficulty placing responsibility. Services are uncoordinated and operate independently of each other. On Navajo lands, disconnected PAS efforts reflect the disconnected federal and state funding sources upon which they draw. For all tribes, federal, state, and tribal jurisdictional conflicts make even benefits to which American Indians with disabilities are entitled difficult to obtain. Local officials often fail to recognize an Indian's legal right to use services provided by the states and send applicants to tribes for PAS (regardless whether any such tribal services exist). The Bureau of Indian Affairs and Indian Health Service (IHS) pay for institutional care, but not for community services. One regional IHS director recognized the potential benefits of PAS for reducing medical costs from secondary disability, but could not see releasing any IHS funds to support services.

## Recommendations

Provide information about PAS and its availability. Barriers of distance, language, and reading level must be overcome. The IHS, serving more than two thirds of all Native Americans, should become a better vehicle for distributing information about PAS. Outreach should be done in the context of American Indian culture by incorporating American Indian designs in materials; contacting people at traditional Indian gathering places, such as Navajo Chapter Houses and urban American Indian Centers; emphasizing how the family can be included and respected while using paid services; and, in traditional areas, conducting outreach in American Indian languages.

Assure availability by providing Medicaid directly to tribes. More paid PAS are needed for American Indians, both on and off the reservations. Federal Medicaid Personal Care Option and Waiver funds fail to reach American Indian Nations because states administer them on an optional basis, and rural states opt out. American Indian Nations, which remain economically dependent on the U.S. despite being politically self-governing, need access to Medicaid PC Option and Waiver monies directly from the U.S. government, regardless whether the state(s) within which their lands lie have adopted these programs. When a tribe elects to have Medicaid programs directly from the U.S. government, they may be asked to provide matching funds based on tribal per capita income. Generally, match rates among American Indian tribes will be lower than among states. Just as individual American Indians can opt to rely on federal and state resources rather than on tribal ones, tribes should also be able to opt to use state programs. When tribes work through states, they should not be required to pay any portion of the state match.

Empower tribes as entry points. Tribes should be permitted to develop their own community programs with funding similar to other government programs serving adjacent geographic areas.

Make existing publicly-funded PAS accessible. The most important and consistent American Indian value needing accommodation by PAS services is the high value placed on family. Allow paid family providers, including programs using PC Option and Waiver money, at least for people who reside on tribal lands. Most Indian consumers are young and fit the independent living model well. Individual provider models allow more user control and are more easily integrated with community services.

Provide services that consider cultural needs, skills, and language of specific tribes. State programs should hire more American Indians in locations where American Indians are concentrated. Values to be considered include serving entire families, having no time expectations for time units smaller than a day, cultural relativism, intuitive communication and economy of words, teaching by example, provider participation in native communities and friendships with native individuals, and allowing spiritual concern for all to guide activities and expectations. There is also need to further define specific Indian values which are relevant to providing effective PAS. Program design must consider the degree of acculturation of individuals receiving or managing PAS.

Train officials. Train local PAS eligibility administrators about their legal obligations to supply PAS to American Indians with disabilities. State programs need a liaison person from within the tribal community. American Indian individuals and tribes also need representatives on state councils, and they may need advocates in the highest U.S. government levels to get adequate attention (Liebowitz, cited in Powers, 1989).

Conduct a tribal demonstration project which combines PAS provided by the project with paid and volunteer family providers. The project should include a sub-component demonstrating PAS delivery in remote areas. Peer support and consumer training in the management of attendants should be available as well as respite and emergency services. The project and any other new programs must take a long view of change and need long-term funding commitments. Tribal programs should employ American Indian people for both skilled and unskilled services. A demonstration should be followed by suitable funding for more widespread services based on the plan and on discoveries of the demonstration project.

Disseminate PAS information to American Indian tribes and information on the provision of culturally-appropriate services to publicly funded PAS programs.

#### References

- Adler, M. (1990). Preliminary analysis of the 1989 Supplement on Income and Program Participation. Unpublished manuscript.
- Altman, B.M. (1990, April). Disability among Native American adults: Self reports of functional, activity and work limitations. Paper presented at the Annual Meeting of the Western Social Science Association, Portland, OR.
- Bureau of the Census. (1991). American Indian population by tribe for the United States: Regions, divisions and states: 1990, CPH-L-99. Washington, DC: United States Department of Commerce.
- Clay, J.A. (1992). Native American independent living. Rural Special Education Quarterly, 11(1), 41-50.
- Locust, C. (1985). American Indian beliefs concerning health and unwellness. Tucson, AZ: Native American Research and Training Center, University of Arizona.
- Powers, L. (1989, Spring). Arizona RSA of Native American populations. American Rehabilitation, 15, 5-6, 32.

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## Continuity of Care for Minorities with Disabilities

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In 1987, approximately 38 million American adults (ages 18-64) reported either having a work disability or limitations in non-work activities (Cornelius & Altman, 1995). African and Latino Americans were disproportionately represented among persons with disabilities (Keil, Gazes, Sutherland, Rust, Branch, & Tyroler, 1989; O'Donnell, 1989). African Americans with and without disabilities face many access problems, including a lack of a usual source of care, a lack of insurance, and having to travel farther and to wait longer to see a provider than white Americans (Cornelius & Altman, 1995; Cornelius, Beauregard, & Cohen, 1991). In addition to encountering similar barriers to care, Latinos also encounter language barriers (Andersen, Giachello, & Aday, 1986; COSSHMO, 1990).

However, even when they gain access to medical care, African Americans and Latino Americans rely on a different type of care for meeting their medical needs. Traditionally, they have been disproportionately dependent on hospital outpatient clinics and emergency rooms for their care, settings reported to provide less continuity of care to their patients than physicians' offices or clinics (Fleming & Andersen, 1986).

The purpose of this paper is to examine the degree of continuity of care experienced by persons with disabilities, given their health needs, and to determine whether the degree of continuity of care varies by race/ethnicity.

### Method

The data for this study come from the 1987 National Medical Expenditure Survey (NMES) (Edwards & Berlin, 1989). NMES, sponsored by the U.S. Department of Health and Human Services, is part of a series of national health care expenditure surveys, most recently the 1980 National Medical Care Utilization and Expenditure Survey and the 1977 National Medical Care Expenditure Survey. Like these earlier surveys, NMES uses a national probability sample of the U.S. civilian noninstitutionalized population. A national probability sample of approximately 15,000 households was selected for this study, producing a total of 36,400 respondents. The survey was fielded in four rounds, with interviews conducted at approximately four-month intervals, to collect information on sociodemographic characteristics, insurance coverage, use of services, expenditures, and sources of payment for the period of January 1 to December 31, 1987. A fifth short telephone interview obtained tax filing and other supplementary information. The cumulative response rate for the five rounds of data collection was 79.7%.

### Measurement of Disability

In this study disability is defined as difficulty in performing the major social role, work, or other activities associated with non-major social roles which are attributable to specific health problems. The measure is based on answers to four questions from NMES. Two questions reflect whether or not the individual is able to work, and two indicate if the individual has difficulty performing other roles related to shopping, recreation, etc. There are four categories of disabilities defined: 1 "none"; 2 "limits in non-work related activities"; 3 "limits in kind or amount of work or major activity"; or 4 "unable to work at all." This is a measure found frequently in analyses using data from the National Health Interview Survey of the U.S. Department of Health and Human Services, National Center for Health Statistics. Thus, for the purposes of these analyses, persons with disabilities were defined as having either limits in non-work related activities, limits in kind or amount of work or major activities, or unable to work at all.

### Computation of the Indicator of Usual Provider Continuity

The overall degree of continuity of care was computed by dividing the number of visits to one's regular physician by all physician visits. All physician visits for persons who were pregnant during 1987 and all persons with fewer than three physician visits were excluded from the analysis. After the overall score was computed, the data were then split based on the continuity of care score, where a score of zero through 0.5 on the index was defined as low continuity, and a score over 0.5 and less than or equal to 1 was defined as high continuity. It should be noted that, unless otherwise indicated, only statistically significant differences ( $p < .05$ ) are discussed below.

### Findings

Displayed in Table 1 are characteristics of the continuity of care with one's regular physician by disability status. The most important finding that should be noted is that persons with disabilities are more likely than persons without disabilities to have low continuity of care with their regular physician. Overall, 37.7% of the persons without a disability had low continuity of care with their regular physician. By contrast, 56.5% of Americans who reported some limitation in activities have low continuity of care with their regular physician.

Regardless of disability status, insurance and perceived health were correlated with differences in the continuity of care, while race/ethnicity, the characteristics of the usual source of care, and the characteristics of the respondents regular physician were not. Among persons with disabilities, 56.7% of those with private insurance had low continuity of care, compared to 65.4% of persons with Medicare insurance. Among persons without disabilities, 38.4% of persons with private insurance had low continuity of care, compared to 50.5% of persons with Medicare insurance. At the same time, while close to half of the persons with disabilities in good or excellent health had low continuity of care, 62.4% of those in fair or poor health had low continuity of care. Finally, while 36.7% of persons

Table 1. Percent of those with low continuity of care with their regular doctor, by selected characteristics, 1987

Population	Total	With Disability			Total	Without Disability		
		White	African <sup>a</sup>	Latino <sup>a</sup>		White	African <sup>a</sup>	Latino <sup>a</sup>
Overall	56.5	57.3	53.9	47.5	37.7	38.6	34.7	27.2
Health Insurance <sup>b</sup>								
Private insurance	56.7	57.4	51.1	42.7	38.4	39.0	34.8	29.8
Medicaid	62.8	64.5	61.7	56.7	42.9	49.2	42.1	26.6
Medicare	65.4	66.1	61.3	56.1	50.5	50.2	58.9	42.8
Uninsured	45.6	47.1	49.6	32.9*	29.8	33.3	19.6	20.0
Perceived Health Status								
Fair/poor	62.4	64.3	55.7	49.2	45.8	48.1	47.2	29.2
Good/excellent	49.4	49.6	49.2	43.5*	36.7	37.7	31.9	26.7
Services Provided at Source								
Emergency care after hours	60.8	61.4	58.2	53.1	44.3	45.1	42.1	32.3
Evening hours	53.9	54.5	51.2	43.7	39.7	40.8	36.5	27.9
Saturday hours	56.9	57.0	59.5	50.9	42.7	43.8	38.1	32.5
Other weekend	50.1	50.2	52.5	43.6	34.5	34.8	38.7	29.4
Characteristics of Regular Physician								
White American	62.6	62.6	62.0	63.1	47.6	47.9	45.2	45.2
African <sup>a</sup> American	68.8	70.0	68.9	49.5	52.6	55.7	52.7	26.4
Latino <sup>a</sup> American	63.8	63.8	72.8	59.7	44.1	49.5	43.2	39.9
Male	63.3	63.4	63.3	63.1	47.7	47.9	49.3	41.2
Female	61.3	63.5	58.5	26.7*	51.9	54.1	42.2	38.1
Generalist <sup>c</sup>	61.2	61.1	64.2	58.1	44.1	44.6	46.5	33.9
Specialist <sup>c</sup>	66.0	66.5	62.3	61.8	53.6	53.9	44.9	53.2
Visit for Preventive Care	60.1	60.7	56.7	52.8	40.2	41.3	34.9	29.2

<sup>a</sup> Persons identified in NMES as "Blacks" are referred to as "African Americans" in this analysis, persons identified as "Hispanic" are referred to as "Latino Americans" in this analysis.

<sup>b</sup> Insurance coverage in round 4

<sup>c</sup> Respondents were asked to determine whether their regular physician was a generalist or in primary care or whether he/she was a specialist. If respondents stated that their regular physician was a specialist, then the specialty of the physician was asked.

\* relative standard error of a percent  $\geq 30\%$

Source: Agency for Health Care Policy and Research, 1987 National Medical Expenditure Survey

without disabilities who were in good or excellent health had low continuity of care, 45.8% of persons without a disability who were in fair or poor health also had low continuity of care.

### Conclusions

In summary, the biggest difference in the continuity of care was by disability status. Persons with a disability were much more likely than persons without a disability to have low continuity of care (56.5% vs. 37.3%). Second, there were differences in the continuity of care that were unrelated to disability status. In particular, differences were found by insurance status and perceived health.

These findings suggest that persons with disabilities are at risk of not receiving the type of medical care they need. At the same time, the data suggest that factors such as insurance can improve the continuity of care. Other studies have noted how continuity of care can lead to less duplication of services, lower costs, and greater patient satisfaction (Becker, Dracchman, & Kirscht, 1974; Breslau & Haug, 1976; Fletcher, O'Malley, Earp, Littleton, Fletcher, Greganti, Davidson, & Taylor, 1983). In light of these findings, it is important to develop insurance packages that provide more flexibility and better reimbursement to enhance the continuity of care for persons with disabilities.

### References

- Andersen, R.M., Giachello, A.L., & Aday, L.A. (1986). Access of Hispanics to health care and cuts in services: A state of the art overview. Public Health Report, 101(3), 238-252.
- Becker, M.H., Dracchman, R.H., & Kirscht, J.P. (1974). A field experiment to evaluate various outcomes of continuity of physician care. American Journal of Public Health, 64(11), 1062-1070.
- Breslau, N., & Haug, M.R. (1976). Service delivery structure and continuity of care: A case study of pediatric practice in the process of re-organization. The Journal of Health and Social Behavior, 17(4), 339-352.
- Cornelius, L.J., & Altman, B.M. (1995). Have we succeeded in reducing barriers to medical care for African and Hispanic Americans with disabilities? Social Work in Health Care, 22(2), 1-17.
- Cornelius, L.J., Beauregard, K., & Cohen, J. (1991). Usual sources of medical care and their characteristics (DHHS Pub. No. PHS 91-0042). Rockville, MD: U.S. Department of Health and Human Services, Agency for Health Care Policy and Research.

- COSSHMO (National Coalition of Hispanic Health and Human Services Organizations). (1990). . . . And access for all: Medicaid and Hispanics. Washington, DC: COSSHMO--National Coalition of Hispanic Health and Human Services Organizations.
- Edwards, W.S., & Berlin, M. (1989). National medical expenditure survey: Questionnaires and data collection methods for the household survey and the survey of American Indians and Alaska Natives (DHHS Publication No. PHS 89-3450). Rockville, MD: U.S. Department of Health and Human Services, Agency for Health Care Policy and Research.
- Fleming, G., & Andersen, R.M. (1986). The municipal health services program: Improving access while controlling costs? Chicago, IL: Pluribus Press.
- Fletcher, R.H., O'Malley, M.S., Earp, J.A., Littleton, T.A., Fletcher, S.W., Greganti, M.A., Davidson, R.A., & Taylor, J. (1983). Patients' priorities for medical care. Medical Care, 21(2), 234-242.
- Keil, J.E., Gazes, P.C., Sutherland, S.E., Rust, P.F., Branch, L.G., & Tyroler, H.A. (1989). Predictors of physical disability in elderly Blacks and Whites of the Charleston Heart Study. Journal of Clinical Epidemiology, 42(6), 521-529.
- O'Donnell, R.M. (1989). Functional disability among the Puerto Rican elderly. Journal of Aging and Health, 1(2), 244-264.

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## Predictors of Chronic Depression among Elderly Blacks: Gender Differences

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Depression represents one of the most common lifetime mental disorders among older Americans. The lifetime prevalence rate is reported to be 10%, which is second only to the 13.3% lifetime prevalence rate for alcoholism (Robins, Helzer, Weissman, Orvaschel, Gruenberg, Burke, & Regier, 1984). In fact, during any six-month period, nine million American adults suffer from a depressive illness. Depression often interferes with normal functioning, and it also contributes to the suffering of those who take care of the depressed individual.

Previous studies have pointed to three etiological factors which contribute to the onset of depression: (1) medical problems; (2) stressful life events and other social stressors; and (3) lower levels of social support. Specific medical problems such as thyroid dysfunctioning, arthritis, and circulatory, digestive, genitourinary, and endocrine system problems, either individually or collectively, have been reported to contribute to elevated levels of depression symptoms (Aneshensel, Frerichs, & Huba, 1984; Hall, 1983; Hankin & Locke 1982; Haug, Belgrave & Gratton, 1984; Husaini, 1984; Husaini, Moore, Bryant, & Cain, 1994). Similarly, individuals experiencing general stress and acute life changes resulting from stressful episodes are more likely to manifest both physical and psychiatric symptoms, including severe depression (Husaini & Moore, 1991; Husaini, Linn, & Whitten-Stovall, 1988). Moreover, the depression level is likely to elevate when such events (e.g., death of a spouse) are unexpected (Husaini & Neff, 1980). It is important to note that among elderly females, compared to their male peers, undesirable events increase depression levels (Murrell & Norris, 1984).

Studies of both instrumental and emotional social support show its significant role in an individual's psychological well-being. Those with high levels of social support (resulting from large network size and high frequency of contact with the network) live longer, report fewer chronic medical problems, and are better able to cope with life stressors (Berkman & Breslow, 1983; Berkman & Syme, 1979; Blazer 1982; Dean & Ensel, 1982; Dean & Lin 1977; House, Robbins, & Metzner, 1982; Husaini, Moore, & Cain, 1994; Husaini & Von Frank, 1985; Russell, 1986). Because previous studies were based primarily on elderly Whites, it is not clear whether these predictors are similar for elderly Blacks, and whether these predictors vary by gender.

## Method

### Sample

The data presented are from a randomly selected sample of elderly Blacks (n = 600) residing in Nashville, Tennessee. The sample had more females (70%) than males (30%). Only 25% were married, and more than half (56%) lived alone. Approximately 60% lived in their own homes, while the remaining 40% lived in high-rises for the elderly. The median education level of the sample was below 11th grade (with no gender differences), and the median age was 70. The median income was less than \$9,000, with one-third living on Social Security Income.

### Concept Measurements

Depression. Prevalence of depressive symptoms was measured by the Center for Epidemiologic Studies Depression (CES-D) Scale, which measures depressive symptoms experienced during the last seven days. Subjects scoring above 16 are considered to be highly symptomatic (Radloff, 1977). This scale has been widely used in community and patient studies and is reported to be highly reliable (Husaini, Neff, Harrington, Hughes, & Stone, 1980; Radloff, 1977).

Socio-medical stressors. Chronic medical problems were measured by a checklist of chronic medical disorders which included problems of all organ systems that are chronically affected by aging (e.g., heart diseases, diabetes). Social stressors were measured by Holmes & Rahe (1967) list of 32 stressful life events along with an item which focused on general stress currently being experienced (highly stressed = 5; no stress = 1).

Supportive network. Social support measurements covered three areas: (1) network size, that is, the number of relatives, confidants, and friends nearby; (2) instrumental and emotional support received from the network; and (3) perceived support as measured by a scale developed by Cutrona, Russell, & Rose (1986). These items of social support have been widely used by Husaini and his colleagues in previous cross-sectional and longitudinal studies (e.g., Husaini & Linn, 1985).

Data were collected at three different times (T1, T2, & T3) with a lag of about twelve months between T1 and T2, and six months between T2 and T3. Multiple regression models were developed to determine variation over time in predictors of depression for each gender. In each analysis, both the present and past set of hypothesized predictors were included when examining current depression. For example, the equation predicting T2 depression included depression scores at T1 along with T2 values of other variables.

## Results

### Predictors of Depression among Females

The analyses indicate that prior level of depression among females significantly contributed to current depression at both T2 and T3. Depression at T1 was related to depression at T2 ( $\beta = .20, p < .05$ ), and depression at T2 contributed to depression at T3 ( $\beta = .39, p < .05$ ). Further, greater number of medical problems, as well as stress in general and a decreased supportive network in the preceding 12 months, were also significant predictors. Stressful life events, however, did not emerge as a predictor of depression among the elderly females in any year. This finding is similar to the one reported by Blazer (1980).

### Predictors of Depression Among Males

Regression analyses revealed that prior depression among the males also predicted current level of depression, whether measured at T2 ( $\beta = .23, p < .03$ ) or at T3 ( $\beta = .25, p < .05$ ). Further, stressful life events, stress in general, and a decreased supportive network also emerged as strong predictors of current depression. Chronic medical problems were unrelated to current depression either at T2 or T3 among the elderly males.

## Discussion

Within the context of the longitudinal data, the analyses revealed that predictors of depression among elderly Blacks are very similar to those reported for Whites in previous studies. Chronic depression among both groups exists over time because of prior depression, increasing medical problems, general stress, decreasing size of networks, and overall lower social support. However, within the Black elderly group, there are gender similarities and differences in the factors that contribute to the chronicity of depression. While prior depression, decreasing social support, and smaller network predict depression among both males and females, the major gender differences in predictors pertain to chronic medical problems and stressful life events. Among females, depression is significantly elevated by chronic medical problems and not by stressful life events. The obverse is true for males in that current depression is unaffected by chronic medical problems, but the chronicity of the depression is increased by stressful life events. This suggests that depression among elderly Black males is more sociogenic in nature, while, among elderly females, depression may be precipitated by both medical and social factors.

From a programmatic perspective, these findings suggest that programs aimed at reducing depression among elderly persons should focus on activities that reduce general stress, help prevent certain chronic illnesses, and develop social skills which are necessary to increase the network size. Such a program was offered by us through a six-week, twice-weekly group therapy program for a sample of elderly residents of high-rises in Nashville. The program had several modules, including health maintenance, cognitive therapy, reminiscing therapy, grief therapy, social skills, and management of stress. The program was successful in significantly lowering depression and increasing network size among

program participants (Husaini, Castor, Whitten-Stovall, Moore, Naser, Linn, & Griffin, 1991). The long term effects of the program are currently being evaluated.

#### References

- Aneshensel, C., Frerichs, R., & Huba, G. (1984). Depression and physical illness: A multiwave, nonrecursive, causal model. Journal of Health & Social Behavior, 25(4), 350-371.
- Berkman, L., & Breslow, I. (1983). Health and ways of living. New York, NY: Oxford University Press.
- Berkman, L., & Syme, S.L. (1979). Social networks, lost resistance, and mortality: A nine-year followup study of Alameda residents. American Journal of Epidemiology, 69, 186-204.
- Blazer, D.G. (1980). Life events, mental health functioning and use of health care services by the elderly. American Journal of Public Health, 70, 1174-1179.
- Blazer, D.G. (1982). Social support and mortality in an elderly population. American Journal of Epidemiology, 115, 684-694.
- Cutrona, C.E., Russell, D., & Rose, J. (1986). Social support and adaptation to stress by the elderly. Journal of Psychology & Aging, 1, 47-54.
- Dean, A., & Ensel, W. (1982). Modelling social support, life events, competence, and depression in the context of age and sex. Journal of Community Psychology, 10, 392-408.
- Dean, A., Lin, N. (1977). The stress-buffering role of social support. Journal of Nervous & Mental Disease, 165, 403-417.
- Hall, R.C. (1983). Psychiatric effects of thyroid hormone disturbance. Psychosomatics, 24(1), 7-17.
- Hankin, J.R., & Locke, B.Z. (1982). The persistence of depressive symptomatology among prepaid group practice enrollees: An exploratory study. American Journal of Public Health, 72, 1000-1007.
- Haug, M., Belgrave, L.L., & Gratton, B. (1984). Mental health and the elderly: Factors in stability and change over time. Journal of Health & Social Behavior, 25(2), 100-115.
- Holmes, T.H., & Rahe, R.H. (1967). The social readjustment rating scale. Journal of Psychosomatic Research, 11, 213-218.

- House, J.S., Robbins, C., & Metzner, H.C. (1982). The association of social relationships and activities with mortality: Prospective evidence from the Tecumseh community health study. American Journal of Epidemiology, 116(1), 123-140.
- Husaini, B.A. (1984, October). Types of physical illness and depressive symptoms among rural blacks and whites. Paper presented at the Fifth Biennial Research Symposium of 1890 Land Grant Colleges and Universities, Dallas, TX.
- Husaini, B.A., Castor, R., Whitten-Stovall, R., Moore, S.T., Naser, W., Linn, J.G., & Griffin, D. (1991). An evaluation of a therapeutic health program for the black elderly. Journal of Health & Social Policy, 2(2), 67-85.
- Husaini, B.A., & Linn, G. (1985). Predictors of depression: A rural followup study. Nashville, TN: Center For Health Research, Tennessee State University.
- Husaini, B.A., Linn, J.G., & Whitten-Stovall, R. (1988). Stress and depression in rural and urban American communities: Longitudinal studies. Indiana Journal of Social Psychiatry, 2(4), 331-334.
- Husaini, B.A., & Moore, S. (1991). Social and psychological well-being of the black elderly living in high-rises for the elderly. Journal of Gerontological Social Work, 16(3/4), 57-58.
- Husaini, B.A., Moore, S.T., Bryant, C., & Cain, V.A. (1994, April). Arthritis disability, depression, and life satisfaction among the elderly: Racial differences. Paper presented at the Annual Meeting of the Western Social Sciences Association, Albuquerque, NM.
- Husaini, B.A., Moore, S.T., & Cain, V.A. (1994). Psychiatric symptoms and help-seeking behavior among the elderly: An analysis of racial and gender differences. Journal of Gerontological Social Work, 21(3/4), 177-195.
- Husaini, B.A., & Neff, J.A. (1980). Characteristics of life events and psychiatric impairment in rural communities. Journal of Nervous and Mental Disease, 168(3), 159-166.
- Husaini, B.A., Neff, J.A., Harrington, J.B., Hughes, M.D., & Stone, R. (1980). Depression in Rural Communities: Validating the CES-D Scale. Journal of Community Psychology, 8(2), 20-27.
- Husaini, B.A., & Von Frank, A. (1985). Life events, coping resources, and depression: A longitudinal study of direct, buffering, and reciprocal effects. Research in Community and Mental Health, 5, 111-136.

- Murrell, S.A., & Norris, F.H. (1984). Resources, life events, and changes in positive affect and depression in older adults. American Journal of Community Psychology, 12(4), 445-464.
- Radloff, L.S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. Applied Psychological Measurement, 1, 385-401.
- Robins, L.N., Helzer, J.E., Weissman, M.M., Orvaschel, H., Gruenberg, E., Burke, J.D., & Regier, D.A. (1984). Lifetime prevalence of specific psychiatric disorders in three sites. Archives of General Psychiatry, 41, 949-968.
- Russell, D.W. (1986, November). Stress, social support, and physical and mental health among the elderly: A longitudinal causal model. Paper presented at the Annual Meeting of the Gerontological Society of America, Chicago, IL.

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## Meeting the Needs of Women with Disabilities: A Blueprint for Change

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Women with disabilities often face double discrimination and multiple barriers to achieving important life goals. Some of these barriers are gender-related and shared by nondisabled women; some are disability-related and shared by men with disabilities. But many barriers and needs are simply unique.

Berkeley Planning Associates, a small employee-owned company operated and staffed principally by women (including several with disabilities), was awarded a three-year Field Initiated Knowledge Dissemination Research Grant from the National Institute on Disability and Rehabilitation Research designed to promote increased access for women with disabilities to services that meet their needs. This project focuses on access to mainstream (non-disability focused) social services systems that are important to women. The project involves identifying key service access issues; conducting a national Delphi process of women with disabilities to identify priority issues for in-depth study; and disseminating information to practitioners, policy-makers, and women with disabilities about service barriers and approaches to make services more accessible.

### The Problem

The types of barriers women with disabilities face are many and varied. They include employment discrimination, poor access to health care (particularly reproductive health services), and limited educational opportunities. Women with disabilities are often ill-served by mainstream service systems on which many women rely and which many need, such as child care centers and organizations assisting victims of domestic violence. Unique problems are faced by older women, as well as girls and young adult women, with disabilities. Minority women with disabilities face even greater discrimination. Despite the difficulties women with disabilities have encountered in these areas, their concerns have largely been neglected by organizations and service systems aimed at meeting the needs of either women or persons with disabilities. These problems permeate all levels of service delivery from the individual hotline counselor to the directors of relevant organizations and the major policy researchers in the field. Individual service providers may discriminate against women with disabilities by making insensitive remarks, referring them to inappropriate agencies, being physically inaccessible, or having policies which deny service access. These barriers can occur at all stages of the service process—prior to intake (e.g., a service provider neglects to assess a woman's need for a service, such as treatment for an alcohol problem); at the point of intake (e.g., a sign language interpreter is not provided at a reproductive health center); or when she tries to use a service (e.g.,

a battered women's shelter is inaccessible). Addressing these problems will require working with a variety of people in the service system including program administrators, service providers, consumers, and policy-makers.

### Participatory Action Research

The project is guided by the principles of participatory action research. One reason why the concerns of women with disabilities have been ignored or inadequately addressed by mainstream service systems is because few women with disabilities have had visible roles within these systems. Therefore, this project has a strong commitment to use the principles of participatory action research.

These principles influence this project in a number of ways. First, the research team is comprised primarily of women with disabilities. In addition, we work closely with an Advisory Board, which is presently made up of 19 women, 17 of whom have disabilities. It is disability-diverse and ethnically-diverse, and advisory members are experts in various fields of study. The Advisory Board assists with and monitors all aspects of the project including referring staff to relevant experts, helping identify research and literature in the areas of study, and reviewing written materials. Members also referred participants for the Delphi process, and they will assist with planning for the dissemination of project materials.

### Common Themes: Barriers To Mainstream Social Services

We have identified barriers within each of the nine service systems under study. These service systems include:

- Sexual Assault/Domestic Violence: Both of these topics involve violence against women with disabilities. For girls and women with disabilities, the risks are increased (Sobsey, 1994).
- Adoption: Adoption agencies, like other social services agencies, tend to assume that women with disabilities cannot be good parents because of their disabilities, an issue made more difficult by the fact that, currently, there are not any standardized definitions or agreed-upon assessments of good parenting ability (DeAngelis, 1995). Little attention has been paid to the problems of adults with disabilities who want to adopt children.
- Aid to Families with Dependent Children: Mothers who have disabilities are eligible for these benefits, just like any other mothers who are poor, but they may have considerably greater difficulty negotiating the complicated system of eligibility rules and requirements, which increasingly require that adults receiving assistance either work or participate in training as a condition of benefit receipt.

- **Child Custody/Child Protective Services:** These topics involve the public welfare system, which tends to assume that women with disabilities cannot be good parents because of their disabilities (Kirshbaum, 1994).
- **Child Care:** Although many child care programs are beginning to integrate children with disabilities, they generally are not becoming more accessible to mothers with disabilities (Cohen, 1994).
- **Aging:** Since the incidence of disability is higher for women than for men over the age of 50, and since women tend to live longer than men, we can expect to see substantially higher numbers of older women with disabilities (Hasler, 1991). People with disabilities that were acquired at a younger age are also living longer. These factors are resulting in higher numbers of older women with disabilities who need access to aging services.
- **Reproductive Health Services:** Access to reproductive health services is a huge problem of great concern for women with disabilities. Common beliefs that women who have disabilities are asexual and are not valued as prospective mothers contribute to this lack of access.
- **Substance Abuse:** The literature and experts in the field of substance abuse and disability strongly indicate that women with disabilities face a unique set of risk factors for substance abuse, although both substance abuse programs and disability agencies are largely unaware of these factors and provide little access to programs which meet their needs.
- **Youth Program Services:** Although female adolescents with disabilities can benefit greatly from mainstream school and community-based youth programs, there are many barriers which prevent their inclusion.

For each of these nine service areas, we have identified some unique problems and barriers that need to be addressed. In those areas selected for more in-depth study, additional barriers are likely to be identified that are specific to each field. However, there are also a number of common barriers that have emerged across these different systems: (1) They all require both physical and programmatic access for women with disabilities. (2) They are often influenced by common (often demeaning) stereotypes about the personal lives of women with disabilities--for example, in the adoption, child care, AFDC, reproductive health, and domestic violence service systems, a common theme emerges that women who have disabilities are asexual and are not expected to be mothers. These stereotypes can affect both the likelihood of receiving services and the quality of service delivery. The belief that girls with disabilities are too naive or childlike to be at risk of drug and alcohol abuse, teen pregnancy, or sexually-transmitted diseases is a barrier to girls receiving substance abuse services and reproductive health services. (3) They all involve agencies that are covered by the ADA; and (4) They have ongoing needs for staff training and education.

Through our review of the literature and discussions with experts around the country, we have identified a number of common themes across different service areas. In establishing policy to address barriers to these services, it is important that public policy researchers and advocates keep in mind the following: (1) Women with disabilities need information in order to become better informed consumers and more effective advocates. They must be empowered with facts to back up their claims to services. Knowledge of the ADA is critical, too. Knowledge about what groups of women are doing in other parts of the country to gain access to services can provide networking opportunities that can strengthen local efforts to effect change. (2) All women with disabilities are not affected the same way, and all do not need the same accommodations or services. We must be careful when establishing public policy that we do not stereotype either all women with disabilities or all women with a particular type of disability. (3) Minority women are left out of the discussion of service needs to a large extent. Too little is known about cultural differences and the impact of these differences on needs for women's services. (4) The disability movement has focused on "traditional disabilities." Women with hidden disabilities, such as cognitive disabilities and environmental illness, historically, have received little attention.

Women in various parts of the country who have disabilities are accomplishing excellent work in areas such as access to reproductive health and substance abuse services. This project can have a vital role in promoting their efforts and in drawing attention to their need for these services.

### References

- Cohen, A. (1994, April). Accessible child care, Mainstream, 18-21.
- DeAngelis, T. (1995, January). Custody battles challenging for parents with disabilities. American Psychological Association Monitor, 39-40.
- Hasler, B. (1991). Barriers to living independently for older women with disabilities: Executive summary. Washington, DC: American Association of Retired Persons. (Available from the American Association of Retired Persons, 601 E Street, NW, Washington, DC 20049)
- Kirshbaum, M. (1994, Fall). Family context and disability culture reframing: Through the Looking Glass. The Family Psychologist, 8-12.
- Sobsey, D. (1994). Violence and abuse in the lives of people with disabilities. Baltimore, MD: Paul Brookes.

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## Social Constructions in AIDS Policy: Discrimination against Women

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The social constructions of target groups associated with AIDS underlie numerous aspects of AIDS policy. These social constructions are crucial for understanding the political debate surrounding AIDS and the public policy designed to cope with the disease. Moreover, social constructions explain the relative benefits and burdens distributed by AIDS policy because they often serve as rationales for policymakers and administrators.

This paper examines the social constructions of target groups associated with AIDS in an attempt to reinforce the theory that social constructions drive not only the formation, but also the implementation of public policy (Schneider & Ingram, 1993). It is also my intention to show how these social constructions have influenced the scientific community, and the public policy that has led to abhorrent discrimination against women in AIDS policy.

Social construction theory, as articulated by Helen Ingram and Anne Schneider in several of their works (Ingram & Schneider, 1991, 1993, 1995; Schneider & Ingram, 1990a, 1990b, 1993, 1994), asserts that social constructions are the emotional evaluations attributed to different groups in our culture. They consist of commonly held beliefs about specific groups; they determine how a policy is both formulated and implemented. This is especially true in policy fields where issues of "deservedness" mediate the political debate. Social constructions affect the priorities, the goals, and the rationales in the policymaking process, as well as the benefits and burdens placed on those for whom the policy was targeted. In essence, social constructions shape the politics that surround the policy.

This issue of "deservedness" is a substantial portion of the political discussion surrounding AIDS policy. Unfortunately, individuals with the disease are dichotomously construed as either victims (hemophiliacs or children) or social deviants (IV drug users, homosexuals, or prostitutes). In both cases the notion of deserving the disease is prevalent. Beyond the social construction of "deservedness," there is a second dimension, power, which in combination affects the distribution of benefits and burdens in AIDS policy. Mark Donovan (1994) has discussed this point in greater detail in his analysis of the Ryan White Act of 1990.

Further, the social constructions of those infected with AIDS usually do not include women unless they are considered a "vector of transmission" by which someone else became infected with HIV (a prostitute, a drug addict, a mother). Interestingly, women, as described in AIDS policy, are not individuals dying of the disease; they are only potential sources for others to become infected. Thus, women are socially constructed as either victims or deviants, and neither group has significant power to affect public policy.

While this situation has changed dramatically since 1993,<sup>1</sup> our prior knowledge of women with AIDS is severely limited, and the data we have is most likely invalid. Beyond this, the emphasis placed on women as "vectors of transmission" has led to even greater gaps in our statistical data about women with AIDS. Consequently, most doctors did not believe that women contracted AIDS, the scientific community did not know the epidemiology of AIDS in women or the effects of different treatment therapies on women, and public policy either excluded or marginalized women with AIDS.

An example of this exclusion and marginalization from a lack of statistical data occurred in the drug trials for AZT. The first published results about AZT in August of 1992 included only four percent women, which is well below the amount needed to satisfy statistical significance tests (Laurence & Weinhouse, 1994). Historically, drug trials have a long history of under-representing women, in part because of the guidelines established by the FDA about participation in clinical trials, and in part because of the relatively few women research scientists. Nan Hunter (Hunter & Rubenstein, 1992) describes this exclusion of women by the FDA:

The current guidelines of the FDA require that selection of subjects for clinical trials be "equitable," but they also categorize all women of "child bearing potential" as excludable. . . . Drug manufacturers and investigators justify the exclusion of women by their fear of liability for in utero injuries. . . . In the meantime, drugs for a number of conditions, including HIV disease, are being licensed and marketed without ever having been tested in women. (pp. 14-15)

Consequently, women who are HIV positive are being prescribed AZT, even though the side effects for women have not been sufficiently determined.

In conclusion, this paper expands on the theoretical framework of Ingram and Schneider by applying social constructions of target groups to the case study of women and AIDS policy. This is important to the study of political science because social constructions attempt to highlight motivations and rationales of political actors within the policymaking process. Thus, this framework allows for greater foresight in the political debates, and it assists in the formulation of more prescriptive designs.

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<sup>1</sup> In 1993, the Center for Disease Control (CDC) issued a new definition for diagnosing AIDS in patients who were HIV positive that greatly improved the "objectivity" of the definition. Prior to 1993, the CDC issued a definition of AIDS that was a list of twenty-three opportunistic infections associated with AIDS (supposedly "all" of the infections were listed, that, in combination with an HIV positive blood test, defined AIDS). Unfortunately, this list has been inadequate and exclusionary of women because most women die of gynecological complications, none of which were included on that list. Hence, women were not diagnosed as having AIDS, even though many HIV positive women were dying of opportunistic infections. (For greater explanation, see the full length version of this paper or Donovan, in press.)

## References

- Donovan, M.C. (1994, September). Social constructions of people with AIDS: Target populations and United States policy, 1981-1990. Paper presented at the Annual Conference of the American Political Science Association, New York, NY.
- Donovan, M.C. (in press). The problem with making AIDS comfortable: Federal policy making and the rhetoric of innocence. In M.A. Hallet (Ed.), The struggle for legitimacy: Activism and marginalization in the AIDS crises. San Francisco, CA: Haworth Press.
- Hunter, N.D., & Rubenstein, W.B. (Eds.). (1992). AIDS agenda: Emerging issues in civil rights. New York, NY: The New Press.
- Ingram, H., & Schneider, A. (1991). Target populations and policy design. Administration and Society, 23, 333-356.
- Ingram, H., & Schneider, A. (1993). Constructing citizenship: The subtle messages of policy design. In H. Ingram & S.R. Smith (Eds.), Public policy for democracy (pp. 68-94). Washington DC: The Brookings Institute.
- Ingram, H., & Schneider, A. (1995). Social constructions and target populations, (Continued): A rejoinder to Robert Leiber. American Political Science Review, 89(2), 441-446.
- Laurence, L., & Weinhouse, B. (1994). Outrageous practices: The alarming truth about how medicine mistreats women. New York, NY: Fawcett Columbine.
- Schneider, A., & Ingram, H. (1990a). The behavioral assumptions of policy tools. Journal of Politics, 52, 511-529.
- Schneider, A., & Ingram, H. (1990b). Policy design: Elements, premises, and strategies. In S. Nagel (Ed.), Policy theory and policy evaluation (pp. 77-101). New York, NY: Greenwood Press.
- Schneider, A., & Ingram, H. (1993). Social constructions of target populations: Implications for politics and policy. American Political Science Review, 87(2), 334-347.
- Schneider, A., & Ingram, H. (1994). Social constructions and policy design: Implications for public administration. Research in Public Administration, 3, 137-173.

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## Section VIII

### Research Methods

The chapters in this section are clustered around methodological issues for conducting disability research. Each paper contributes in a different way, to a different level of our own reflective analysis on how we do what we do and a desire to do it better. For example, one paper looks at making the data collection process more accessible to visually impaired and blind people so that they are included as research respondents. Another paper looks at using qualitative methods to access the meaning and depth of issues, and the last paper details the need for and the endless possibilities of data sets archived at the national level. For some people the qualitative method is an accessible way to reach information and analysis about disability issues that is elusive to surveys and experiments. However, other researchers thirst for a large data set of longitudinal responses to standardized questions, giving the power and ability to run regressions only possible in our dreams!

The first chapter, by Jaclyn Packer, "Assuring Inclusiveness in Data Collection among People with Visual Impairments," is a very practical and informative review of ways to accommodate people in the research process. Information about Braille, alternate format, telephone responses, and sighted readers is provided clearly and serves to remove the technical barriers to inclusion. The paper is not exclusively targeted to people doing research on issues of visual impairment or blindness, but looks at ways that traditional and mainstream research can include and accommodate people with visual impairments when doing data collection. For some, the accommodation is to have survey instruments read aloud in the form of an interview so that the answers can be recorded by the sighted researcher. This format retains the administration of a survey, but accommodates the person answering the questions.

The next chapter looks at using interviews as a method for a whole range of purposes. Peggy Quinn gives an overview of qualitative methods in her instructive "Qualitative Research: How to Do It." There is a mystique that surrounds qualitative methodology, particularly among those more comfortable with numbers and close-ended questions, but this paper demystifies the particulars of qualitative work. The paper focuses on using interviewing as an accessible and flexible research strategy that responds to the variety of needs and communication styles among people with disabilities. Quinn also includes information on data analysis, budgeting, and planning. The technical suggestions related to transcription, timetables, and data interpretation are invaluable for the novice researcher and veteran alike.

The last chapter in this section, written by Eric Lang, is an example of how current information technology can make our work easier. Lang's paper, "The Research Archive on Disability in the US (RADIUS): Distributing National Data Sets for Statistical Analysis," answers that famous question--Where have all the results gone? For many

researchers, the administration of national surveys and the collection of large scale data are impossible, yet other projects have huge archives that have been inaccessible or unmanageable. The paper describes a system of archiving data sets so that they can be used with popular software such as SPSS and SAS on both PCs and MACs. The issues of measurement, definition, and methodology notwithstanding, the provision of this accessible database is an incredibly important service. The chapter also discusses the data sets of more than 15,000 variables using the National Health Interview Survey on Disability, the NOD Survey of Americans with Disabilities, and the National Longitudinal Transition Study. These data sets, provided through the archives, can be used as a base for both qualitative and quantitative research or can be used as the data for a project looking at relationships and variables not considered until recently. In addition to actual data, there will also be measurement instruments available that correspond to the data so that researchers can analyze the results using the original instrumentation.

## Assuring Inclusiveness in Data Collection among People with Visual Impairments

Jaclyn Packer, Ph.D.  
American Foundation for the Blind

Making data collection materials accessible to people with disabilities leads to a high level of inclusion. This is important, both in research specifically targeted to people with disabilities and in studies of the general population in which disabled people are likely to be a significant minority of the group being studied. Only with accessible materials can the greatest inclusion of people result. Without accessible materials, the following issues arise:

- The need for a proxy (a person, such as a family member, who can answer for someone). Information obtained this way is often less accurate than the data one would get directly from the person targeted for the sample.
- Issues of confidentiality, when a third person is required to convey information from the person targeted for the sample. Often surveys ask personal questions (for example, yearly income or existing medical conditions) that respondents might be willing to share under conditions of confidentiality with a bona fide researcher, but not with a third party whom they personally know.
- Exclusion of disabled persons in research because the data cannot be collected due to inaccessible methods.

Flexibility in one's approaches to data gathering is of ultimate importance, since no one method will be sufficient for including all potential participants, even among people who have similar disabilities. By being flexible, one can allow respondents to participate in a manner that works best for them, resulting in obtaining the most accurate and complete input from participants.

### Visual Impairments

Most accessibility issues related to collecting data on people with visual impairments occur when using written materials that participants must read and to which they must respond. For this reason, this paper will address some practical issues related to making self-administered written survey materials accessible to blind or visually impaired persons.

For greatest accessibility, your materials should be available in a number of different formats, including Braille, large print, voice (e.g., cassette tape or automated telephone system), and digital (e.g., on diskette, over the Internet). Issues relevant to each of these formats are discussed below.

If respondents are participating in an in-person self-administered survey, you may be able to ask in advance for their preferred format and have it ready for them. If you are doing a mail questionnaire and initially mailing out print questionnaires to all respondents, you should indicate that the survey is available in alternative formats upon request (e.g., by sending back a stamped postcard or by calling an 800 number), and you should list which formats are available. If you happen to know in advance that a large number of your participants are visually impaired, but do not know which format they prefer, you may want to send out all your initial questionnaires in large print (14 point or larger).

If you are mailing questionnaires, you may be able to send and receive them as "Free Matter for the Blind" (i.e., with no postage) if the recipient is legally blind, and if no part of the document is in regular print. Contact your local post office for details about the specific regulations.

If you want your questionnaire to take a particular length of time to complete, keep in mind that respondents answering questions in alternative formats may need extra time.

### Braille

Self-administered questionnaires must be easy to read. It is important to try to avoid breaking up questions between pages, although this can be difficult since Braille takes up more room than print on a page.

In order to have people respond to close-ended questions (e.g., multiple choice), one might set up the pages so that there is a raised line beside each choice where the respondent can mark his or her answer. For example:

- .. .. a) choice 1
- .. .. b) choice 2
- .. .. c) choice 3

These raised lines need to be lined up on the same side of the choices for each of the questions. Most Braille readers will be able to use a pen or pencil to mark the appropriate choices (e.g., by using a check mark or by circling the raised line), which may then be read visually by a data entry person. If interpointed (i.e., Brailled on both sides of the page), be certain to leave wide enough margins so that words from one side of the page are not directly beneath the raised lines--otherwise, respondents' answers on one side may push through and interfere with their reading the Braille on the other side. If you choose to use this method, allow respondents the flexibility of answering using alternative methods in case they are not able to answer using a pen or pencil. You might suggest that they respond on a separate sheet of paper in print (using a computer printer or typewriter) or in Braille, or that they record their answers on a cassette tape, listing question numbers as they give their answers. In addition, these alternative methods will be necessary if your survey contains open-ended questions in which participants must respond in words, rather than responding to a limited set of choices.

If you do not have the facility to produce Braille, there are a number of services around the country that produce Braille from word-processed documents on diskette. Producers of Braille are listed in the AFB Directory of Services for Blind and Visually Impaired Persons, published by the American Foundation for the Blind.

### Large Print

Large print documents can be produced easily if your original document has been created on a word processor, just by increasing the font size and making sure the formatting is still easy to read. Because each word takes up more room, you will probably have to insert new page breaks to keep questions from breaking between pages. Large print is a font of 14 points or larger. Eighteen point fonts use up just a little more space on a page than 14, but they may make for easier reading.

### Voice

Reading a questionnaire onto cassette is another alternative. However, it is difficult for people to answer questionnaires in this manner. It is likely that people who prefer using cassettes are probably not able to use, or are not comfortable with, large print or Braille. Therefore, it is unlikely that these participants will be able to return their answers in writing. One could leave room after each question for the person's response, but this leaves open the very likely possibility that the respondent may tape over and, therefore, erase the beginning of the following question. An alternative may be for the person to use two cassettes and two cassette players--one for questions, one for answers. However, this would necessitate the person having two tape recorders available for use, and this method may also be difficult for people to carry out. One additional problem with recording surveys on cassette is the intrusiveness of "skip patterns." Usually a survey allows the respondent to take different paths in the survey depending on their answers so that, if the person indicates, for example, that they are not employed, they will be instructed to skip a series of questions about employment. A participant listening to a questionnaire on cassette will not be able to easily skip over irrelevant questions.

Surveying by telephone may be the best alternative for people who cannot, or prefer not to use Braille or large print. Surveys may be conducted using an 800 number, which would be free to callers. There are three alternatives using the telephone that can range from "low-tech" to high. The first alternative is having staff available to answer the 800 number who can read the survey to participants and record their answers. To keep costs down, you may want to have staff members call respondents back, rather than conduct the complete interview over an 800 line, which tends to be more expensive. A second alternative is to have participants call and record their answers over an answering machine with unlimited time (although it may end up taking just as much staff time to get the answers off the tape as it would to have the staff read the survey and record the answers). The more elegant "high-tech" solution is to set up a push-button answering system which will read the questions electronically, record the answers, and choose the appropriate skip patterns. If this option is chosen, one should allow for the possibility that some people

will call from rotary phones and, therefore, will still need to have someone read the questionnaire and record the answers.

### Digital

Participants can be given the option of receiving and answering the questionnaire on computer diskette, and they can then use whatever computer adaptations they have to access and answer the questionnaire. Of course, because people use different computers, word processing programs, and sizes of diskettes, all these different possibilities must be kept in mind. You can also let participants know that you can send them the questionnaire over the Internet if they provide you with an electronic-mail address; they can also send their answers back in this manner.

For close-ended questions, you can instruct respondents to place an "x" at the beginning of the lines that represents the choices they wish to pick. For open-ended questions, respondents can be instructed to enter their answers directly below the question and use as much space as they wish. Make sure participants know that they must use the "insert" mode, and not the "typeover" mode; otherwise, they will inadvertently type over and erase the questions that are there.

You may wish to distribute your questionnaire widely over the Internet through the World Wide Web or through newsgroups. It is important to realize, however, that you would be reaching a very select group of people through this method, and that the results of your survey would not be generalizable to a wider population. This method may be very useful to get some quick feedback about a particular issue in which you are interested, or some quick feedback about the wording of particular survey items while you are still in the pre-testing stage.

### Conclusion

Making the extra effort to have your materials available in accessible formats will assure the greatest inclusion of people with disabilities in your research that, in turn, will assure that your sample of participants truly represents the population you wish to study. While these efforts toward inclusion are of obvious importance to those conducting research on people with disabilities, it is of equal importance to those conducting research on the general population, which is likely to include a large number of disabled people.

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## Qualitative Research: How To Do It

Peggy Quinn

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In studies of, or with, people with disabilities, qualitative research seems to be very appropriate. An underlying theme of qualitative research is a belief that what is happening, even in mundane activities, is important. In addition, qualitative researchers identify their stance and their biases, and they utilize or bracket these rather than denying their existence. Such research demands that the researcher become a well-trained and attentive listener and observer. It involves a researcher in working with participants in the research rather than acting as a scientist doing research on her/his subjects. In qualitative research, those in the study often have an opportunity to ask questions of the researcher about her/his background and experience as well as about the nature of the study and its potential uses (Oakley, 1980; Quinn & Allen, 1989).

Qualitative research is an old and respected tradition in the social sciences. In recent decades, it appeared to decline in popularity as some disciplines focused on demonstration of their "scientific" base. Currently, qualitative research is enjoying a resurgence in popularity. A number of authors in a wide variety of disciplines have written about the theoretical base and the conceptualization of this research method (Strauss & Corbin, 1990; Taylor & Bogdan, 1984).

There are some basic differences between qualitative and quantitative research. Quantitative research generally proceeds from a positivistic base, assuming that the researcher knows enough about the situation or person to form a hypothesis and then test it. In contrast, qualitative research begins with a curiosity or a question about what is happening, rather than a statement. For example, the question might be, "I wonder how midlife women with disabilities deal with the aging process." This type of study has been utilized extensively by feminist researchers who insist that it be used to generate information for as well as about women (Thompson, 1992). Such an approach seems appropriate for working with people with disabilities as well.

Qualitative studies are valid whether or not they are generalizable. The expectation is that any person's life is unique and valuable. What is learned from one participant can lead to questions to ask others--perhaps questions never before imagined by the researchers. Questions and ideas raised in the research can then be utilized in designing further studies.

Results that seem contradictory to the general themes emerging from the data may lead to new questions and alternative directions. In qualitative research, this does not signal failure. Rather, it is an opportunity for even more learning.

## Doing Qualitative Research

This chapter focuses only on interviewing as a research strategy. This approach is appropriate for work based on phenomenology or ethnomethodology. Interviews can also be the foundation for development of a grounded theory.

This paper proposes a timetable and suggests a list of equipment needed for interviewing. If a person is seeking funding for research, this provides a sense of the time frame, money for research assistants or transcribers, and equipment and software purchases that may be necessary.

### Timetable

Once the question or issue has been selected, the researcher engages in the usual examination of the literature. In addition to determining what studies have been done, the qualitative researcher notes the questions that were used and the reason these were selected. The next step is the development of the interview protocol, and the piloting of this instrument with people similar to those who will participate in the study.

Selection of participants is the next important phase. The researcher must be able to state clearly why these particular people were chosen. Random sampling is not a concern in qualitative research; purposive sampling or even negative case sampling may be utilized. Successful recruitment of participants may depend on their sense of trust in the researcher. It is very helpful to have a gatekeeper, perhaps the researcher, who has access to the community of participants. Once the initial participants have been contacted, more names can be gathered through snowball sampling (Taylor & Bogdan, 1984). This technique is frequently used in qualitative research.

After completion of the pilot study, the researcher has a sense of the time required for each interview. It is important, however, to be flexible in scheduling; participants frequently continue to talk well after the hour or two that were planned, and more information can be gained the longer they talk. In this author's experience, people are generally delighted to talk about their own lives, especially when the information is to be used to develop further knowledge.

At the start of each session, request permission to tape record the interviews, set up the microphone, and begin the discussion. The presence of the recorder does not seem to be a problem for most people. Even the necessity for changing tapes during the conversation does not interfere with the information.

For qualitative work, it is appropriate to begin transcription of the interviews as they are completed. Adequate time must be allowed for this task, which can easily require two to four hours of typing per hour of tape. Transcripts should be reviewed as they are typed. This may lead to additions or changes in the original interview protocol.

Data analysis is the next step. Several content analysis software programs are available to assist in this task. Transcripts need to be read and re-read five to ten times or more. During this process, themes and concepts begin to emerge. This, again, may lead to additions or changes in the rest of the interviews.

Once the analysis is complete, the data is compiled into a report. It is optional, but preferred when possible, to invite participants to review the draft of the report once it is written. This can be done through the mail or in person. Using the comments of the participants, the report is then re-written and prepared for submission.

### Equipment

Conducting qualitative research does not require a large outlay of funds. There are, however, some items which make the project much easier. For the actual interview sessions, take a small tape recorder, a multi-directional microphone, tapes to record a minimum of two hours of interview per person, several spare batteries, an extension cord, and a city map or Mapsco. In addition, have copies of the interview protocol and any demographic forms to be completed.

### Conducting the Interviews

For the interview itself, several methods are possible. One choice is to write the questions on a small card to hand to the person so s/he can choose the order in which to answer the questions. It is important to offer the participant the option of skipping any question to return to it later, or simply not to answer it at all. The interviewer can feel free to use probes, self-disclosure, and new questions as they seem appropriate. Information from previous interviews may spark new questions or ideas. The goal in this type of research is to learn as much as possible from the person, not to support a previously established hypothesis.

Once the interview has been completed, it is necessary to convert the taped conversation to hard copy. A computer with the capability of converting text to ASCII files is essential. In addition, a wide variety of transcribers are available. One with a foot pedal for controlling the tape is essential. It is possible to manage with a recorder and foot pedal from a local department store or electronic store. The better choice is a transcriber/recorder setup which is designed for transcription. These transcribers automatically back up a few words after each pause. Otherwise, the typist must use the foot pedal to back the tape up after pausing to type. The recorder/transcriber setups are more expensive than the regular tape recorders, but they can save many hours in what is a slow and tedious task. It is wise to allow two to three hours of typing time for each hour of taped interview.

When the transcription is complete, it is helpful to utilize a software package for the data analysis. Transcripts are prepared in the required format and imported into the software program. The researcher then codes the materials and utilizes the various capacities of the software to examine demographic or other variables in relation to the various codes.

Ethnograph (Seidel, Kjolseth, & Seymour, 1988) and HyperResearch (1994) are two qualitative analysis packages. Others are available, but they have not been tested by this author.

### Summary

Qualitative research is appropriate for work in areas that have been ignored or sparsely researched. This paper has focused on the mechanics of the process in order to provide specific data for those wishing to embark on this work. Information about theories undergirding qualitative work as well as assistance in data analysis are available from several of the sources in the reference list.

### References

- HyperResearch [computer software]. (1994). Randolph, MA: Research Ware Inc. (Available from Research Ware Inc., P.O. Box 1258, Randolph, MA 02368-1258)
- Oakley, A. (1980). Women confined: Towards a sociology of childbirth. New York, NY: Schocken.
- Quinn, P., & Allen, K.R. (1989). Facing challenges and making compromises: How single mothers endure. Family Relations, 38 (4), 390-395.
- Seidel, J.V., Kjolseth, R., & Seymour, E. (1988). Ethnograph [computer software]. Littleton, CO: Qualis Research Associates. (Available from Qualis Research Associates, P.O. Box 3129, Littleton, CO 80161)
- Strauss, A., & Corbin, J. (1990). Basics of qualitative research: Grounded theory procedures and techniques. Newbury Park, CA: Sage.
- Taylor, S.J., & Bogdan, R. (1984). Introduction to qualitative research methods: The search for meanings (2nd ed.). New York, NY: Wiley.
- Thompson, L. (1992). Feminist methodology for family studies. Journal of Marriage and the Family, 54, 3-18.

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## The Research Archive on Disability in the U.S. (RADIUS): Distributing National Data Sets for Statistical Analysis

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The Research Archive on Disability in the U.S. (RADIUS) is being established with the guidance of a National Advisory Panel of experts. The purpose of the project is to facilitate access to the best data sets on the prevalence, incidence, correlates, and consequences of disability in the U.S.

### The Need for a Disability Data Archive

Several national committees and councils, e.g., Committee on a National Agenda for the Prevention of Disabilities, the Task Force on Medical Rehabilitation Research, the National Council on Disability, Interagency Subcommittee on Disability Statistics, and the National Advisory Board on Medical Rehabilitation Research, have suggested that progress on basic and applied aspects of disability and rehabilitation will require a systematic national effort on several fronts, including improvements in surveillance, demographic research, treatment and program design and evaluation, access to care and preventive services, public education, professional training, conceptual measurement and modelling, and national leadership to maximize the coordination and coherence of activities across these domains. Many of these areas will require collections of new information as well as improvements in the availability and analysis of existing data.

Federal and state government agencies, for the most part, have relied on project reports from its grantees and contractors, conferences, papers presented at professional meetings, monographs, and journal publications to disseminate the results of the disability-related research it supports, and to make findings available to policy makers, practitioners, and other researchers. However, a greater yield on the research investment can be gained for science, policy, and practice if data collected for the most important studies are made available for secondary analysis by others. Although an increasing number of government agencies require or strongly encourage grantees and contractors to deposit their data with appropriate data archives, the usability of such resources may be limited by a number of factors including: (1) inconsistent or incomplete documentation; (2) inclusion of studies with unreliable methods; and (3) original data file formats that are difficult to convert for use with popular statistical software packages, e.g., SPSS and SAS, and common computing platforms, e.g., mainframe computers, PCs, and Macs.

There are many benefits to using a well-constructed data archive and performing secondary data analysis. First, the work of the original investigators can be validated and extended by other researchers using the same data. Second, data (particularly those from national studies) usually lend themselves to analyses of several topics in addition to the ones intended and pursued by the original investigators. Third, when relevant data are

available from secondary sources, timely analyses of pressing issues of policy or practice can be carried out without the long delay and high costs necessitated by original data collection. Fourth, bringing together topically-related data sets facilitates quantitative comparisons and meta-analysis across similar studies. Fifth, the use of the same data by multiple investigators and the use of multiple data sources by the same investigator foster the building of a network of colleagues and strengthen the research community. Sixth, the ready availability of high quality data sets for secondary analysis expands the number of scholars undertaking research using the best data in the field. The interchange promoted by this network serves to stimulate further innovation and development of the field. Taken together, these advantages result in a much greater economy in the use of scarce research funds: Given the high cost of original data collection, it is appropriate to view each data set as a public resource to be drawn on repeatedly whenever each is appropriate to a scientific, policy, or program question.

#### Sociometrics' Research Archive on Disability in the U.S. (RADIUS)

RADIUS is being established with the guidance of a National Advisory Panel of experts and is being funded by the National Center for Medical Rehabilitation Research (NCMRR) within the National Institute for Child Health and Human Development (NICHD). The purpose of the project is to facilitate access to the best data sets on the prevalence, incidence, correlates, and consequences of disability in the U.S. The RADIUS Principal Investigator is Dr. Eric Lang, the NCMRR/NICHD Project Officer is Dr. Louis Quatrano, and the National Advisory Panel Chairperson is Dr. Mitch LaPlante.

RADIUS consists of three kinds of machine-readable materials: (1) technically and substantively outstanding *data sets* (raw data, SPSS and SAS statistical program command files, and documentation); (2) original *measurement instruments* and questionnaires (corresponding to the archived data sets); and (3) *computerized search & retrieval software* to retrieve those portions of the data sets and measurement instruments that are relevant to users' specific research questions.

#### The Archive of Data Sets

The heart of the archive is a collection of 16 studies comprised of over 15,000 variables that address the topic of disability. The data sets from these studies will permit analyses on topics such as the incidence and prevalence of specific diseases, disorders, and impairments, including deficits of cognition, physiology, and anatomical structure; functional limitations across a variety of specific organ systems; disabilities in relation to major life roles and activities, such as work, parenting, education, and recreation; societal limitations including physical, attitudinal, and economical barriers that restrict full participation in society; psychosocial and interpersonal factors such as coping with stress, sexuality, feelings of control and productivity, quality of life, and family relations and support; health care and rehabilitation issues such as medical costs, coverage, service utilization, use of orthotic, prosthetic, assistive devices, and effectiveness of rehabilitation; and a variety of basic demographic factors on respondents such as age, race, sex, income, occupation, marital status, family size, and living arrangements.

Studies and data sets for the archive were selected with the help of a National Advisory Panel of experts using scientific criteria of technical quality, substantive utility, policy relevance, and potential for secondary data analysis, such as the *1994-1995 National Health Interview Survey on Disability* (phase I), the *Next Generation of Upper-Limb Prostheses 1994*, the *1994 National Survey on Sexuality Issues among Women with Disabilities*, the *1994 NOD Survey of Americans with Disabilities*, the *1987-1991 National Longitudinal Transition Study*, and other studies. Because more high quality data sets were identified than could feasibly be archived, the National Advisory Panel chose not to select several high quality data sets that were readily available from government sources. A full list of data sets considered by the Panel appears as an appendix in the RADIUS Comprehensive User's Manual.

Each data set in the RADIUS collection has been archived according to standardized conventions similar to those Sociometrics Corporation has developed for other social science data archives. These conventions are designed to make the data sets accessible and easy to use for secondary analysis. Each data set in the archive includes (1) a printed User's Guide to the machine-readable files; (2) a raw data file for microcomputer use (CD-ROM or diskettes) as well as mainframe computers; and (3) machine-readable program statements that fully document the variables and values in the data file and facilitate its use with SPSS and SAS, the leading statistical analysis packages for social science data.

### RADIUS Topic and Type Codes

To facilitate search & retrieval of RADIUS variables of interest--among over 15,000 variables across 16 studies--standardized Topic and Type codes were developed and assigned to all RADIUS variables. Topic codes classify variables on a substantive dimension, typically the construct that the variable measures such as age, race, education, or occupation, as well as health- and disability-specific categories. Type codes classify variables on a measurement dimension that is independent of the Topic code, such as attitude, behavior, history, or aggregate-level characteristics.

A number of disability-specific Topic codes represent the NCMRR model of pathophysiology, impairment, functional limitation, disability, and societal limitation as well as the similar ICIDH (*International Classification of Impairments, Disabilities, and Handicaps*) single-digit codes for "impairments" and "disabilities." Assigning both primary and secondary Topic codes is especially useful for items that measure disabilities and societal limitations across a variety of roles and environments. For example, an item that focuses on a job-related disability is coded for *occupation* (OC) and *disability* (DS). Similarly, an item that focuses on a barrier to education is coded for *education* (ED) and *societal limitation* (SL).

### The Archive of Original Measurement Instruments

In addition to data sets, the archive contains a collection of the original measurement instruments corresponding to the archived data sets. The instrument archive is linked to

the data archive so that an archive user who has identified a set of variables for further inspection can, for any variable of interest, immediately view the page of the original questionnaire/instrument containing the corresponding question as it was presented to respondents. The user can then view preceding and following pages in the instrument. In addition, a related function allows the user to immediately view unweighted frequencies and univariate statistics for any variable of interest.

The ability to examine immediately, for any variable of interest, the text of the original questionnaire item and the corresponding sample statistics, empowers the archive user in several ways including: (1) a complete understanding of the full text of the original item, rather than relying on the standard 40 character variable label; (2) the ability to examine neighboring questions/items in the instrument to better understand potential context effects and skip pattern logic; (3) the ability to view earlier pages in the instrument to better understand how that section of the questionnaire was introduced or described by the data collector; and (4) an immediate evaluation of the resulting valid and missing data statistics, which are useful for determining whether the variable would be suitable for further statistical analysis or replication in future data collections.

#### Search & Retrieval and Extract Software

Search & retrieval software allows the user to retrieve information about the Archive's contents, both at the level of the individual variable and at the study level. At the variable level, this is possible through the classification of all study variables in the data archive by substantive "Topic" and analytic "Type" as well as the availability as part of the search space of all words in the variable labels (question descriptors) and value labels (response descriptors). This software is an enhanced version of search & retrieval and extract software already developed for Sociometrics' other data archives. The enhanced software allows: (1) full-text keyword searches across all variables in the data archive, including variable names and words in variable labels and value labels (response options); (2) searches by the assigned Topic and/or Type codes of variables; and (3) searches by study name or assigned data set number. Within each of these three search dimensions, standard Boolean operators (and, or, not) can be used to create more specific and powerful search strategies. In addition, any resulting search sets of variables can be combined with Boolean operators to further modify a final set of variables of interest. As stated above, the search & retrieval software also includes the ability to immediately view, for any variable of interest, the text of the original questionnaire item and the corresponding sample statistics. The search & retrieval software also allows resulting search set(s) of variables (which includes the full documentation of each variable's name, label, study, Topic codes, Type code, and value labels) to be saved as an ASCII file on hard disk or diskette or to be sent to a printer.

The "extract" software allows the user to efficiently create customized program files from search sets of variables created by the search & retrieval software that are compatible with several statistical packages such as SPSS-mainframe, SPSS/PC, SPSS/Windows, SAS-mainframe, and SAS/PC.

Thus, the search & retrieval and extract software allows RADIUS users to efficiently search for and evaluate variables of interest from over 15,000 variables among many archived studies on disability, and then move directly to statistical analysis of those variables on any of several computer platforms and statistical packages.

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## Section IX

### Re: Modeling

The ideologies and epistemologies which underlie our research are so significant that they incite passion and anger. The work being done by scholars with and without disabilities is questioned on levels far beyond the instruments and sample size. This section includes papers which look at or re-visit questions of the paradigms or models for disability research.

Harlan Hahn's chapter, "Antidiscrimination Laws and Social Research on Disability: The Minority Group Perspective," presents the argument that the social construction of disability is based on the stigmatizing attitudes that are a source of discrimination toward disabled individuals. Referring specifically to the situation in courts and to the enforcement of anti-discrimination laws, Hahn points the reader to the issues of "stranger anxiety" and the response or aversion felt by nondisabled people to disabled children and adults. The minority model is then applied to both the situation causing the discrimination and the administration of justice to address/redress the discrimination.

Kay Schrinier and Richard Scotch propose taking the social construction argument another step further and looking at the ideal. In their chapter, "Beyond the Minority Group Model: An Emerging Paradigm for the Next Generation of Disability Policy," they suggest that, even when/if all attitudinal barriers are removed and anti-discrimination laws are in place, there will still be differences or "variations" among and between people that are not socially constructed. They recognize, of course, that fundamental constructions exist in language, behavior, policy, and the built environment, but present a compelling argument that variations and disability exist even within a "neutral" or non-discriminatory situation. The chapter focuses attention on how systems could respond to human variation (disability) and how to design responses that acknowledge needs and differences among people in society. Schrinier and Scotch take readers beyond the minority model by arguing that stereotyping and attitudinal barriers create the disability and deny the need for people with various physical and mental disabilities to have individualized responses, rather than simply non-discriminatory ones.

In a similar vein, Anthony Hogan argues in his chapter, "Towards a Genealogy of the Governance of Deafness," that the Oralism versus sign language debate is more complex than a simple struggle for power. Using a historical framework, Hogan presents a new paradigm in which attitudes toward Oralism (and Oralism through cochlear implants) parallel expectations for social dependence (or interdependence) and independence. He concludes that "Ultimately, it is within a social context that the idea of a public good is premised on the elimination of interdependency rather than upon the promotion of equity" (p. 219).

## Antidiscrimination Laws and Social Research on Disability: The Minority Group Perspective

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In recent years, assessments of the difficulties confronting disabled persons have been altered both by the passage of antidiscrimination laws and by an emerging "minority group" model, based on a sociopolitical definition of disability, that has challenged studies shaped by the "functional limitations" paradigm founded on medical and economic concepts. The latter approach has traditionally sought to ameliorate the effects of disability primarily by changing the individual instead of the environment. In many respects, this view seems especially compatible with policies reflecting paternalistic sentiments of sympathy or pity, which have been misinterpreted by the courts as indicating the relative lack of a strong need for the strict enforcement of antidiscrimination measures. Both legal scholars and behavioral scientists also have neglected the research on "stranger anxiety" and reactions to drawings of disabled children that seems at least comparable to the evidence cited by the Supreme Court to support the Brown decision. Unlike the medical or economic orientations, the sociopolitical definition indicates that stigmatizing attitudes are the primary source of discrimination against disabled individuals. In addition, further investigations based on the postulates of the minority group model and the concept of "aesthetic anxiety" may provide a means of combatting the effects of unconscious aversion toward disabled people in the courts.

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## **Beyond the Minority Group Model: An Emerging Paradigm for the Next Generation of Disability Policy**

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For the past two decades, public debate about the status and rights of people with disabilities has been increasingly framed by the characterization of persons with disabilities as a minority group. A corollary proposition is that the most appropriate policy response to this disadvantage is the establishment of civil rights protections that prohibit discrimination on the basis of disability. This strategy culminated in the enactment of the Americans with Disabilities Act of 1990.

In the contemporary politics of identity, minority group status has been attached to people who occupy a wide range of social categories, including ethnic and racial communities, women, gays and lesbians, and people with disabilities. The term has gained such power in political and legal contexts that it is a coveted designation, with presumed implications for legal status as a protected class and public policy decisions allocating social and economic resources based on group membership. At the same time, its contribution to our ability to make precise distinctions may have diminished.

People with disabilities share many of the experiences and characteristics of other groups commonly recognized as minorities (Gliedman & Roth, 1980; Hahn, 1985; Safilios-Rothschild, 1970). They are subject to prejudiced attitudes, discriminatory behavior, and institutional and legal constraints that parallel those experienced by African-Americans and other disadvantaged and excluded groups.

The minority group model goes beyond the simplistic and stereotyped definitions of disability found in the medical and functional limitation models by focusing on the contextual dimensions of disability. Its emphasis on stigma and the built environment allow for policy objectives of institutional change rather than simply individual adaptation or support. Such an emphasis more accurately reflects the interaction of how people live within social settings that can either limit or empower them, and it helps to explain the dynamics of stigma and discrimination to which alternative models cannot speak.

However, the model also implies that, if societal discrimination and prejudice were eliminated, the "problem" of disability would be solved. According to this perspective, discriminatory conduct is the sole explanation for the dismal socioeconomic status of people with disabilities. Unfortunately, this conclusion is at odds with evidence that, at least to some extent, this disadvantaged position is due to multiple factors. The employment status of people with disabilities illustrates our contention. People with disabilities are disadvantaged in the labor market by inadequate education and cultural

capital, disadvantages that can be attributed to the legacy of stigmatization and isolation, but the problem may not be solved solely by protecting the rights of people with disabilities to education and employment. Here disability interacts with class, race, gender, and age in complex ways that compound isolation and inequity.

Applying the minority group paradigm to the employment problems of people with disabilities implies that the major problem facing them has been intentional and institutional discrimination on the part of employers. Now that such discrimination is legally prohibited, accommodations to impairments mandated, and stigmatizing attitudes about disability changing, equity in employment should eventually be achieved, according to the logic of this analysis.

Both survey data (Louis Harris and Associates, 1986) and econometric studies have supported the contention of disability advocates that discrimination is widespread and has serious negative consequences. However, achieving the social goal of full employment for people with disabilities will require efforts on multiple fronts. In some circumstances, increased employment must be traded off against productivity. We are willing to make such a choice, but we believe that the existence of such tradeoffs must be acknowledged and analytically confronted.

We contend that the field of disability studies would be served by a theoretical perspective that incorporates the multidimensionality of disability, what Paul Higgins (1992) has referred to as human variation. Such a perspective would address diverse institutional spheres and different levels of social analysis, including the individual, the family, and the community, as well as the economy and the polity. We believe that a new model should emphasize the variability inherent in disability, and that disability, thus, may be seen as an extension of the natural physical, social, and cultural variability of the human species. Disability could be defined as an extension of the variability in physical and mental attributes beyond the present (but not the potential) ability of social institutions to routinely respond.

In this conception, which we label here the human variation model of disability, the problems faced by people with disabilities might be seen as the consequence of the failure of social institutions (and their physical and cultural manifestations) that can be attributed to their being constructed to deal with a narrower range of variation than is, in fact, present among any given population. Thus, those individuals whose mobility, communication, medical needs, or cognition differs from social norms find themselves confronting institutions not well suited for their abilities and potential.

Historically, all societies have adapted to some types of human variation, while demanding adjustment or marginalization from others. Of the various possible social structural arrangements, large scale bureaucratic institutions may be the most resistant to dealing positively with individual level variation because of technologies that "rationally" emphasize standardized inputs to maximize productivity. However, a post-industrial global society cannot afford to invest heavily in fixed and standardized technology and must have the capacity to adjust to diverse and changing contexts.

In these terms, the overriding goal of the disability movement of the past three decades has been to broaden the ways in which our society adapts to variation by promoting inclusion and accommodation. To the extent that society fully accommodates a condition, it ceases to be a disability under this concept. Social systems with what Irving Zola (1989) has called "universal design" minimize the relevance of impairments at relatively low social or economic cost.

However, where the compatibility between individual variation and societal institutions is limited or strained, secondary effects may ripple through family and community systems as ad hoc or partial adaptations are made, exacting financial, time, and emotional costs from those involved. Disability can be viewed as introducing complexity and disequilibrium into individual lives, family relationships, and the various social systems in which people live, learn, play, and work. When a child is born with a severe impairment, for example, more complex support systems may be required to support the child and her or his family. Additional resources and new approaches to the challenges of daily life may need to be developed because economic, social, and cultural systems are not geared to the needs of the child and the family. In instances where systems have incorporated routinized mechanisms for meeting needs associated with a disability, systemic strain may never occur, nor will the conflict that can accompany such strain. More frequently, some systems can integrate disability without substantial effort, while others may not.

By focusing attention on how systems respond to the variation introduced by disability, a new model of disability might help us address issues of how to best design institutional responses to such variation. A model that acknowledges the variation associated with disability can help us to address what we believe are legitimate issues of resource allocation and the need for creative adaptation by established institutions.

The emphasis of the minority group model on discrimination and discrimination-focused remedies means that the model is of limited help in guiding needed reforms of medical, educational, and human service delivery systems to best promote independence and full social participation by people with disabilities. By characterizing all barriers faced by people with physical and mental impairments as discrimination, we risk trivializing the still prevalent and often vicious stereotyping and exclusive practices by confounding them with the general incapacity of social systems to respond to individual variation.

Incorporating individual variations requires greater initial effort than following rigid standard operating procedures. Control may also be compromised if employers engage in a dialogue with employees to identify individual needs. Individualized employment may be impractical or costly in industries based on inflexible technologies such as assembly lines, but such technologies are generally becoming obsolete. In most firms, adapting to the situations of individual employees should have substantial payoffs in enhancing productivity and reducing turnover. Since the workplaces and jobs of the coming century will require constant redesign to cope with rapid technological changes and the demands of a global economy, employers who can maximize productivity by adjustment to individual needs should be at a competitive advantage. In the context of constant

environmental and technological change, most accommodations due to disability will be trivial, and they can be incorporated easily into the overall process of needed organizational adaptation.

The minority group model has made a major contribution to our understanding of disability, but it is of limited value in addressing many of the social issues associated with disability. An alternative model of disability based on the concept of human variation may imply additional strategies for achieving the goal of integration, and may suggest how a society would look in which disability was not a handicapping condition. As the national debate on rights-based strategies of social change continues, this may be an opportune moment for discussion of new paradigms such as the one suggested here.

### References

- Gliedman, J., & Roth, W. (1980). The unexpected minority: Handicapped children in America. New York, NY: Harcourt Brace Jovanovich.
- Hahn, H. (1985). Toward a politics of disability: Definitions, disciplines, and policies. The Social Science Journal, 4, 87-105.
- Higgins, P.C. (1992). Making disability: Exploring the social transformation of human variation. Springfield, IL: Charles C. Thomas.
- Louis Harris and Associates. (1986). The ICD survey of disabled Americans: Bringing disabled Americans into the mainstream. New York, NY: International Center for the Disabled.
- Safilios-Rothschild, C. (1970). The sociology and social psychology of disability and rehabilitation. New York, NY: Random House.
- Zola, I.K. (1989). Toward the necessary universalizing of a disability policy. Milbank Quarterly, 67, Supp. 2, Part 2, 401-428.

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# Towards a Genealogy of the Governance of Deafness

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## Introduction

In this paper I want to begin to contest the centralised notion of power often used to depict the sign language/oralism debate concerning Deaf and deafened people. I hold that Oralists have justified their system of intervention by presenting themselves as being consistent with the key moral issue of the day--social dependency. Previous researchers writing on this issue have identified key aspects falling *within* the overall debate, such as social Darwinism (see Baynton, 1993a, 1993b). Rather, I hold that issues such as eugenics and *pure speech* (rather than a mixed method) became important because they provided Oralism with the opportunity to develop a network of acceptability with other social movements within their respective communities. As a result of the work conducted within such synergistic networks, interests were able to exercise power.

## Dependency

Fraser and Gordon (1994) identified the notion of dependence as a focus of social concern that underwent a radical transformation commencing in the sixteenth century. They observed that in feudal times mutual dependency between land owners and the people who lived on and/or worked the land was integral to the fabric of a functioning, ordered society. Disabled people were supported within such communities and were left unfettered unless they were disruptive (Dean, 1992). However, the influence of various revolutionary movements and the growth of the industrial state disrupted this system of social relations, particularly in Europe: "In the age of democratic revolutions, the developing new concept for citizenship rested on independence; dependency was deemed antithetical to citizenship" (Fraser & Gordon, 1994, p. 312).

Independence and, therefore, citizenship came to be equated with a notion of normality centred on wage labour and financial autonomy (French, 1993). Fufeld (1994) observed that Malthus developed a rationality which justified the religious pursuit of individualism, the accumulation of wealth, and an abrogation of the need to support the poor whom he considered were poor as a result of their own vice. Malthus held that poverty existed as a result of natural laws that served to "hold the population in check," and that poor relief was simply a misdirection of scarce resources away from those in society who were productive to those "who were idle" (Fufeld, 1994, p. 40)--themes which would later be developed by Darwin (Pfeiffer, 1994). Liberal individualism deemed the failure to provide for one's self and family to be evidence of personal immorality and a threat to ordered society.

Similarly, judgments were made about the presence of disability in a family: "The moral to be drawn from the existence of the individual idiot is this, -- he, or his parents have so far violated the natural laws, so far marred the beautiful organism of the body, that it is an unfit instrument for the manifestations of the powers of the soul" (Howe, 1848/1976, p. 34). Dependency was individualised and understood to reflect the corrupt, flawed moral character of the individual (Fraser & Gordon, 1994). Society needed to be protected from such people who have elected to negate the implied social contract of personal sustainability. The poor were to work and sustain themselves. As such, people able to work were not to be the target of relief (Dean, 1991). A *moral economy* emerged, the efficiency of which pivoted on the moral hygiene of its constituents. It was an economy predicated upon inequality. Autonomy and equity were defined within a polity that considered people with disabilities to be deficient. Maintenance was offered to worthy people who required assistance to participate in society--the deserving poor. Under the moral care of the philanthropist, carefully honed self-sufficiency would serve to shape the poor into a group that could co-exist in a non-threatening manner with the richer classes. People with disabilities were to be the objects of such assistance. As Pfeiffer (1994) remarked, the consequences of this movement was the institutionalization and sterilization of people with disabilities. In the United States, it was evident that people with disabilities would not be independent, that they would not work. Rather, they would be held in custody, as *icons* of the stigmatised state of dependents in a society that had no history of the feudal social relations of reciprocal dependency (Fraser & Gordon, 1994). The issue, thus, focused on the nature of participation in the social structure--not on the equity of outcomes.

The deafness debate was then caught up within a much broader social movement focused on the elimination of a reified notion of economic dependency. It was a moral project. Similarly, the Oralism movement in Europe was as much about nationalism as it was about dependency (Waller, 1990; Haddock, 1990; Quartararo, 1993). Supporting spoken language allied such groups with the nationalist movement sweeping Europe.

Movements against sign language based their arguments upon assumptions about the nature and consequences of difference widely regarded as self-evident and universal at the time--a self-evidence that assumed a deficit model of disability. Rationalities such as eugenics or pure speech served as a gloss that justified the *common sense* intervention indicated. The primary focus of the administrative form was to ensure that people fitted into dominant society and that they behaved in morally acceptable ways *unlike animals, sinners, paupers, or dependents*. If people were to behave *like that*, then they should be incarcerated for the good of society (Pfeiffer, 1994). Oralism then succeeded because it formed an integral part of a broader power base within communities that shared different, yet complimentary rationalities that were taken as self-evident and, thus, politically acceptable.

## From Then to Now

Today the same synergistic strategy is being deployed around the cochlear implant. The dominant values of economic rationalism serve as yet another site for synergistic interests to coalesce into action. Within this framework, the cochlear implant is depicted as the most cost effective strategy for minimising dependency resulting from deafness (Wyatt, Niparko, Rothman, & de Lissovoy, 1995). The unravelling of processes of governance makes evident the inter-relationship between interest groups and systems of administration. That the wielding of power comes about through interconnections between such interests and regulatory bodies that make decisions "based in a social context, constrained and shaped by forces of economics, ideology, personal psychology and established power structures" (Rowland, 1994, p. 6). Ultimately, it is within a social context that the idea of a public good is premised on the elimination of interdependency rather than upon the promotion of equity. It is evident that the politics of deafness is influenced by the social, and that such politics determine the fate of people who are unable or unwilling to conform themselves to the regimens of the day.

Finally, in my forthcoming work, *A Cochlear Odyssey*, I seek to take this analysis one step further. I identify and track the web of moral and social networks associated with the deployment and broad acceptance of Oralism via the adult cochlear implant program. I then insert into the analysis the issue of technologies of the self (Foucault, 1988), while contesting Lane's (1993) notion that the medical model of disability is acceptable to deafened adults. Deafened adults often seek to remake themselves into the type of socially autonomous individuals prescribed within discourses that support so-called models of normality. However, as most do not have access to alternative discourses and practices, it is vitally important to unravel and critique the mechanisms of this process because they seek to attack the heart of the social model of disability. Firstly, notions of the *overcomers* are extolled and generalised to all people with disabilities. Secondly, the social context of disability is denied and represented as a matter of personal misfortune. Thirdly, these values, in turn, are imposed on deaf children who, in turn, are somehow supposed to become able to participate equally in a society from a position of structural and cultural disadvantage. The adult implant program, therefore, is a social issue of concern to the whole disability community. Finally, I seek to contest the dualism surrounding deafness and this technology. Despite the many problems associated with it, the cochlear implant does have some uses for deafened people. The question remains, however--Is it worth it?

## References

- Baynton, D.C. (1993a). Foreigners in their own land: The cultural origins of the campaign against sign language in nineteenth-century America. Doctoral dissertation, The University of Iowa. (UMI Dissertation Services, Michigan)
- Baynton, D.C. (1993b). "Savages and deaf-mutes": Evolutionary theory and the campaign against sign language in the nineteenth century. In J.V. Van Cleve (Ed.), Deaf history unveiled: Interpretations from the new scholarship (pp. 92-112). Washington, DC: Gallaudet University Press.

- Bender, R. (1970). The conquest of deafness--A history of the long struggles to make possible normal living to those handicapped by lack of normal hearing. Cleveland, OH: The Press of Case Western Reserve University.
- Dean, M. (1991). The constitution of poverty: Toward a genealogy of liberal governance. London, England: Routledge.
- Dean, M. (1992). A genealogy of the government of poverty. Economy and Society, 21(3), 215-251.
- Foucault, M. (1988). Technologies of the self. In L.H. Martin, H. Gutman, & P.H. Hutton (Eds.), Technologies of the self: A seminar with Michel Foucault (pp. 16-49). Amherst, MA: University of Massachusetts Press.
- Fraser, N., & Gordon, L. (1994). A genealogy of *dependency*: Tracing a keyword of the U.S. welfare state. Signs, 19(2), 309-336.
- French, S. (1993). What's so great about independence? In J. Swain, V. Finkelstein, S. French, & M. Oliver, M. (Eds.), Disabling Barriers--Enabling Environments (pp. 44-48). London, England: Sage Publications.
- Fusfeld, D.R. (1994). The age of the economist Harper Collins (7th ed.). New York, NY: College Publishers.
- Haddock, B.A. (1990). Italy: Independence and unification without power. In B. Waller (Ed.), Themes in modern European history: 1830-1890 (pp. 213-240). London, England: Routledge.
- Howe S.G. (1848/1976). On the causes of idiocy. In M. Rosen, G.R. Clark, & M.S. Kivitz (Eds.), The history of mental retardation: Collected papers (pp. 31-60). Baltimore, MD: University Park Press.
- Jackson, J, & McConnell, C.R. (1988). Economics (3rd ed.). New York, NY: McGraw-Hill.
- Lane, H. (1993). The mask of benevolence. New York, NY: Vintage Books, Random House.
- Oliver, M. (1993). Disability and dependency. In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), Disabling barriers--Enabling environments (pp. 49-60). London, England: Sage Publications.
- Pfeiffer, D. (1994). Eugenics and disability. Disability and Society, 4(9), 481-499.

- Rowland, R. (1994, December). The human right's project: How can it be right, when the context is so wrong. Paper presented at The Australian Sociology Association Conference, Deakin University, Melbourne, Australia.
- Quartararo, A.T. (1993). Republicanism, deaf identity, and the career of Henri Gaillard in late-nineteenth-century France. In J.V. Van Cleve (Ed.), Deaf history unveiled-- Interpretations from the new scholarship (pp. 40-52). Washington, DC: Gallaudet University Press.
- Waller, B. (1990). Germany: Independence and unification with power. In B. Waller (Ed.), Themes in modern European history: 1830-1890 (pp. 99-122). London, England: Routledge.
- Winzer, M.A. (1993). Education, urbanization, and the Deaf Community: A case study of Toronto, 1870-1900. In J.V. Van Cleve (Ed.), Deaf history unveiled-- Interpretations from the new scholarship (pp. 127-145). Washington, DC: Gallaudet University Press.
- Wyatt, J.R, Niparko, J.K, Rothman, M., & de Lissovoy, G. (1995). Cost effectiveness of the multichannel cochlear implant. In G.M. Clark, & R. Cowan (Eds.), International Cochlear Implant, Speech and Hearing Symposium--Melbourne 1994: Annals of otology, rhinology and laryngology supplement, 166, Volume 104, No.9, Part 2, 248-250.

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## Section X

### The Changing Roles of Independent Living Centers

The research reported in these chapters comes from Robert Wood Johnson (RWJ) projects funded to look at independent living centers (ILCs) in the United States over a four-year period. The first chapter, "The Changing Roles of Independent Living Centers 1992-1995," explores the ways that independent living centers changed between 1992 and 1995. The paper reports on two national surveys conducted among the universe of independent living centers and the eleven Robert Wood Johnson Foundation funded sites. The majority of the approximately 200 ILCs were relatively young organizations, but several of the earliest ILCs were also included. The chapter presents findings on the financial growth of these organizations, the characteristics of the population using the services, and the role of the ILCs in the community. An interesting conflict identified in this research was the priority for ILCs to focus on advocacy, but the need to spend more time on information and referral functions to meet funding requirements.

The second chapter looks at twelve ILCs funded by the RWJ Foundation, and the ILCs' relationship to the medical care system. In their paper, "Independent Living Centers and the Medical Care System: Approaches to Change," the four authors discuss the conflicts between the independent living philosophy and the medical model, and how ILCs operationalize their relationships with the medical profession. The chapter discusses the program evaluation of the ILC projects, including an IL health clinic, a mental health clinic, and an ILC project that retails and services medical equipment. The effort to establish case management programs received the most attention. Several of the projects were able to develop relationships with insurers and medical professionals to sustain these efforts. Discussion of results includes the inherent tension between service and advocacy roles, and the "medical model" versus the independent living philosophy.

The last chapter also reviews the changes and progress made by the ILCs among eleven of the RWJ Foundation funded ILCs. "Changes in Organizational Ties and Networks Among Eleven Robert Wood Johnson Foundation-Funded Independent Living Centers" discusses the specifics of relationships over the previous four years for the sample studied. The longitudinal evaluation involved the administration of the national survey and the specific monitoring of eleven sites. The paper reports on the findings of the make-up of organizational partners, the nature of the relationships, and the perceptions of the partners. The partners included organizations which gave funds or made referrals, provided technical assistance, or received any of those three services. Partners primarily saw the ILCs as providing direct service and advocacy. Both patterns and exceptions are discussed, including particularly successful relationships that developed with ILCs acting as consultants or professional technical assistance providers. Interaction with government agencies is also considered, and the progress of ILCs studied over the four-year cycle is summarized.

## Changing Roles of Independent Living Centers: 1992-1995

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This paper explores the ways in which the roles, activities, and services of independent living centers (ILCs) changed from 1992 to 1995. The study was conducted as part of the evaluation of the Robert Wood Johnson Foundation (RWJF) Program, "Improving Service Systems for People with Disabilities." ILCs are community-based organizations run by and for people with disabilities. This paper adds to the growing body of knowledge about these centers and the important work they have undertaken (Budde, Petty, Nelson, & Couch, 1986; Lachat, 1988; Nosek, Jones, & Zhu, 1989; Nosek, Roth, & Zhu, 1990; Nosek, Zhu, & Howland, 1992). Note that, while only preliminary data were available when this paper was presented at the meeting of the Society for Disability Studies in June 1995, final descriptive data from the study are presented here. Analysis of the final data did not substantially alter the results that were presented in June 1995.

### Sample

In order to describe the context for the RWJF Program, evaluators conducted two surveys of ILCs nationwide. The first step in the research was to define the universe of interest. A major purpose of the study was to survey the universe of ILCs to which the 11 RWJF-funded sites could be compared. Since not all of the RWJF-funded sites were funded by Title VII of the Rehabilitation Act, the comparison group was not limited to Title VII funded centers. The initial 1992 sample was compiled by contacting all organizations that had applied for the RWJF funding as independent living centers, all organizations known to Independent Living Research Utilization (ILRU) as ILCs in 1992, and all organizations that received Title VII funding as ILCs in 1992. There was considerable overlap among these three lists. In 1995, we also conducted a snowball sample by asking the responding ILCs to identify any other independent living centers with which they had had contact in the past year. Surveys were sent to the executive director and, in most cases, were completed by the executive director.

In both the 1992 and 1995 samples, the major inclusion criterion was an affirmative answer to the question, "Would you describe your organization as an 'independent living

center,' (regardless of the sources of your funding)?" We also looked at whether the centers were run by and for people with disabilities and whether they served people across a range of disabilities, but these were not exclusion criteria. Only ILCs in the United States were included. Satellite offices were excluded, but their data were included in the responses of the parent sites. Because we did not count satellite offices as separate sites, our universe of interest was smaller than in some other studies of ILCs which separately included satellite offices. The 11 sites funded by the RWJF Program were not included as part of this sample.

We received surveys for one or both years from 266 ILCs, or 80% of the 333 ILCs that existed and met our inclusion criteria in one or both years. The 1992 sample included 194 ILCs (67% of the 1992 population). The 1995 sample included 213 ILCs (73% of the 1995 population).

In preparing this paper, we examined the data in two ways. First, we compared the 1992 and 1995 samples. Then we analyzed changes from 1992 to 1995 in the subsample for which we had both data points.

## Results and Discussion

### Organizational Characteristics of ILCs

In order to understand changes in roles and services among ILCs, we thought it important to understand how other organizational characteristics have changed or remained constant. This paper looks at the following attributes: age of organization, revenues, size of staff, and whether the sites had satellite offices.

In the 1992 sample of ILCs, the median year of establishment was 1983. In the 1992 sample, about three quarters of the sample (74%) had been established during the decade of the 1980s. Eighteen percent had been established before 1980; and 8% were established in the 1990s. In the 1995 sample, the median year of establishment was 1986. Sixty-three percent of the sites responding in 1995 had been established in the decade of the 1980s; 16% were established before 1980; and 21% were established since 1990.

Even though some ILCs have been established for twenty-five years or more, the majority of independent living centers are relatively young organizations that have existed for less than a decade. We identified many new ILCs that were established in the 1990s. Nevertheless, it appears that the 1995 sample may be biased toward relatively newer ILCs, which would tend to underestimate changes in the group as a whole. In that case, the subsample for which we have two data points may give a more accurate portrayal of overall change in the group.

### Growth in ILCs from 1992 to 1995

The median annual revenues of ILCs increased from \$303,000 in the 1992 sample to \$356,000 in the 1995 sample. There was also a statistically significant increase in revenues in the 1992-95 subsample, from \$303,000 to \$399,000 ( $t=5.3$ ,  $df=119$ ,  $p<.0001$ ).

Another measure of growth was the increase in number of full-time employees (FTEs). The median number of full-time employees rose from seven employees in the 1992 sample to nine FTEs in the 1995 sample. In the subsample for which we had two data points, there was also a significant increase in the median number of staff from eight to eleven FTEs ( $t=4.7$ ,  $df=120$ ,  $p<.0001$ ).

Finally, we noted a growth in the number of sites with satellite offices. In the 1992 sample, 30% of the sites had satellite offices. This rose to 40% in the 1995 sample. There was also a statistically significant increase in the percentage of sites with satellite offices in the 1992-95 subsample, from 30% to 42% ( $t=3.2$ ,  $df=136$ ,  $p=.002$ ). This indicates that ILCs are increasingly reaching out to serve people who are far away from the main offices.

### Consumer Characteristics

From 1992 to 1995, there was little change in the characteristics of consumers of ILCs. The median number of consumers directly served by ILCs dropped very slightly, from 348 consumers in the 1992 sample to 343 consumers in the 1995 sample. In the 1992-95 subsample, the median number of consumers did not change significantly (374 in 1992; 376 in 1995). The ages and minority status of consumers also remained fairly constant from 1992 to 1995. Approximately three-quarters of consumers were adults, about 5-7% were children, and about 13-15% were seniors in both 1992 and 1995. Similarly, approximately three-quarters of consumers were white, and about one-quarter were ethnic minorities in both 1992 and 1995. Overall, ILCs tended to serve primarily white adults between the ages of 18 and 64. However, it is important to note that there was a good deal of variation among ILCs. There were individual ILCs whose consumer population was 98% minority consumers, while other ILCs served up to 60% seniors, and others up to 45% children.

### ILC Roles in the Community

The centers were asked to rank six different ILC roles in the community from most important to least important. At both points in time, ILCs consistently rated individual advocacy, systems advocacy, and direct services provision as the most important roles of ILCs. (These roles were tied for first place.) ILCs also consistently ranked information and referral, case management, and revenue generation for the ILC as less important roles, in declining order of importance.

ILCs across the country are extremely consistent in their ranking of these roles over time. This suggests that a shared independent living (IL) philosophy guides these centers, particularly in terms of their beliefs about important roles of ILCs. However, qualitative

analysis of respondents' comments revealed evidence of role conflict. For example, centers noted that while they believe that advocacy is the most important role of the center, they actually spend the most staff time and resources on maintaining their funding and providing information and referral.

### Changes in Activities

The survey asked questions about nearly 100 specific activities of ILCs in six different categories, including health care, personal assistant services (PAS), housing, health care, activities related to the Americans with Disabilities Act (ADA), other systems advocacy, and other business enterprises. Space limitations do not allow presentation of all of these data. Instead, we concentrate here on new activities to generate revenues for the ILC, which was an important focus of the RWJF Program. Table 1 presents the areas in which the largest numbers of centers were generating revenues through third party payments, fee-for-service, or product sales.

Table 1. Percentage of ILCs engaged in different activities to generate revenues (1995 data)

<u>Activities</u>	<u>% charging fees</u>
ADA-related activities	
ADA/504 consulting	43%
ADA-related technical assistance	41%
Any fee-for-service IL activities	42%
IL assessments	20%
IL skills training	19%
Health-care related activities	
Medicaid services coordination/case management	18%
Training for health-care providers	7%
Mental health services	3%
Personal assistance services (PAS) activities	
PAS contract with non-Medicaid state agency	10%
PAS Medicaid contract	7%
Housing activities	
Consultation with housing developers	9%
Renovation of existing housing to make it accessible	7%
Other activities	
Communications services	15%
Sale, rental, repair of assistive equipment or technology	6%
Sale of durable medical equipment or medical supplies	4%

The results presented in the table show that the greatest numbers of ILCs were generating revenues through ADA-related activities (43%) and fee-for-service IL activities (42%). The Americans with Disabilities Act has created a financial opportunity for many centers to generate revenues through consulting to businesses and other related activities. Another growing source of income for ILCs comes from charging third party payers for IL activities that, in the past, were frequently offered for free.

A sizable number, 18% of the centers, had a Medicaid contract to provide services coordination/case management for consumers. Other centers responded vehemently to this question with the written comment, "We do not manage cases!" These responses suggest that contracts to provide services to consumers represent both a possible source of income for ILCs and a potential source of role conflict, especially given that IL philosophy has consistently criticized the "medical model."

The table also shows that other activities, such as housing, PAS, communications, and assistive equipment represent smaller, but substantial areas of revenue generation for ILCs.

### Summary

This paper presents descriptive findings from two national surveys of independent living centers (ILCs) in 1992 and 1995. These findings provide a context for understanding changes in the 11 RWJF-funded sites, discussed in subsequent chapters in this section. The study found evidence of a strong, shared commitment of ILCs to IL philosophy; centers were in particularly close agreement about their appropriate roles in the community. ILCs were found to be providing increased outreach to underserved areas through more satellite offices. This paper has also explored emerging roles of ILCs, with an emphasis on areas of revenue generation for independent living centers.

### References

- Budde, J.F., Petty, C.R., Nelson, C., & Couch, R.W. (1986). Evaluating the impact of independent living centers on consumers and the community. Journal of Rehabilitation, 52(2), 68-71.
- Lachat, M.A. (1988). The independent living service model. Hampton, NH: Center for Resource Management, Inc.
- Nosek, M.A., Jones, S.D., & Zhu, Y. (1989). Levels of compliance with federal requirements in independent living centers. Journal of Rehabilitation, 55(2), 31-37.
- Nosek, M.A., Roth, P.L., & Zhu, Y. (1990). Independent living programs: The impact of program age, consumer control, and budget on program operation. Journal of Rehabilitation, 56(4), 23-35.

Nosek, M.A., Zhu, Y., & Howland, C.A. (1992). The evolution of independent living programs. Rehabilitation Counseling Bulletin, 35(3), 174-189.

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## Independent Living Centers and the Medical Care System: Approaches to Change

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Central to the Independent Living philosophy is a rejection of the "medical model" as an appropriate perspective for interpreting disability (Batavia, DeJong, & McKnew, 1991). This effort to demedicalize disability has had significant consequences for public policy development and for the lives of people with disabilities. As health care reform has become more salient politically, and as various efforts to contain rising health care costs are implemented, however, there is reason for concern that the Independent Living movement will be left on the sidelines as other forces shape the direction of change in the health care system. Since persons with disabilities as a group are heavy utilizers of the health care system (DeJong, Brannon, & Batavia, 1993), the potential implications of inclusion or exclusion as a player in the policy process are significant.

In collaboration with leaders from the disability field, the Robert Wood Johnson Foundation (RWJF) in 1990 authorized the funding of a new program, "Improving Service Systems for People with Disabilities." While this program had multiple goals, central among them was a commitment to strengthen the roles of Independent Living Centers (ILCs) in health and (especially) medical services. This program goal was a natural one for the Foundation, which is the country's most prominent philanthropy in health care, but was the subject of much debate among the disability leaders advising RWJF. In 1991, twelve ILCs in ten states were selected for four years of program funding, and our research group was chosen to conduct a program evaluation. The ILCs proposed a variety of program initiatives. Those related to health care included development of an IL health clinic, initiation of an IL mental health clinic, ILC entry into the retailing and servicing of medical equipment and supplies, efforts to enhance and modify the disability-relevant curriculum of local medical schools, and establishment of IL "case management" programs.

Of these, case management had received the most attention and effort after four years of program planning and implementation. Half the sites formulated plans to market IL-designed case management (CM) services to insurers and managed care organizations, both to influence the health services provided to persons with disabilities and to generate

revenues for the ILCs. Other sites rejected such initiatives either because they did not consider CM an appropriate role for ILCs or because they were not convinced that their local markets were receptive to paying ILCs to perform this role. Four sites sustained their CM efforts through at least two years of the program period. These sites established CM relationships variously with managed care organizations, a local "long-term care authority," labor unions, auto insurers, local hospitals, and other private and public insurers, including state workers compensation. A year after the end of Foundation funding, the results of these CM efforts can reasonably be described as modest.

Various problems hampered the program sites in their efforts to become players in the local health care arena. The most important was the relative shortage of IL expertise about how the health care system worked and how change within it might be fostered. Since 1990, health care has been rapidly changing, and the sites (like many others) were not prepared for the fluidity and complexity they confronted as new participants, with little but moral capital and untested expertise to offer. Specifically, the sites were not well-equipped to address the shifting sands of managed care arrangements, which seemed at first to offer promising opportunities for partnerships in addressing the needs of enrollees with disabilities. However, a host of issues hampered ILC efforts to implement their CM initiatives.

First, ILCs had to convince managed care organizations (MCOs) that they could not only arrange appropriate services for members with disabilities, but also contain utilization and costs. This proved difficult since the program sites had little or no prior experience and no data that demonstrated the costs or impact of their (proposed) services. Second, sites struggled with issues related to packaging and pricing their services. Since they considered MCOs a potential new source of revenues, they expected reimbursement for their services. But they had no experience with bundling versus unbundling planned services or pricing them to meet their (usually unmeasured) costs. Third, ILCs that received CM referrals from MCOs or insurers had little control over who was referred. Frequently, early referrals were "heavy care" or complex cases, and most sites saw this as an opportunity to demonstrate their effectiveness on the most difficult clients. They quickly learned, however, that costs for such clients are high and that a mix of "severity" is often preferable. Moreover, experience showed that relatively simple interventions for relatively simple problems (e.g., referrals for a hearing aid and sign language training) often proved very effective. Fourth, some challenging staffing issues arose as sites tried to recruit marketable expertise (e.g., nursing credentials) while also assuring allegiance to IL principles. This balance was often difficult to strike.

As a result of efforts by the national program office at ILRU, the sites were well prepared to market their services to MCOs and insurers. Some (but not all) encountered ongoing problems with their own staffs and boards, however, over the language of CM. Both elements of the "CM" label can create issues for IL advocates: people are not cases, and they should never be managed. To varying degrees, the language of CM generated debate about compromising IL principles for uncertain gains.

Those sites that undertook CM initiatives continue to weigh the tensions between service and advocacy roles in defining an IL approach to health care. Is it more appropriate and/or feasible for ILCs to play a paid case manager role, to train consumers to be their own case managers, or to be advocates who monitor and challenge MCOs and others who are enrolling growing numbers of people with disabilities? Arguments for all three positions, as well as for combinations of them, have been made across the program sites. What is widely held is that changes in the health care system are likely to have significant consequences for people with disabilities. The experience of this program suggests that CM initiatives by ILCs are unlikely any time soon or in many places to generate a substantial number of client referrals or much significant revenue for the centers. Paradoxically, this venture into health care may have proven more successful in educating ILCs in the ways of health care financing and managed care and, thus, in preparing them to play their traditional advocacy roles more effectively in the rapidly-changing health care arena.

### References

- Batavia, A.I., DeJong, G., & McKnew, L.B. (1991). Toward a national personal assistance program: The independent living model of long-term care for persons with disabilities. *Journal of Health Politics, Policy and Law*, 16, 523-545.
- DeJong, G., Brannon, R., & Batavia, A.I. (1993). Financing health and personal care. In G.G. Whiteneck, S.W. Charlifue, K.A. Gerhart, D.P. Lammertse, S. Manley, R.R. Menter, & K.R. Seedroff (Eds), *Aging with spinal cord injury* (pp. 275-294). New York, NY: Demos Publications.

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**Changes in Organizational Ties and Networks  
among Eleven Robert Wood Johnson Foundation-Funded  
Independent Living Centers**

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This paper, presented at the 1995 Society for Disability Studies (SDS) Meeting, reports on an evaluation headed by Ted Benjamin and conducted by the authors listed above of a four-year Robert Wood Johnson Foundation (RWJF) Program entitled "Improving Service Systems for People with Disabilities." Eleven Independent Living Centers (ILCs) across the country were funded from 1990 to 1994 to develop new and innovative strategies for service delivery for people with disabilities. This evaluation contained several key components: a nationwide longitudinal survey of the universe of ILCs, which inquired about consumers served, services provided, and ILC priorities and goals; individual case studies of the 11 RWJF-funded ILCs; and a longitudinal network survey that examined the organizational partners of the 11 RWJF-funded ILCs. It is this last survey that is the focus of the research presented in this paper.

The organizational network survey was first completed in the Spring of 1992 and repeated in the Fall of 1994. We asked each of the 11 RWJF-funded ILCs to name up to 30 (some named fewer) organizational partners that they considered to be most important to their current mission. We then sent out detailed surveys to the 11 ILCs and to all of their partners and inquired about the relationships between the organizations from both the partners' and the ILCs' perspectives. This paper deals with the responses of the partners at both points in time. The response rate was 85% in 1992 and 90% in 1994, leading to a sample of 280 partners in 1992 and 256 in 1994.

The evaluation team addresses four primary research questions in this paper. First, who are the organizational partners, and how have they changed over the course of the RWJF program? Second, what resources are exchanged between the RWJF-funded ILCs and their organizational partners, and how have the resource flows changed over the course of the RWJF program? Third, what are the partners' perceptions of the roles of the ILCs, and how have these changed over the course of the RWJF program? And fourth, what variations exist among the partner networks of individual ILCs?

### Who Are the Partners?

Perhaps one of the most interesting findings from the survey is that there was a great fluctuation from 1992 to 1994 in the specific identities of the partners named, and a small decrease in the total number of partners named. In 1992, 296 organizational partners were named by the 11 RWJF-funded ILCs. Of this original group, only 106 were renamed in 1994; 190 were dropped. Another 180 new partners were named in 1994, making a total of 286 partners named in 1994. Despite these changes in partner identities, several key aspects of the partners remained constant over time. For example, partners' tax status remained relatively stable, with 42% of the partners being governmental organizations in 1992, and 47% in 1994. Non-profit organizational partners decreased some from 49% in 1992 to 39% in 1994. For-profits and other organizations (including ad-hoc groups and associations) increased slightly over the program period. (See Table 1.)

Table 1. Partner Types

<u>TAX STATUS</u> <u>YEAR</u>	<u>GOVERNMENT</u>	<u>NON-PROFIT</u>	<u>FOR-PROFIT</u>	<u>OTHER</u>
1992	42%	49%	6%	3%
1994	47%	39%	9%	5%

<u>PARTNERS'</u> <u>ROLE YEAR</u>	<u>DIRECT</u> <u>SERVICE</u>	<u>FUNDING</u>	<u>ADVOCACY</u>	<u>POLICY/</u> <u>PLANNING</u>	<u>OTHER</u>
1992	48%	15%	21%	12%	3%
1994	44%	15%	19%	13%	8%

Similarly, the partners' primary role (as self-identified) changed very little in the aggregate from 1992 to 1994. The largest single type of partners remained direct service providers (from 48% in 1992 to 44% in 1994). The percentage of funding, advocacy, and policy and planning partners changed very little or not at all during the program period, and the percentage of "other" partners increased from 3% to 8% during that period. Overall, the identities of the partners changed, but the types of partners named did not. However, individual variations did exist within each ILC organizational network. These individual variations are discussed in a later section of this paper.

### How Have Resource Flows Changed?

In the aggregate, the resource flows did not appear to change much between 1992 and 1994. Table 2 shows that resources given to the ILCs by the partners remained constant in the area of funding, increased slightly in referrals given, and decreased slightly in the area of technical assistance given. Likewise, there was little change in the resources received by the partners from the ILCs. Funding received increased slightly from 6% to 9% of the partners receiving funds, referrals received decreased by 4%, and technical assistance received by the partners remained constant at about 63-64%. Again, although

there were few changes in the aggregate, a closer examination of changes within each ILC organizational network reveals significant variation.

Table 2. Resource Flows Between Partners & ILCs

<u>YEAR</u>	<u>GAVE FUNDS</u>	<u>GAVE REFERRALS</u>	<u>GAVE TECHNICAL ASSISTANCE</u>	<u>RECEIVED FUNDS</u>	<u>RECEIVED REFERRALS</u>	<u>RECEIVED TECHNICAL ASSISTANCE</u>
1992	34%	59%	53%	6%	53%	64%
1994	33%	62%	49%	9%	49%	63%

#### How Have the Partners' Perceptions of the ILCs Changed?

In both periods of time, the ILCs were perceived by the partners primarily as direct service providers (60% of the partners saw the ILCs in this role in 1992, and 57% did in 1994). Table 3 shows that the role of advocacy was a primary and stable secondary role across time and the roles of funding organization; policy and planning organization and "other" were all minimal and remained unchanged during the program period. Again, individual variation among particular ILC organizational networks did exist.

Table 3. Partners' Perceptions of the ILCs

<u>YEAR</u>	<u>DIRECT SERVICE</u>	<u>FUNDING</u>	<u>ADVOCACY</u>	<u>POLICY/ PLANNING</u>	<u>OTHER</u>
1992	60%	> 1%	39%	1%	0%
1994	57%	> 1%	40%	1%	2%

#### What Individual ILC Variations Exist?

Throughout this paper and the SDS presentation, we have alluded to the fact that significant individual variations did exist within each ILC organizational network despite the apparent lack of substantial change in the aggregated sample. In the case of partner identities, we found individual ILCs in which there had been significant shifts in interactions with for-profit organizations and government organizations. We also distinguished changes in resource flows and perceptions of the ILCs by their partners that appear to be related to these shifts in partner types. In all, we identified four models of variations that exist for the ILCs. The first is a model of increased interaction with for-profit organizations between 1992 and 1994. Two of the 11 ILCs fell into this category. These two ILCs had increased relationships with direct service for-profits such as professional consultants, lawyers, and financial institutions. The ILCs in this model also had increased referrals from their partners, and increased technical assistance was given

by their partners. Concurrently, these ILCs received funding from fewer partners in 1994 than in 1992 (which seems reasonable given that fewer of their partners were funders). Although the evaluation team knows these two particular ILCs to be extremely innovative and advocacy-oriented, there was an increased perception by their partners that the ILCs were direct service providers. Again, this is a function of the changing nature of the partners who were more likely to be for-profit organizations and who would see the non-profit ILCs as direct service providers in relation to their own organizational structures and missions.

The second model is one of decreased interaction with for-profits over the program period. Again, two ILCs fell into this category. With these two ILCs, there appeared to be a shift toward a more traditional model of an ILC with increased interaction with other non-profit organizations and governmental agencies. These ILCs also had increased interactions with direct service providers, and their partners had a decreased perception of the ILCs as direct service providers themselves and an increased perception of the ILCs as advocacy organizations (again, this may be in relation to the partners' organizational structures and missions). Finally, there was a small decrease in the funds given to the ILCs noted in this model that may have been the result of increased interaction with other non-profit direct service providers.

A third model into which four of the ILCs fell is one of increased interaction with governmental agencies. Particularly, these ILCs had increased interactions with funding and policy and planning partners that were associated with increased funds and referrals being given to the ILCs. Upon closer examination, some of these partners, especially the governmental partners, hired the ILCs for contract work related to the remodifications required under the 1990 Americans with Disability Act. This could also explain the increase in funds and referrals being given to the ILCs. Finally, there were no substantial changes in the partners' perceptions of the ILCs. They were still largely perceived as direct service organizations.

The final model is one of stable interaction and includes the last three ILCs in the study. These ILCs showed a small increase in the number of non-profit organization partners but no change in partners' primary roles, the flow of resources, or the partners' perceptions of the ILCs.

### Conclusion

In conclusion, despite the large changes in the identities of the organizational partners, there were relatively small aggregate changes in the types of partners with whom ILCs interacted, the flow of resources between ILCs and their partners, and the partners' perceptions of the ILCs. However, significant variation did exist at the individual ILC level, leading to the construction of four basic models of interaction with partners: 1) increased interaction with for-profit organizations, 2) decreased interaction with for-profit organizations, 3) increased interaction with government agencies, and 4) stable interactions with partners. Further analysis is currently underway by the evaluation team

to better understand these interaction models and to assess their impact on the ILCs and the ILCs' ability to provide services to their consumers.

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## Section XI

### Parenting with a Disability

This section reviews one of the most valued and yet under-researched social roles in today's society--parenthood. The section's authors are all from *Through the Looking Glass*, and each presents different aspects of parenting with a disability.

Megan Kirshbaum sets the tone with "Parents with Disabilities and their Babies--A Context," which introduces the backgrounds and histories of the projects and the Research and Training Center on Families of Adults with Disabilities. Her chapter points to the fact that the competencies of parents with disabilities are too quickly questioned by professionals, yet services are rarely offered to them, and those that are offered are usually inaccessible. The need for intervention or technical assistance is not framed using a medical model, although clinical services are offered. Instead the research, training, and other activities support the rights and desires of people with disabilities to be active parents. The projects described are strong examples of how cutting edge research is including and benefiting people with disabilities.

The two other chapters in this section address related issues regarding the needs of parents with disabilities--both in applied research contexts. The benefits of these research projects are so concrete and direct that the clients of *Through the Looking Glass* are both research participants and recipients of the results. Judith Roger's "Assessment Issues and Illustrations of the Impact of Adaptive Parenting Equipment and Techniques" demonstrates the use of creativity and planning in accommodating parents' disabilities. Although the focus of the study was on developing adaptive parenting equipment, the research identified many currently available baby care resources that could be modified for use almost immediately. The use of modified equipment can provide parents with disabilities with substantial independence in caring for their children. Not only does the equipment assist in transferring, bathing, dressing, and other routine baby care activities, but it can prevent additional disabilities or injuries resulting from unsafe lifting or carrying techniques. A publication resulted from the project that illustrates the various pieces of equipment tested or tried during the project.

The last chapter in this section shows how the equipment in use by parents with disabilities affects the relationships between child and parent. This paper by Anitra DeMoss is titled "Research Issues in Evaluating the Impact of Adaptive Parenting Equipment on Baby care and on the Relationships between Parents with Physical Disabilities and their Babies." While the title is quite explicit, the paper illustrates how basic research can be very complex. This study, using qualitative and quantitative measures, involved analysis of videotaped interactions and interviews as well as the occupational therapist's assessment. The consequences of having new or adapted equipment included more positive interaction and reduction of stress during baby care.

Parents in this project were active participants, contributing to the creation of ideas and solutions that met their own needs, as well as answering researcher's questions.

## Parents with Disabilities and their Babies--A Context

Megan Kirshbaum, Ph.D.  
Through the Looking Glass

This introduction provided a framework for a panel at the 1995 meeting of the Society for Disability Studies that focused on parents with disabilities and their babies: De Moss' summary of a research project, and Rogers' presentation of videotaped illustrations of adaptive parenting equipment development on the same project. The panel concluded with a discussion of public policy issues regarding parents with disabilities.

Since 1982 Through the Looking Glass (TLG) has focused on parents with disabilities and their children. At this point approximately 100 culturally-diverse families in which at least one parent has a disability are regularly served each year. This includes parents with all categories of disability--i.e., sensory, physical, cognitive, medical, and psychiatric/emotional. In 1993 the National Institute on Disability and Rehabilitation Research funded TLG as a Research and Training Center on Families of Adults with Disabilities. Over four years this center has conducted 11 different research projects focused on parents with disabilities, as well as training projects such as a national clearinghouse, a parent network, and a newsletter, "Parenting with a Disability." More than 3,000 sites--families and programs--are connected to this center.

There has been a great need for a central resource such as this RRTC because of the rapid growth in the number of parents with disabilities--estimated to be 10.9% of parenting families, or 8 million families currently. The rapid social change in the number of families is assumed to be due to social integration and the expectation of a fuller life for people with disabilities. The difficulty has been that the social change has far outpaced the resources, so that many problems have emerged that are especially critical for the most vulnerable families--those in which parents have cognitive or psychiatric disabilities, those who are low income, and/or those who are extremely stressed by factors beyond the disability.

In 1984 we conducted an interviewing project with a particularly articulate and independent high-functioning group of parents with disabilities, including deafness, who reported that it was common for professionals to question their ability to care for their children, and to do so in a way that seemed to doubt the parents' awareness of their own physical or sensory limitations. For instance, a deaf parent would be asked, "But how will you hear your baby cry?" when the parent had already purchased a baby cry alarm. At this time a number of parents with physical disabilities reported feeling vulnerable to analogous comments because of a lack of role models and a sense of isolation. There had been essentially no images of parents with disabilities in the media, so that children with physical disabilities had often matured without experiencing such images. Many also reported having been socialized to believe that parenting was not for them.

In response to all these issues, we decided to conduct research that included videotaped documentation of baby care by people with physical disabilities. In 1985 the Easter Seal Research Foundation funded a three-year groundbreaking descriptive research project on interactions between mothers with physical disabilities and their babies. Basic care in 11 families was regularly videotaped from birth through toddlerhood, and there was an analysis of how babies and mothers reciprocally dealt with disability obstacles during this care. Early adaptation in babies, ingenuity and inventiveness in parents, and teamwork in parental couples were documented, despite the absence of community resources or any specialized parenting equipment.

What we learned from "good enough parents" was used to seed and support the adaptive strategies of parents who were more stressed, or whose babies were temperamentally or physically less able to adapt. Our analysis was also used to inform court situations involving custody. For instance, in this study we analyzed videotaped diapering sessions, noting the "bridging techniques" used by parents and the coping techniques of babies that led to the dyads managing what were sometimes extremely long diaperings. In a subsequent court case, a videotape of diapering by a mother with significant cerebral palsy was presented as evidence of her supposed inability to care for her baby. It was possible to draw many analogies between her diapering interactions and those of the appropriate and capable mothers with significant disabilities whom we had previously studied, discrediting the tape as valid negative evidence.

Involvement with court-involved parents raised another important assessment issue. Our early research had shown how adaptive collaboration between the baby and the parent with a physical disability evolves gradually over time, apparently beginning during the first weeks of life. Removal into foster care, or even excessive use of able-bodied helpers, may disrupt this adaptive process, making the potential of the parent and baby to work around any disability obstacles very unclear.

In the course of clinical work, we were asked to assess and intervene with some families who were multiply stressed, isolated, and receiving treatment by systems without disability expertise or disability culture sensitivity. We were startled by the degree to which professionals were pathologizing many of these families. Therefore, we began to conceive of our work as involving a depathologizing process through familiarity with cultural norms as well as culturally-derived expertise about solutions to disability obstacles.

We were drawn into poignant and tragic situations in which disability ignorance irreparably damaged an already tenuous chance for parent/child reunification. For example, the Department of Social Services asked that I do an assessment of a young African-American mother with quadriplegia and her baby. The baby was already six months old, had been removed at birth, and had been exposed to drugs pre-natally. The teenage mother lived in a particularly hazardous housing project where she was supplied with and given street drugs by family and attendants. The children's protective services social worker said that the mother was uncooperative with substance abuse treatment. However, she had only been referred to two different programs, both of which were inaccessible to her wheelchair and both of which had refused to deal with her catheter in

order to get the required urine analyses to monitor drug use. She had been instructed to travel to these programs on the bus, though bus disability access in her city was then largely mythical. The social worker had been unaware of disability transportation systems or the scarce disability-sensitive substance abuse programs. She described the mother as forming no relationship to her baby despite weekly visitation. However, since the baby had been born, the mother had been provided no assistance in order to make it possible for her ever to hold or care for her baby in any way. Everyone just assumed this was impossible. The able-bodied grandmother did the care or left the baby in a playpen during visitations. During the first visit, I saw a depressed mother who indeed appeared estranged from and disinterested in her baby. But when I showed her videotapes of parents with disabilities, she asked if I could help her hold and feed her baby. So, in the second visit, by experimenting with a variety of frontpacks and pillows, the mother was able to begin caring for her baby. When she held her baby for the first time, she tenderly nuzzled and murmured to her, caressing with her lips, as mothers greet their babies immediately after giving birth.

It is clear one cannot assess the potential of a relationship between a baby and a parent with a significant physical disability without first providing disability-appropriate services and providing whatever adaptive techniques and adaptive babycare equipment make it possible for infant/parent interaction to occur and for a relationship to develop.

Because of the absence of appropriate adaptive parenting techniques and babycare equipment, and the absence of appropriate assessment tools, we decided to focus on these issues. The National Institute on Disability and Rehabilitation Research funded the Field-Initiated Research Project: "Developing Adaptive Equipment and Adaptive Techniques for Physically Disabled Parents and Their Babies Within the Context of Psychosocial Services" (#H133G10146). This project sought to add technological expertise to the creative solutions generated by parents in our community through the years.

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## Assessment Issues and Illustrations of the Impact of Adaptive Parenting Equipment and Techniques

Judith G. Rogers, OTR  
Through the Looking Glass

Through the Looking Glass (TLG) recently completed a Field Initiated Research project (#H133G10146) funded by the National Institute on Disability and Rehabilitation Research that served 14 families in which at least one parent had a physical disability. During this study a number of important areas were examined regarding adaptive parenting assessment and intervention, including transitional tasks, emerging danger, developmental issues, child capabilities, and equipment solutions. TLG also developed more than 50 pieces of equipment to help parents with a variety of physical disabilities during the physical tasks of baby care. Detailed information regarding this equipment is published in Adaptive Parenting Equipment: Idea Book i.

"Transitional tasks" consist of carrying/moving, transferring, or holding. An important concept discovered during the study was that transitional tasks were pivotal to parents' ability to do primary baby care activities (e.g., feeding, diapering, bathing, dressing, or soothing). Transitional tasks are important not only because they are an essential link to the baby care activities (BCAs), but because they require close physical proximity and provide an opportunity for emotional closeness. Many times, transitional tasks are the primary problem area for parents and, consequently, can affect multiple BCAs. Accessible surfaces on which parents can safely transfer their babies allow parents to do a BCA that they might otherwise find too difficult or dangerous. Some parents, for example, were unable to transfer their babies to a highchair, thereby making it difficult to participate in the parenting task of feeding. Carrying/moving is another transitional task that is a necessary link to many BCAs. For example, one parent who was able to do the BCAs of bathing and dressing her baby could not carry her wet baby to the changing table after bathing due to balance problems. She bathed her baby, but chose not to dress him after bathing because she needed someone else to carry him to the changing table. Equipment solutions to these problematic tasks make it possible for parents to complete the entire task.

Another area that the occupational therapists (OTs) found important to assess was "emerging danger." There are two areas that should be considered when thinking about possible future danger. The first is the child's safety as it relates to upcoming developmental changes. For example, the child may learn to roll in the next month. The OT must ask if the BCA surface will accommodate this inevitable change. The second area to consider is the parent's risk for secondary injury or disability due to extra body stress. A common problem that puts the parent at risk for personal injury, such as back strain, occurs when the parent tries to transfer a child who has increased in weight. Inappropriate surfaces can lead to problems in body positioning when parents perform the BCAs. Poor body positioning can cause injury if done repetitively, such as when a parent

using crutches has to lean over a bed to diaper the child. Over time this positioning could lead to problems, including back injuries or damage to lymph nodes.

Child development is another important area of assessment in relation to equipment/technique intervention. Evaluating how much assistance the child can provide requires knowledge of the child's developmental capacities. Having the child assist in the BCAs can make the task easier. The following example illustrates this. A father wanted to diaper his baby independently to give his wife a break. As a parent with limited upper extremity strength, he had difficulty placing the diaper under the baby's bottom. The occupational therapist taught him how to elicit the cooperation of his fifteen-month-old baby by having her lift her bottom during diapering. The father puts a hand under the baby's bottom and taps it to encourage the baby to lift up. This technique can be used with babies from the age of five months. This father reported: "It was very useful. I didn't realize how cooperative she [the child] could be. She could do more for herself. Since the intervention, we have relied more on her ability to cooperate."

One of the most difficult tasks for a wheelchair-using parent is lifting his or her child up from the floor. Combining an adaptive parenting device such as a "wheelchair climbing step" with an adaptive parenting technique may solve this problem. A piece of webbing is attached to the manual wheelchair, or an extra attachment is made for a motorized wheelchair to be used as a step for the toddler. In our experience, most toddlers like climbing up onto the foot pedals of the wheelchair, but they need to be taught how to climb onto the adapted step. It is initially difficult for toddlers to climb up the step because they are not used to seeing it, since it is usually hidden by the parent's legs when not in use. This transfer is also challenging because balancing on one foot while climbing up the step is difficult, even when the parent assists the child by holding his or her hands. The technique is introduced to the child as a game by placing a toy on the parent's lap. One parent who had a step attached to the wheelchair said: "It was fun for her. She loves to climb." Another parent added that having the climbing step provided a way for his child to climb into his lap without assistance from his wife. This parent reported: "We became independent, and therefore it increased our bond as father and daughter."

A major focus of the study was on developing adaptive parenting equipment. There were two major challenges to equipment development: locating reliable, dependable fabricators who completed work in a timely manner, and the limitations of the home environments in terms of room layout and space.

The adaptive parenting equipment was divided into four categories:

1. Commercial baby care equipment. Equipment that was already available on the market and could be used without modification. For example, baby bottles that have a hole in the middle for easier grasp are commercially available.
2. Modified use of commercial baby care equipment. Commercial baby care equipment that was used for a different purpose than its original design. For example, a large fanny pack was stuffed to provide a firm, stable seat on which

wheelchair-using parents, or parents with neck and/or back problems could place their babies.

3. Adapted baby care equipment. Commercial baby care equipment that was adapted or altered in order to be more efficiently utilized by the parent. For example, diaper rings were added to commercially available diaper wraps so that a parent with little or no capacity to grasp could attach and detach the Velcro strap.
4. Newly created baby care equipment. Equipment that was designed and fabricated "from scratch" by the occupational therapist or the research team with input from the parent. For example, the baby care tray and play center are not available on the market and were created for the first time by the team (occupational therapist, parent, rehabilitation engineer/fabricator, and researchers) on this project.

The equipment developed for parents during the course of this project can also be grouped according to the baby care activity for which it was used and the functional needs of the parent. Below are selected examples of adaptive parenting equipment developed during the project for specific activities:

- Adapted changing table. For parents who were wheelchair users, an adapted changing table (card table) provided easy access. The table was fitted with a safety pad and a safety strap for the child.
- Toy mobile. For parents who used a wheelchair and had either hand coordination or upper arm strength limitations. In addition to the adapted changing table, the toy mobile was an essential piece of equipment. It occupied the baby during the long task of diapering and was also used to entice the child onto the diapering table. One parent in the study had problems transferring his child to the changing table as the child grew heavier. This child had also become resistant to being changed. The parent did not want to struggle with her and was able to use the toy mobile as an enticement to get her onto the changing table. This toddler found the toy mobile so attractive that she climbed onto the diapering table to play with it even when she had a diaper rash and had previously been unwilling to be changed. The toy mobile eliminated the need for the father to lift his child.
- Adapted cribs. Commercial cribs often have either a foot release or high-positioned hand releases for lowering the side of the crib, which are difficult or impossible for wheelchair-using parents to operate. Parents who have difficulty lowering the crib side find it challenging to put their babies to sleep in a conventional crib because this set-up requires lifting the baby above the parent's head and over the side of the crib. The body mechanics of this transfer places stress on parents' bodies. One parent commented, "I pulled my back muscles as I was putting her [the baby] in the crib." Cribs were modified with either a sliding side opening or a swinging gate opening to allow parents using wheelchairs to transfer the child to and from the crib at lap level. When she received the new crib, the mother reported that "my back pain was alleviated."

Equipment alone is not sufficient for intervention. It is important for professionals to have knowledge of what to assess when providing intervention for baby care activities. The combination of appropriate equipment, adaptive techniques, and knowledge of intervention issues provides parents with a wealth of options that can increase their parenting enjoyment and participation.

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# Research Issues in Evaluating the Impact of Adaptive Parenting Equipment on Babycare and on the Relationships between Parents with Physical Disabilities and their Babies

Anitra DeMoss, M.A.  
Through the Looking Glass

## Overview

The purposes of this study were to design and develop adaptive parenting equipment and techniques within a psychosocial context for parents with physical disabilities, and to develop assessment/intervention guidelines. This in-depth quasi-experimental study of 14 families used qualitative and quantitative measures within a pre-post design to analyze the impact of adaptive equipment or adaptive technique on babycare activities and the parent-child relationship. The study also produced recommendations for parents and professionals to increase their awareness of possible solutions, and recommendations for professionals and policy makers to increase understanding of parenting with a physical disability. A major focus of the research study was using a disability-sensitive framework from which to approach intervention, assessment, and recommendations.

## Sample

The 14 participants in this study (four fathers and ten mothers) represented diverse ethnic and cultural backgrounds and wide variation in type and degree of disability. Babies' ages at the outset of the project ranged from five weeks to sixteen months. Eleven additional families were involved in the "pre-piloting" stage of the research, during which they received adaptive babycare equipment. Participants were recruited through the agency newsletter, referral, and parent networks.

## Definitions of Relevant Terms

Adaptive parenting equipment: Adaptive parenting equipment is assistive technology that is specifically designed to help with babycare or play. For example, a crib that has been adapted with an opening gate accessible to wheelchair users allows the parent to place her or his child into the crib.

Adaptive parenting techniques: Adaptive parenting techniques are strategies taught by the occupational therapist that allow the parent to do a babycare task in a way that is easier and/or less physically stressful. An adaptive parenting technique may involve teaching parents how to use their bodies in different ways to avoid injury or how to elicit their babies' cooperation in completing the task.

Adaptive stress: Adaptive stress is stress produced by a disability obstacle. This obstacle is often a "mismatch" in the environment, i.e., a physical element in the environment

(including anything outside of the parent and his or her mobility aid) that does not match the functional abilities of the parent or is not ergonomically good for the parent's body.

### The Study

Through the Looking Glass (TLG) designed and developed adaptive parenting equipment to help parents with physical disabilities take care of their babies. Because we could not find existing measures that were adequate in addressing issues relevant to parents with physical disabilities, we developed most of our own measures. Previous research at TLG identified areas of parenting activities and parent-child interaction during babycare that seemed particularly relevant to parenting with a physical disability. The new measures were based on TLG's past research and clinical experience as well as on pilot results from the current study.

The project emphasized using a non-pathological approach to measurement and intervention that included disability-appropriate measures. The measures developed by TLG during the course of this study rely on parents' perspectives along with the expertise of those trained in occupational therapy and psychology. Too often service providers or researchers assume that they know what parents need or what they must do. Parents' perceptions were essential in the design of equipment and in the interpretation of the study results. The hypotheses and predicted results of the study were as follows:

Hypothesis 1. Adaptive parenting equipment and/or techniques will increase parents' involvement in babycare as seen in an increase in the number of tasks parents are able to do post-intervention and/or the frequency of doing these tasks.

Predicted results. It was predicted that equipment would allow parents to do babycare activities not previously possible, either because of worry about the potential danger to the child or to parents themselves, or because the task was too difficult, painful, or fatiguing. Equipment solutions would also allow parents to do babycare activities more frequently that had been too difficult, painful, or fatiguing to do pre-intervention.

Hypothesis 2. Adaptive parenting equipment and/or techniques will improve parents' physical ability to do the task.

Predicted results. It was predicted that parents would be able to do babycare activities post-intervention with less difficulty, pain, fatigue, and worry.

Hypothesis 3. Adaptive parenting equipment and/or techniques will improve the quality of parent-child interaction during babycare.

Predicted results. It was predicted that the quality of parent-child interaction would improve as parents became less "adaptively stressed" in doing the physical babycare as a result of using adaptive equipment and/or adaptive techniques. As

the parent became less adaptively stressed, it was predicted that the infant would become less stressed, enhancing parent-child interaction.

We asked parents to rate themselves before and after intervention on difficulty, pain, fatigue, and worry. Parents' involvement was critical, not only with respect to identifying areas of babycare with which parents wanted help, but also with respect to designing and refining the equipment. Occupational therapy and parent-child measures were also used to measure the outcome of equipment intervention. Through occupational therapy measures, we evaluated mismatches between environmental obstacles and the parents' physical abilities. We used parent-child measures to assess parent-child interaction and how parents elicited cooperation from their babies during the babycare task.

### Methodology/Ethical Considerations

One of the challenges in designing the measures was determining the standard of comparison with respect to the variables under study--nondisabled parents or other parents with physical disabilities. Another measurement issue was how to take into account the unique disability and equipment needs of individual parents. Given the variation in type and degree of disability among the parents in our study, we could not always assume there would be normal variation on a variable. Quantitative statistical analysis, therefore, is not always appropriate when analyzing improvement post-intervention. A qualitative assessment of parents takes into account each parents' uniqueness in terms of how she or he needs to move her/his body in order to function.

In this study, a compromise consisted of using rating scales (including parent self-rating scales) to compare participants to what would be expected of the population of parents in general, with or without disabilities, and using individualized assessment to measure parents' abilities in relation to their environments.

### Findings

The study sample is too small to report statistical results, but patterns of responses did emerge from the parent questionnaires. Analyses of videotapes of parents doing babycare tasks also revealed improvements in a number of areas. Overall, our findings suggest that adaptive parenting equipment increases the babycare role of parents with physical disabilities. In addition, some parents demonstrated significantly less preoccupation with the babycare task and increased pleasure interacting with their children as babycare became easier. The results are summarized below.

- Difficulty in doing the babycare activity decreased after equipment intervention for most parents. A reduction in difficulty was also associated with improvement in other parent-child variables.
- After equipment intervention, parents engaged in more positive interactions with their babies during the babycare activity. We hypothesize that this is the result of parents being less burdened by the physical demands of completing the task.

- The parents in the study had minimal to no problems keeping their babies or themselves stable during babycare activities even before intervention. The parents in our study avoided doing parenting tasks that put their babies or themselves at risk for falling. This is an important finding because it counters the perception that parents with physical disabilities will not be able to care for their children safely.
- Many parents were doing the babycare tasks independently before intervention, but they were placing themselves at risk for secondary disability. For example, some babycare tasks were potentially stressful to parents' backs or could have exacerbated their disabilities if they had continued to do them. Therefore, the equipment was designed not only to make the tasks easier, but to decrease body stress and, subsequently, potential secondary injury.
- Successful babycare equipment intervention involves periodic home follow-ups for two reasons. First, it is important to monitor customized or prototype equipment for safety and repair. Second, it is important to assess changes in equipment needs as the child develops.
- During the course of their observations of parents doing babycare tasks, the occupational therapists discovered that transporting, holding, and transferring children are crucial activities because they are the essential links to most babycare activities. One occupational therapist's recommendation was to begin intervention with an assessment of these linking activities.
- A number of parents reported that the equipment helped them feel more confident as caregivers. Several parents reported feeling more central in their parenting role after the equipment intervention.

#### Additional Research/Ethical Considerations

- Parents as active participants in brainstorming and in assessing the equipment and the babycare activities, as well as the concept of mismatch, are examples of approaching intervention and assessment from a disability-sensitive framework. In addition, disability culture is brought into the home by the occupational therapists through their experiences with peers or by being peers.
- A control group with random assignment to intervention/no intervention groups would be one way to compare parents in our project to parents not receiving intervention. However, not providing services to parents who needed them was not an ethically feasible option.
- Sometimes it was not possible to delay intervention before all the research data could be collected. For instance, when there were safety concerns or when there was an urgency in helping a mother take care of her newborn baby, intervention requirements preceded research requirements.

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## Section XII

### Cultural Identity Issues

People with disabilities as a group are not homogenous, but there exists a desire to speak as a united front. Part of the tension evident in disability studies as a field today is the conflicting perspectives on inclusions, integration, or separation. The proponents of various models of identity have looked at the positive impact of having a disability on identity and its contribution to selfhood. In this section are three quite different approaches to the issue of cultural identity for people with disabilities.

The first chapter, perhaps most unlikely in some ways, yet most widely accepted in others, looks at Deaf parents and their hearing children. Perhaps more so than people with any other "disability," Deaf people form a culture based on shared values and language. This value system and language is passed on to their children--whether or not they can hear. Yet Deaf people have traditionally avoided the term "handicapped" or "disabled," and they claim cultural identity as a linguistic minority. Children of Deaf parents, as author Paul Preston points out, are not technically "Deaf" nor disabled, yet they are members of this minority group and act as culturally Deaf despite their hearingness. In "Daughters before Sons: Interpreting for Deaf Parents," Preston also examines the difference between sons and daughters in both their roles and their identities. He found that more daughters than sons became fluent in sign language and acted as interpreters, yet both sons and daughters culturally identified as being members of the Deaf community.

This gender difference (and similarity) among physically disabled people is examined from a different perspective in the second chapter. Mary Beresford considers the impact of gender and age of disability onset on the level of comfort with disability--or, more specifically, with one's own disability and with those of others. In her chapter, "The Effects of Age of Disability Onset and Gender on Social Anxiety, Self-Esteem, and Attitude toward Others with Disabilities," Beresford examines the results of three separate scales that were administered to nondisabled people and to her own sample of people with physical disabilities. Surprisingly, she found gender had little impact, yet the use of wheelchairs seemed to increase self-esteem and comfort with other people with disabilities. The paper explores how self-identity as a person with a disability--particularly a physical one--has similar impact on men and women. She espouses the possibility that more severely disabled people, and those who use a wheelchair all the time, compared to those with less severe disabilities, may have adjusted better to disability and to their own situation.

The question of the impact of disability, the age of onset, and gender is not asked by the third author. Instead, he takes a different tack altogether, asking whether it matters that a person identifies as having a disability when teaching or researching disability issues. Steve Brown takes a back door approach (perhaps the only accessible one) to disability identity. He presupposes that disability culture exists and states this as part of his world

view in "Constructing Disability Studies: More Questions of Identity." He asks, and answers, what are studies and what is ideology before treading the dangerous ground of identity politics. His chapter reflects on the importance of personal identity in general, and, specifically, of having a disability. He does not argue, however, that a disability identity is a prerequisite to teach, study, or research disability issues, although he cautions against barriers placed in front of scholars who have disabilities by those who do not.

The importance of disability identity to scholars looking at disability studies is mirrored by the importance of disability identity for people who have disabilities or who have children who may assume this identity. These papers express diverse and important perspectives on cultural identity.

## Daughters before Sons: Interpreting for Deaf Parents

Paul Preston, Ph.D.  
Through the Looking Glass

Gerald sat scrunched in a chair when I asked him what it was like growing up with two profoundly deaf parents:

I'm constantly looking at my face in the mirror and [Here Gerald temporarily stopped using spoken English and switched to American Sign Language. Signs: *I don't know who that is.*] It's one of the first questions everybody asks me, "What was it like being the child of deaf parents?" As a boy, I felt like a chameleon. I just adapted to every situation, I could be any role. . . . I assumed the personality of whoever was speaking at any given time. I was that person. I was whatever anybody thought I should be. You know, I fit into that mold just like a chameleon.

Gerald's description highlights a recurrent theme among the narratives of other hearing men and women with deaf parents interviewed during this study: the relationship between childhood experiences and present adult identity. As these women and men recounted and explored their family histories, they often dwelt upon one particular childhood role: that of interpreter. Although individual interpreting responsibilities ranged from sporadic to incessant, interpreting emerged as a seminal aspect of being the hearing child of deaf parents. Regardless of the degree or nature of their interpreting duties, the interpreter role itself came to embody hearing children's ambiguous alignment between two distinct and often opposing cultures: the Hearing and the Deaf.

This paper focuses on the ramifications of childhood interpreting responsibilities among hearing children of deaf parents: How did the experience of interpreting differ for a son or a daughter? In particular, how and why was the role of interpreting "genderized," that is, more often the responsibility of daughters than of sons? What are the social mechanisms and cultural values which determine the gender of the way we communicate with one another? And how does this bias, this genderized communication, affect the cultural alignment of hearing sons versus hearing daughters?

This discussion is taken from a four-year study of adult hearing children of deaf parents throughout the United States. Data included life histories and interviews with 150 men and women throughout the United States--all of whom are hearing, but were raised by profoundly deaf parents. Although hearing children of deaf parents do not overtly share their parents' functional condition, they potentially inherit a sensibility and a cultural legacy unlike that of any other hearing child. Unlike many of their own parents, these hearing children have been raised on the peripheries and often within the heart of an exclusively Deaf community.

Hearing loss is not the defining characteristic of those who are culturally Deaf. Within the Deaf community, there is wide variation in hearing as well as oral speaking abilities. Rather, those who are culturally Deaf share a much more broadly based system of values, behaviors, and ideas. Language is instrumental in this socialization process and, although often overstated, the relationship between culture and language is especially heightened among the Deaf. Language is an integral feature of Deaf culture: its soul and its demon, the barrier to and the means of social interaction. From among myriad varieties of human exchange, sign language and spoken language emerge as two distinct and often competing modes of communication. As the dichotomy between speaking and signing emerges within the routines of daily life, these different ways of communicating reinforce distinct cultural boundaries and patterns of interaction. Hearing children of deaf parents disrupt this dichotomization, resting squarely at the intersection of two cultures and two languages.

Like many other immigrant groups, deaf parents often encouraged their children to use the dominant English language--even at the expense of intra-family communication. Although these linguistic fissures routinely cut across a number of individual and family variables, it was markedly different for men than for women. Regardless of the amount of interpreting any one daughter did, the women in this study were far more likely to be fluent in sign language as well as in English. Nearly three-fourths of the 76 women in this study described themselves as bilingual as children: using and being fluent in both English and American Sign Language. Yet, less than one-third of the 74 men knew sign language as children. Compared to the women in this study, men were far more likely to express frustration over limited and superficial interaction with their deaf parents. Informants of both sexes noted that male hearing children of deaf parents--whether their own siblings or from other families--were more likely to have poorly-developed sign language skills.

The narratives of informants of both sexes are replete with examples of differences between speaking and signing. The associations and meanings attributed to speaking and to signing were similar for both men and women. Set within the context of American culture, the attributions to speaking or signing appear to mirror stereotypic masculine or feminine behaviors and values. Informants identified speaking as useful for information-gathering, protection, and negotiation. Speech was repeatedly characterized as "limiting," "distancing," "formal," or "tight." In contrast, informants described themselves as using sign language informally, for "just talking." When they signed, informants described themselves as feeling more "intimate," "natural," "expressive," and "comfortable." Separate usages and settings enhanced the contrast between the two languages: speaking was used in public, often for a specific purpose or to fit in; signing was used conversationally, at home and among friends.

Along with the perceived "feel" of sign language as symbolically paired with feminine qualities, the actual use of sign language was sometimes labeled by outsiders as feminine. One woman described how her propensity to gesture when she spoke was interpreted both

as feminine and as a liability. She explained that she had been given lower marks for her oral presentations in a college class because the professor reminded her that gesturing was "something that many women do that undermines their credibility . . . an announcement that you don't know what you really want to say." These symbolic pairings and public evaluations suggest culturally-prescribed interactions in American Hearing society. Men are expected to communicate with more controlled body movements and with more decisive and forceful oral skills. Conversely, women are given more latitude with body language and gesturing while, at the same time, not expected to be as orally articulate. Verbally outspoken women are more likely to be perceived negatively ("brash," "shrewish," "loud"), while similar vocal characteristics in men are praised ("forceful," "determined," "confident").

The narratives of these women and men do not support a view of speaking and signing as two different but equal languages. Rather, their descriptions of these polarized communication systems clearly indicate a dominant versus inferior language hierarchy. Grosjean (1982) describes how a culture's dominant language typically opposes secondary languages. This opposition has consistently placed sign language at the bottom of the language totem pole--regardless of cultural setting or the particular dominant spoken language. These informants suggest that this language hegemony has an overlay of gender: Male children more often took on (or were encouraged to take on) the language of the oppressor, while female children assumed the language of the oppressed. As the inferior method of communication, sign language becomes cast as inalterably deviant and more likely to be relegated to those who are socially and economically inferior. Socially handicapped by gender or by physical condition, women and persons with disabilities confront a racism of expressiveness, of communication: The more conforming and the more rigid the presentation, the more recognizably masculine the speaker is seen to be. The pairing of gender with specific modes of communication reinforces the asymmetry of social relationships between those who speak and those who do not, those who are male and those who are not, those who are able and those who are not.

The women and men in this study demonstrate gender differences in two overlapping areas: which child was more likely to assume family interpreting responsibilities, and which child was more likely to know sign language. What impact do these childhood differences have on adult lives? Are these hearing children culturally Deaf or culturally Hearing? In examining the relationship between culture and language, Pi-Sunyer (1980) asks whether one can truly be Catalan without speaking the language: "If the answer is in the affirmative, what does it mean to be Catalan once language takes a secondary position as a symbol of identity?" (p. 101). To paraphrase her question, What is the relationship between sign language and Deaf culture, and how does this affect the cultural identity and affiliation of hearing daughters versus hearing sons?

American Sign Language remains a central and cherished symbol of Deaf cultural identity. The persecution of sign language has erupted in an equally visceral response among many members of the Deaf community. For many deaf persons, speaking has become the

enemy. Speaking is considered dishonest, suspect, even treasonous to those who have no choice but to use sign language. To acknowledge and to accept one's deafness is to use sign language. Despite the actual range of hearing acuity or hearing loss in the general population, to be hearing or to be deaf have become two immutable choices symbolized by two exclusive methods of communication. Recent writings about and by many deaf people suggest that they have learned and adopted the fundamental dichotomy which initially set them apart from hearing people: If you cannot speak our language, you are different than us. What, then, of the hearing children of deaf parents, some of whom have been removed from or denied access to their parents' language?

The discrepancies in fluency and use of sign language between hearing daughters and hearing sons in this study suggest that adult women would be far more likely to identify themselves as culturally Deaf and to affiliate with the Deaf world. Indeed, women in this study were more likely to describe fluent and frequent interactions with their deaf parents and other deaf people because of their sign language skills. Women informants were also more likely to work in careers related to deaf people, particularly as professional interpreters and teachers. Yet, in response to my question "Would you consider yourself (culturally) Deaf or Hearing, men were just as likely as women to respond as one male informant did: "There's no question, I'm Deaf. . . . Just because I can hear and speak doesn't mean I'm one of them."

There is little doubt that exposure and access to the wider Deaf community was severely curtailed for some hearing sons and daughters of deaf parents. Yet, many of these informants who did not know sign language as children professed strong allegiance and loyalty to the Deaf community and to sign language. Many of the men and women who knew little or no sign language as children persisted in learning sign language as adults. Gardner and Lambert (1972) found that mastering a second language depends not so much on the person's intellectual capacity or language aptitude, but, rather, on the person's attitude toward the other linguistic group and his or her willingness to identify with that group. For purposes of ethnic identification, certain languages may be associated rather than spoken. Silberstein (1988) calls these "competence markers" in which people legitimize their ethnic belonging by pointing out the use of such language by others (usually family members or themselves as children), even if they themselves did not speak or do not now speak the language.

The women and men in this study suggest three dimensions of the interplay between language, gender, and cultural identity among hearing children of deaf parents. First, a focus on sign language alone ignores non-linguistic forms of communication. These informants' family experiences included not only specific forms of sign language, but the realms of silence, sound, face, and body. For both sons and daughters, each of these features became not only a means of communication, but developed into powerful symbols of cultural experience as well. Secondly, parity between language and cultural identity presumes homogeneous use and fluency among all members of a cultural group. Not only their hearing children, but culturally Deaf people vary in their fluency and use of sign

language. Finally and most significantly, deaf parents and their hearing sons and daughters shared experiences which were outside the Hearing cultural norms. Both parents and children knew first-hand the suppression, the alteration, and the denigration of sign language. Whatever their personal use and history of sign language, the overwhelming majority of informants--sons as well as daughters--expressed strong loyalty and support for their parents' native language. This shared history suggests that, although sign language is an important symbol of Deaf culture, it is not the only measure of cultural affiliation. Oppression, too, contributes to cultural solidarity--for mothers and fathers, for sons as well as for daughters.

### References

- Gardner, R., & Lambert, W. (1972). Attitudes and motivation in second language learning. Rowley, MA: Newbury House.
- Grosjean, F. (1982). Life with two languages. Cambridge, MA: Harvard University Press.
- Pi-Sunyer, O. (1980). Dimensions of a Catalan nationalism. In C. Foster (Ed.), Nations without a state: Ethnic minorities in Western Europe (pp. 101-115). New York, NY: Praeger.
- Silberstein, S. (1988). Ideology as process: Gender ideology in oral courtship narratives. In S. Fisher & A. Todd (Eds.), Discourse and gender (pp. 67-81). Norwood, NJ: Ablex Publishing Co.

### Author Notes

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# The Effects of Age of Disability Onset and Gender on Level of Social Anxiety, Self-Esteem, and Attitude toward Others with Disabilities

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During the past 20 years, a growing social and political movement of people with disabilities has had a major impact on the study of disability. Disabled persons have made great strides toward being accepted as part of the minority group model. A paradigm shift toward viewing disability as a distinct and separate culture has also begun to emerge. To further substantiate the minority group model and the emerging disability culture perspective, it is imperative that we move away from the more negative stigmatizing functional limitations model. Research must be conducted from this minority group and disability culture framework if we are truly going to come to a better understanding of disability. In keeping with this perspective, this study looked within the disability community to explore possible variables that may effect self-esteem, anxiety, and attitudes toward others with a disability.

## Methodology

This study surveyed people over the age of 18 with various types of mobility impairments residing in the Northern California area. Copies of the Social Avoidance and Distress Scale (SAD) (Watson & Friend, 1969), the Coopersmith (1981) Self-Esteem Inventory (SEI), and the Modified Issues in Disability Scale (MIDS) (Makas, 1985) were sent to 11 different agencies, support groups, colleges, and universities in the Northern California area serving people with physical disabilities. Four hundred and fifty packets of the surveys were mailed anonymously via the above mentioned sources. Of these, 214 were returned for a response rate of 48%. Thirty surveys were not used for various reasons, leaving a total of 184 actually used in the research project. Table 1 shows demographic data from the survey.

Research indicates that the SAD and SEI have not been previously used specifically within the disability community. The MIDS was given to a small group of undergraduate students (Makas, 1988) with physical disabilities, but it has not been administered to a larger cross-section of people with physical disabilities.

Although the purpose of this study was not to compare those with disabilities to those without disabilities, it is important to look at the general levels of each of these surveys when given to nondisabled people to gain adequate perspective. Table 2 shows the difference between scores on the SAD, SEI, and MIDS by gender as well as by physical disability/nondisability status.

Table 1. Subject Data

	<u>Total Respondents</u>
Respondents	184
Men	76
Women	101
No response	7
Median Age Category	41-45
Mean Age of Disability Onset	25.29
Mean Education Level	14.10
Marital Status	
Single	69
Married	57
Divorced	28
Separated	6
Widowed	12
No response	12
Cause of Disability	
Illness/disease	82
Trauma/accident	78
Birth defect	14
No response	10
Wheelchair Use	
Nonuser	53
Full-time	22
Part-time	52
No response	57
Type of Disability	
Multiple sclerosis	18
Spinal cord injury	9
Polio	26
Muscular dystrophy	7
Cerebral palsy	2
Paraplegia	8
Quadriplegia	13
Back injury	12
Arthritis	13
Amputee	11
Spina bifida	5
Ataxia	2
Muscle/bone degeneration	8
Mobility (type not specified)	14
No response	36

Table 2. Means on Social Avoidance and Distress Scale (SAD), Self-Esteem Inventory (SEI), and Modified Issues in Disability Scale (MIDS) by Gender and by Physical Disability/Nondisability Status

<u>Means</u>			
<u>Physically Disabled (n=184)</u>			
	<u>SAD</u>	<u>SEI</u>	<u>MIDS</u>
Male	7.94	78.6	183.3
Female	9.96	72.8	183.8
<u>Nondisabled</u>			
	<u>SAD (n=205)*</u>	<u>SEI (n=226)**</u>	<u>MIDS (n=525)***</u>
Male	11.20	70.1	165.4
Female	8.24	72.2	173.3

\* These data are from Watson & Friend (1969).

\*\* These data are from Coopersmith (1981).

\*\*\* These data are from Makas (1993).

### Relationships of Subject Variables to the Three Measures

#### Age of Disability Onset

It appears from these results that the particular age of disability onset is not an important factor in determining a physically disabled person's ability to feel comfortable in possible anxiety-arousing situations as indicated on the SAD. The near significance suggests that people who became disabled at a later age were more likely to exhibit slightly higher levels of social anxiety, but the correlation obtained is quite low. Self-esteem and attitude toward others with disabilities also do not appear to be affected by age of disability onset.

It is certainly possible that age of disability onset, indeed, has an impact on these variables; however, this single study does not establish this. The reasons for age of disability onset not showing an effect on any of these measures within this study could be a result of the biased sample of subjects used. Since only those who use agency services were contacted, the results of this research would only reflect the attitudes of physically disabled people

within that framework. People who generally use the services of the agencies contacted may be those with more significant disabilities, who may need assistance in living independently or require assistance in retraining for job placement. Those not using agency services could fall into one of two categories: 1) those who are able to maintain independence through employment or education without assistance, and 2) those who do not wish to associate with agencies serving people with physical disabilities.

### Gender

T-tests indicated that being male or female did not make a difference in total scores on any of the three measures. Scores on the SAD and SEI normed to the nondisabled population also indicate there is no difference in the average score when gender is considered. However, three separate studies done on the MIDS with the nondisabled population have found a more positive attitude among females toward those with disabilities (Makas, 1993). The difference between men's and women's scores that was apparent in the surveys given to nondisabled people was not found in those with physical disabilities participating in the current study.

### Cause of Disability

Analysis of each measure revealed that people who became disabled due to illness or disease did not differ significantly in their responses on the SAD, SEI, or MIDS from people who became disabled from a trauma or accident or from people who were disabled due to a disability at birth.

### Education

The average education level of respondents was 14.1 years. Surprisingly, education level did not seem to effect either a physically disabled person's level of social anxiety or self-esteem. Based on previous research conducted with nondisabled persons (e.g., Coopersmith, 1981; Watson & Friend, 1969), a difference in both of these measures would have been expected when education is considered. One possible reason for not finding significance could be difficulty with the actual measures that were used. Perhaps, if different measures had been used or further analysis had been conducted, a significant difference would have been found. The MIDS, however, did correlate with education; the higher the level of education, the more positive reaction a physically disabled person had toward others with disabilities. These findings are consistent with other research done with the nondisabled population (e.g., Makas, 1993).

### Wheelchair Use

A serendipitous finding indicated that respondents who used a wheelchair either full-time or part-time had more positive mean scores on the SEI and the MIDS than non-wheelchair

users. Respondents who were full-time wheelchair users had more positive mean scores on the SAD than part-time wheelchair users and non-wheelchair users (Table 3).

Table 3. Means on SAD, SEI and MIDS for Full-Time and Part-Time Wheelchair Users and Nonusers (n=184)

Wheelchair User	<u>Means</u>		
	<u>SAD</u>	<u>SEI</u>	<u>MIDS</u>
Non-user	10.92	69.31	176.74
Full-time	6.86	80.24	186.97
Part-time	11.18	74.76	184.53

These findings could be due to the fact that respondents who are non-wheelchair users or part-time wheelchair users overlap socially with both the nondisabled community and the disability community without having a clear and well-defined cultural identity. This embraces the notion that the state of being mentally healthy is facilitated by a positive sense of connectedness with one's own cultural group (Pinderhughs, 1989).

#### Limitations of the Study

This study was limited in several ways. Only subjects who use agencies designed to assist those with disabilities were contacted. This narrowed the focus to people who are more dependent physically and/or socially, or in need of rehabilitation through job training. In future research, efforts need to be made to contact physically disabled people who do not use the services of agencies. One way this could be done would be to contact the State Department of Rehabilitation and to locate individuals who have used their services in the past, but are now working and living independently. These findings cannot be generalized to individuals not using such services, to other areas, or to other measures of psychosocial development and adjustment.

#### Summary

This study attempted to answer several questions regarding people with physical disabilities and what variables from within that population would have an effect on level of social anxiety, self-esteem, and attitudes toward others with disabilities. Results suggest that, when looking within the disability community, there is little influence from age of disability onset, gender, cause of disability, or education in the way people respond when given surveys to measure these traits and attitudes. However, wheelchair use seems to have a positive effect on physically disabled adults.

The fact that there does not appear to be a difference in gender or education may be significant in itself. Gender and education both appear to have an effect on the SAD and the MIDS in nondisabled persons. Further research is needed to explore this issue.

The findings of this research also substantiate other studies showing that, despite the presence of a disability, persons with physical disabilities report a degree of well-being very similar to those without disabilities (Shulz & Decker, 1985). It is important that further research be done looking within the disability community in an effort to eliminate social and cultural negative stigma toward those with disabilities.

### References

- Coopersmith, S. (1981). Self-esteem inventories. Palo Alto, CA: Consulting Psychologists Press.
- Makas, E. (1985). MID Scale (Modified Issues in Disability Scale). Washington, DC: The George Washington University.
- Makas, E. (1988). Positive attitudes toward disabled people: Disabled and nondisabled persons' perspectives. Journal of Social Issues, 44(1), 49-61.
- Makas, E. (1993). Yet another year: Further testing of the MIDS. In D. Pfeiffer, S.C. Hey, & G. Kiger (Eds.), The disability perspective: Variations on a theme (pp. 143-150). Salem, OR: The Society for Disability Studies and Willamette University.
- Pinderhughs, E. (1989). Understanding race, ethnicity, and power. New York, NY: The Free Press, Macmillan, Inc.
- Shulz, R., & Decker, S. (1985). Long-term adjustment to physical disability: The role of social support, perceived control, and self-blame. Journal of Personality and Social Psychology, 48(5), 1162-1172.
- Watson, D., & Friend, R. (1969). Measurement of social evaluative anxiety. Journal of Counseling and Clinical Psychology, 33(4), 448-457.

### Author Notes

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## Constructing Disability Studies: More Questions of Identity

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In preparing for a panel at the Society for Disability Studies' 1995 meeting, we were all given a series of questions, such as "What is Disability Studies?" "Does it have a connection to an ideology?" "Should personal identity as a person with a disability be a necessary requirement to conduct research on, write about, or teach Disability Studies?"

As I pondered these queries and how I wanted to respond to them, it seemed to me that all the questions had a link in common with the ever-present question of identity. So I want to change these questions for my introductory remarks and put them in a more generic light than they might otherwise find.

The first question is "What is Disability Studies?" I wonder what would happen if we remove the word "disability" from the inquiry and change it to "What are studies?" I wonder how easily any of us can answer those three simple words?

In an academic environment, my guess is that the response to "What are studies?" would be something like this. "Well, ahem, my dear student . . . that is an interesting question. You know, we professors go to school for quite a long time becoming immersed in our specific disciplines, learning about how to utilize libraries and, now, computers and all the rest of this startling new technology; we read, and we write, and we discuss the subtleties and nuances of the most minute and most cosmic of forces in our chosen field of study, attempting to learn and add knowledge to the body of scholarship in our specialty."

A non-academic, non-student might respond, "Studies are getting to know more than you want about some subject."

My own instant definition of studies, conceived for this paper, is "learning about something you want to know." So I might translate "Disability Studies" into "wanting to learn about disability." And, since this was a conference of many teachers and scholars, I refined the definition to "wanting to research, teach, and write about disability."

The second question is "Does Disability Studies have a connection to an ideology?" I think the best way I can answer is that I hope so! But, before anyone gets too defensive, let us broaden this question a bit, too. What is an ideology? In simple terms, it is a belief system, a way of looking at the world. Who, I wonder, can exist in the world without an ideology? It may be possible to have a fairly simple credo--sex, drugs, and rock 'n roll--or

a much more complex philosophical or spiritual system. Most likely, it will be some combination of the simple and complicated, reflecting our own human status.

I am more comfortable posing this question differently: Not does it--or someone--have an ideology, but do individuals recognize the ideology that they do possess, and are they willing to be forthright about sharing it and analyzing it in whatever endeavors they might pursue? I, for example, am fairly well known to have a belief in the concept of a culture of disability. I neither hide nor deny that conviction. I do try to understand why I possess it, how it affects my life, and ways in which I may or may not be willing to hold it under microscopic scrutiny.

In Disability Studies, or in any other aspect of life, we all have at least one ideology. Rather than trying to deny it, smother its impact, or retreat because of it, let us acknowledge our beliefs, our biases, and our roles in the world and then move on to using them in our academic pursuits.

The final question is: "Should personal identity as a person with a disability be a necessary requirement to conduct research on, write about, or teach Disability Studies?" Once again, let us strike the loaded words "person with a disability" and "Disability Studies" from this sentence and ask, "Should personal identity be a necessary requirement to conduct research, write, or teach?"

At the risk of sounding much too facetious and simplistic--YES! Personal identity seems to be an important criteria of being an effective teacher. Knowing who you are, having an notion of what you believe in, and what you want to study and teach seem to be a good idea. The key to this question, then, appears to hinge on adding the loaded words back into the sentence: Should personal identity as a person with a disability be a necessary requirement to conduct research on, write about, or teach Disability Studies?

My initial response would be no. I have learned from colleagues, friends, and teachers, both with and without disabilities. I have read with pleasure discussions of disability issues both by writers who have disabilities and by those who do not. But I have also railed against and have been disgusted with the teachings and writings of individuals both with and without disabilities. What is the common denominator that holds my interest *and my respect*? It seems to be caught up in the first two questions. I do not always agree, but I do pay attention to people who seem to want to learn about the subject of disability and who are honest about their own world view about disabling conditions.

Having said all that in what I hope has been a mostly neutral tone, I must add the following caveat. There are a plethora of writers, teachers, researchers, artists, and representatives of every other aspect of life who are well-qualified to be in positions which have been closed to some of us solely because of our status as people with disabilities. Until we are recognized as competent, valuable resources in our society, then there will be a militant, and necessary, movement to exclude nondisabled people who prevent us

from making a living, being published in mainstream venues, and teaching about our lives.

That, too, is a world view that should be recognized--and respected.

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## Section XIII

### Individual Empowerment

Systemic change is part of the overall strategy to remove barriers to participation for people with disabilities. Individual empowerment is one of the strategies that is often overlooked as we try to see the big picture. The big picture is usually made up of the images and experiences of individual people, and this section reviews a composite of those pictures.

In "Chronic Physical Disability and Secondary Control: Appraisals of an Undesirable Situation," Susan Krantz looks specifically at adults with physical disabilities who are attempting to restore control by accommodating a situation that cannot be changed. This level of empowerment is related directly to how the individual increased knowledge and coping skills to achieve secondary control. Self-esteem and identifying new areas of interest after onset of a disability were part of the process for many, as were reassessing priorities and personal growth.

A creative expression of both personal growth and empowerment is evident in Nathalie Forrest's untitled paper. She introduces a song written after speaking to a man with MS who felt extremely limited by his new disability. The song is motivational and is followed by two others. The meaning in each points to the need for self-actualization and the barriers erected unnecessarily that prevent reaching that objective.

The next two chapters relate specifically to young people or students with disabilities. The students with disabilities in both papers became empowered as individuals in transition and as members of the community. Doreen Wood and Gerianne Johnson review the evaluation results of an ADA Trainers project at San Francisco State University in their chapter, "Students with Disabilities as Americans with Disabilities Act Trainers." The students were both educated and employed in the project, and the paper discusses the impact of the project on both the students and the participants. By familiarizing students with the ADA and general disability accessibility issues and by giving them the role of advisors, teachers, and consultants, students with disabilities were also empowered to seek with own accommodations. This type of project supports both the need for training in the community and the need for self-empowerment in the student.

As students enter university or college, they often leave home for the first time. Marissa Shaw documents the negotiations required by students with disabilities to arrange their own attendant care or other services. Her chapter, "Youth in Transition: New Models in Participatory Action Research," looks at students in high school and in universities as they transition out of using family members as caregivers. Possible conflicts and benefits of using parents as caregivers are discussed, and the significant issues of sexuality and dating are considered both by the students and by the author. For many students the individual empowerment is achieved when paid professional attendants, preferably peers,

are providing services under their direction. This project was organized by a student with a disability as part of an internship at the World Institute on Disability.

The last chapter in this section uses a case study approach to look in detail at the transitions from high school to college or employment. In this case, one of the tools for individual empowerment is the computer and the Internet. Sheryl Burgstahler and Martha Orvis present their paper, "Transition to College: Preliminary Findings of Four Case Studies," as part of a work in progress. This project is part of a larger four-year study, and the qualitative data about their transitions will be combined with other results, such as standardized assessment scores. Empowerment for these students can come through friends, mentors, training, and technology.

## Chronic Physical Disability and Secondary Control: Appraisals of an Undesirable Situation

Susan E. Krantz, Ph.D.  
University of Michigan

People want to control their world, and think they can do it. God laughs. Humans have some control, but there are limits. What do we do about these limits?

Control is defined as changing a problem or leaving a bad situation. This is called "primary control" by Rothbaum, Weisz, and Snyder (1982). Contrast this with "secondary control" that, instead, allows accommodation to a reality that cannot be changed. It is understanding, finding meaning, and working on the inside of the self rather than on the world.

We try to restore control that has been bruised. Control is so highly valued that its pursuit is rarely abandoned; instead, we shift from primary control to secondary control as needed.

What are these secondary control mechanisms that are used to accommodate to an undesirable, permanent situation? This paper will describe them and give examples from 22 adults dealing with chronic physical disability.

### Method

#### Interviewees

I interviewed fifteen female and seven male volunteers aged 20 to 59 with different disabilities. They acquired their disabilities at least two years before the interviews. (See Table 1.)

#### Procedures

In interviews from 45 to 90 minutes long, people were asked about (1) good parts of you that were at least partially lost as a result of the disability, (2) not-so-good parts that improved, (3) any learning about the self or others during this process, and (4) what--if anything--was learned that able-bodied folks often don't realize?

The interviewees could deny control in response to any question.

### Results and Discussion

Eighty-two percent of the interviewees voiced at least one instance of secondary control. Overall, only 5% of all comments were negative.

Table 1

The Interviewees

	<u>Age</u>	<u>Sex</u>	<u>Type of Disability</u>	<u>Duration (Years)</u>	<u>Assistive Device</u>
Lisa	32	F	Spider bite	4	None
Carolyn	50	F	Hearing loss	6	Hearing Aid
Rebecca	40	F	Car crash terminated pregnancy of 8 months	18	None
Carey	29	F	Undiagnosed pain	13	None
Jennifer	30	F	Multiple broken bones	2	Brace
Lynn	36	F	Paraplegia	4	Wheelchair
Eric	33	M	AIDS	5	None
Aaron	43	M	Multiple sclerosis	17	Wheelchair
Karen	48	F	Mastectomy	7	None
Myra	47	F	Multiple sclerosis	11	Wheelchair
Shelly	53	F	Connective tissue problem	11	None
Kristen	47	F	Arthritis	3	None
Kim	43	F	Dialysis, kidney transplant	13	None
Janice	59	F	Orthopedic problems	23	Brace
Laura	48	F	Leg breaks	31	None
Donald	31	M	Post-polio	6	Wheelchair
Jason	30	M	Quadriplegia, visual problems	9	Wheelchair
Charity	34	F	Chronic fatigue	10	None
Anne	40	F	Low vision	7	None
Katie	35	F	Amputation	3	Prosthesis
Wayne	30	M	Quadriplegia	11	Wheelchair
Ralph	56	M	Quadriplegia	25	Wheelchair
Ted	<u>47</u>	M	Quadriplegia	<u>6</u>	Wheelchair

Mean = 42

Mean = 11.14

Common Secondary Control Strategies

These mechanisms can be helpful regardless of physical changes. They did not change the disability, but they may have made it easier to accept.

A. Psychological self-help. Interviewees made dealing with the disability less troublesome.

1. Eric, when asked about losses as a result of his AIDS symptoms, replied "I didn't really lose anything; I just gained frustration." (Eric rejected the word "lose" with its harshness and, instead, chose a gentler word that possibly reduced fear and depression.)

2. Kim reported "reprogramming" her mind. This strategy countered previous thoughts that dialysis "would be the end of the world." Benefits could be that (1) it provided her with a less dire frame regarding the dialysis, and (2) it directed her to a primary control strategy of "taking on less commitments so I wouldn't do things when I shouldn't for my body."
3. Laura, with multiple leg breaks from a car accident, said: "OK, I'm in this traction. I'll make the best of it and deal with it. That is not a minimal thing to find out: I can survive. I'm not saying 'if life gives you a lemon, make lemonade,' which is funny but mawkish." Laura transformed a stressful experience into something that (1) she can "make the best of"--it was not out of her control, and (2) provided data upon which to base self-esteem. She felt better, and she took constructive action.

B. Increasing knowledge of the disability

1. Laura, with multiple leg breaks, told herself: "I don't put up with not knowing. I won't stop asking until you answer. My doctors learned that quickly."
2. Katie, whose leg had been amputated, asserted that, "Everybody who has medical problems like this . . . reads about it. Maybe if you feel you know about it, you have more control over it." Increasing knowledge of the disability is helpful because it is a recognizable bit of progress. As such, it can supersede the losses and frustrations that come from the disability experience.

C. Maintaining self-esteem. Post-disability self-esteem can be bolstered by seeing one's competence in managing the many major difficulties. Over half of the sample made comments such as "I'm resilient" or "adaptable," "I'm a survivor," or "I'm stronger than I gave myself credit for."

1. Ralph, injured in a car accident, was in a coma for over two months, and emerged with quadriplegia. He said, "I find that, as much has been taken away from my friends who are quads, they do more than any able-bodied person will ever do, in their own way." Feelings of satisfaction with the self that are attached to the disability are related to the idea that life is or can be full, and the self with a disability is whole. The person is not relegated to shame and a life devoid of pleasure.

D. Finding new areas for gratification, accomplishment. A former police officer, after being diagnosed with multiple sclerosis, went to college and became a teacher. This switch was notable: He said that he never would have gone to college without needing an alternative career. Flexibility allows the losses of a disability to be

replaced with gain. In this case, the gains were a new career and the appraisal of oneself as strong or resourceful.

- E. Personal growth. A new disability stimulated some to focus better, be more flexible, planful, or patient (according to self-report). Others reported less need for social approval. Gains from the disability in this form not only offer the potential for increased self-regard, but they may also have positive interpersonal and work-related consequences.
- F. Knowing the social world. Societal reactions included the good, the bad, and the ugly. Several persons with disabilities saw kindness, respect, and support.
1. Kristen, whose mobility was limited by severe arthritis, said, "I am noticing that people are . . . feeling close to me. . . . They don't think it's my fault, and they don't feel sorry for me, but they feel part of my pain, and they are respectful also."
  2. Donald, with a disability resulting from polio, was happy that "friends treated me [as the same person I was before]. So, I was able to think of myself as that way."

Not unexpectedly, negative reactions were received as well.

- G. Questioning priorities: What shall we do with our days? What's important? A number of folks started to ask these questions rather than automatically living out some script.
1. Carol asked, "Who wants to die knowing all they did was work?"
  2. Donald realized that "My friends are more important than whether I can play hockey still."

So, work, academia, and sports lost importance, while health and relationships became more significant. Acquiring a disability shatters previous assumptions and makes us look hard at our priorities.

### Summary and Conclusions

To summarize, the majority of interviewees (82%) used secondary control. Most comments were non-negative. So, that which at first may seem to be a catastrophe can also stimulate appraisals of the self and of one's world in ways that can be helpful. Different explanations of these results must be considered. First is the idea that the disability experience stimulates maturation. A competing explanation is that we will grow up anyway. Alternatively, the non-negative comments can be thought of as denial. Unfortunately, we cannot reliably identify what is or is not denial.

Thus, partial loss of primary control may be replaced by secondary control, and this sort of control may be beneficial.

### References

Americans with Disabilities Act (1990) Public Law 101-336.

Rothbaum, F., Weisz, J.R., & Snyder, S.S. (1982). Changing the world and changing the self: A two-process model of perceived control. Journal of Personality and Social Psychology, 42, 5-37.

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## Untitled

Nathalie L. Forrest, D.D.  
United Friendship Church

This song was written after talking with a young man at a center for independent living. He was relating to me his problems after being diagnosed with multiple sclerosis, better known as MS. His chief complaint was that he felt the MS had so limited his activities that he could no longer go places on his own. He resented having to be dependent on others to get around or to do things for him that he used to be able to do for himself.

It seemed also that his family did not or could not give him the support that he needed. They did not know enough about MS and the consequences of having MS to help him understand what was happening to him.

All the while this young man was talking to me, I kept noticing his shoes. They were brand new, very shiny, and beautiful. It may seem strange to say that about a man's shoes, but, yes, they were beautiful. I looked into his eyes and said to him, "You did not get those shoes to sit in the house and let the world pass you by. Those shoes are for you to get up, get out, and live."

I never saw him again, but I hope he believed me, took some inspiration from what I told him, and did get up, get out, and live . . . . .

## I Won't Cry

Chorus:      Sitting here by my window,  
                  I won't let life pass me by  
                  Sitting here by my window,  
                  I won't cry, I won't cry.

1:             Get up  
                  Get out  
                  And live  
                  You have so much to give  
                  The world has need of you  
                  See what you can do.

2:             Let's learn to cherish life  
                  And banish stress and strife  
                  As sure as a bird can fly  
                  I won't cry, I won't cry.

## What Ever Happened to Respect???????

What ever happened to respect?  
We don't seem to get it anymore.

Not even in our place of worship,  
And certainly not in the local store.

Listen brothers and sisters,  
I will tell you where it all starts,  
It starts with each and every one of us,  
Way down deep in our hearts.

Respect is something that money cannot buy,  
But we can all get it if we would only try.  
No matter what language we speak,  
And despite the hue of our skin,  
Just be sure to give respect,  
For that is where it all begins.

Respect, Ah Respect . . . . .  
Tis the most wonderful component of life,  
It can eradicate mountains of stress,  
And completely wipe-out STRIFE. . . . .

Have you ever had something happen to you that was so incredible, that when you told your friends about it, they looked at you as if to say, "SO WHAT ELSE IS NEW?????????????" Well, let me tell you what happened to me . . . . .

On December 5, 1982, a friend took me to the zoo to celebrate my birthday. It was a beautiful day, and all the animals were very interesting to see, but one particular animal caught my eye. I say caught my eye because, not only was I looking up at him, he appeared to be staring down at me. I remarked to my friend, "I think that giraffe is looking at me," to which she replied, "You must be crazy, that giraffe is not looking at you." Well, I just stood there looking up, and he just kept staring. I finally realized that he was looking at my hat, which was a wine-colored, floppy, hand-crocheted hat.

I decided to test this situation, so I took one step to the right, and the giraffe took one step also. Just to be sure, I took another step, and, lo and behold, so did the giraffe. By now I was wanting to jump up and down, I was so excited, but, after all, there were other people standing around who were not aware of what was going on, so I started to speak to this giraffe. "How are you today?" I asked him. "How wonderful it must be to be so tall, to be able to see so far over everybody, to see for miles around." As I stood talking to him, he seemed to understand every word and bowed that long neck down as if to

answer me. I was so thrilled, I continued to speak to him. Standing beside him were his mate and their offspring, so I said to him, "Is this your wife and baby?" With that question, he bowed again. Let me tell you, if you have never communicated with a giraffe, you have something to look forward to. It is something I shall never forget even if I live to be one hundred plus . . . . .

Finally, my friend said to me, "Come on. We cannot stand here all day with you talking to that giraffe." As for me, I could have stayed there all day, all night, and the next day, too, but I knew she was not experiencing what I was, so I reluctantly started to move away. As I started to walk, the giraffe started to walk, too. At the end of his enclosure, I turned the corner, and he looked over the wall and trees, watching me for as long as he could. I turned to wave good-bye to him, and he bowed to me for the last time.

The next day I was still thinking about that giraffe and the experience I had with him, so I called the zoo, spoke to his keeper, and found out that his name was TOPPER. That was truly the most wonderful birthday present I have ever had (or ever expect to have), and I am a grandmother.

This experience brought about the writing of the song "Topper."

### Topper

Topper is an animal you will surely love  
He looks down upon you from far up above  
And Oh, my friend, I hope that you won't laugh  
For you see Topper is a giraffe.

A giraffe you say? Yes I do  
I met him when I visited the zoo  
I spoke to him and he bowed to me  
From way up above the tall, tall trees.

I think he liked that hat I wore,  
The color was called wine  
And maybe he was thinking Oh,  
I wish that hat was mine.

This is a true story  
And don't think it's a whopper  
For this is a story (a)bout me and  
TOPPER. . . . .

### Author Notes

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## Students with Disabilities as Americans with Disabilities Act Trainers

Doreen Wood, R.N., M.Sc.  
Gerianne Johnson, Ph.D.  
San Francisco State University

This conference presentation was conducted as a panel at the Society for Disability Studies conference on June 16, 1995, in Oakland, California. Doreen Wood gave an overview of the program, and Gerianne Johnson gave evaluation results. Three students, Elizabeth Dunlap, Robert Hourula, and Judy Doane, spoke of their experiences as ADA Trainers during the Spring 1995 semester. They talked of their own benefits in the areas of ADA knowledge acquisition and their own personal empowerment.

### Significance to Persons with Disabilities

To date, much of the ADA training offered to business and academic audiences has been conducted by lawyers, architects, or others with strict legal and/or technical orientations--at substantial cost to the training recipients. An active cottage industry has sprung up in which trainers are often persons without disabilities and with no professional disability training. This sort of approach is seen as inadequate by many people with disabilities and by disability activists. Such training often emphasizes the perceived potential negative aspects of the ADA, rather than the more positive aspects of the law. Estimates of reasonable accommodation costs are sometimes inflated, and frightening portrayals of persons with disabilities as potential litigants are used to "encourage" businesses to comply with the letter of the law.

### Benefits to Students with Disabilities

This paper addresses both education and employment, and recommends an educational approach that is unique and innovative. It is also powerful in its simplicity: Students with disabilities at San Francisco State University (SFSU) are trained in the spirit and requirements of the ADA using a consultative model that focuses on the information needs of clients. Toward this end, the students attend classes (for which they receive academic credit) that combine information about the ADA with modeling and practice in consultative behaviors (e.g., establishing credibility, asking questions, solving problems). The students gain skills to help them effect positive attitude shifts toward the inclusion of people with disabilities. These students-turned consultants know their rights under the ADA and are able to offer an experiential view of their reasonable accommodation needs, as well as potential strategies for meeting the needs of others.

A training project involving students with disabilities from SFSU is being conducted during 1993-1995, continuing into 1996, with the support of a FIPSE Community Service grant. The ADA training teams delivered presentations to small business owners, to industry representatives of the Western College Placement Association, the Bay Area Small

Business World Exposition, and the San Francisco Jewish Vocational Center. In addition, students consulted with numerous community groups. Presentations were also made on campus to interested university students and faculty. The audiences rated these presentations as highly relevant, valuable, and understandable. The students reported increased skill and ease in speaking; this was corroborated by the Project Evaluator's analyses of their videotaped training presentations. Furthermore, of the ten students with disabilities who entered this project in January 1995, all were unemployed; seven are now gainfully employed. Eight of these ten students are still in college; one graduated and acquired a full-time job in her field, counseling; and another one (Elizabeth Dunlap) is now a staff member of the current ADA Training Project.

An all-university course in the ADA was offered for the first time in Fall 1995, under the auspices of the SFSU Career Center. Seventeen students with varied disabilities registered for the Fall program. The focus has changed from a presentation format to a consultative mode. It is expected that there will be at least 25 students in the Spring 1996 program. In conjunction with the Career Center's TempIntern program, the course allows SFSU students with disabilities to combine course credit with financial reimbursement while learning about the ADA and developing work-related skills.

This education, both of students with disabilities and, consequently, of employers, educators, and others in the realm of public access, is innovative and unique. There is no model to emulate. As previously mentioned, most ADA training work has been done in a formal presentation mode. There is no core curriculum to educate students with disabilities in a consultative mode or in this most valuable educational arena. Developmental problem-solving in the areas of educating and training the students, and in the area of recruiting and enrolling participating employers, educators, and community groups has been ongoing and challenging. Our first training work has been very fruitful.

### Assessing Participant Learning

#### Primary Project Goals

1. Train students with diverse disabilities *how* to teach and consult with educators, employers, and non-profit entities about the key concepts of the Americans with Disabilities Act.
2. *Empower* students to familiarize and advise educators, employers, and non-profit entities about the Americans with Disabilities Act.
3. Experience the process of *negotiating* reasonable accommodations, both from a personal perspective and as a means of establishing future employment standards.

## Two Hypotheses

The first prediction is that businesses, educators, and non-profit entities will be in more positive compliance with the ADA as a result of this unique student-consultative approach. The model is one of skill development of students who will then share their expertise on the law, along with their own experiential view of it, and this will lead to favorable attitude change and greater compliance with the law on the part of employers.

The secondary hypothesis is that "the students themselves will experience greater success in negotiating their own accommodations, and thereby increased employment rate as a result of their participating in this project." Persons with disabilities have significantly more difficulty obtaining and keeping employment than persons without disabilities. Students with disabilities take longer to complete their education.

*Evaluation* of changes in employers' knowledge of the ADA and their attitudes toward disabilities is being measured using a pretest/posttest research design to determine whether information was successfully disseminated, and the degree of attitude change, if any, resulting from the clients' interactions with these consultants. Additional evaluation data are also being collected each semester to assess students' content knowledge of the ADA. Student retention rates will also be monitored. Finally, a telephone survey procedure will be used to follow student project participants and consultation clients for two years afterward. The purpose of this will be to assess access and employment compliance for the employers; and, for students, graduation rate, success in negotiating their reasonable accommodations, and subsequent employment rates.

## Conclusions

San Francisco State University has nearly one thousand students with disabilities registered with its Disability Resource Center, and more who are unidentified. Larger universities may have higher numbers. These students are a previously untapped resource for improving the quality and quantity of useful individuals in the workplace and in the public arena. The possibilities for eventually disseminating this proposed model on a national level are far-reaching. Benefits affect both the students with disabilities and the community at large. The project has interdisciplinary support from the campus community, and potential academic and business targets from the San Francisco State University Career Center.

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## Youth in Transition: New Models in Participatory Action Research

Marissa Nicole Shaw, A.A.  
World Institute on Disability

### Question

When, where, and how is it appropriate for youth to direct their own personal assistance services?

### Method

Youth In Transition--youth with disabilities who are making the transition from living with parents to living independently--is one of the newest underserved groups to be studied. This study examined Youth In Transition heuristically, using Participatory Action Research plus my own experience to formulate the survey.

The best published source to serve as background for this study was Young Disabled and Their Care Attendants (MacCready, 1984).

Mary MacCready interviewed people with disabilities between the ages of 20 and 33, and one man aged 52; all were white and had some college education. Many of MacCready's informants had already made the transition from their parents' homes to an apartment or home of their own. The participants in the present study were more ethnically diverse: three African Americans, two Latinos, one Afghani, a Middle-Easterner, and three Caucasians. The youth are between 17 and 21 years of age. Table 1 describes the sample.

Six of the participants were students at Skyline High School in Oakland. Two were current UC-Berkeley students in the Disabled Students' Residence Program, and two were previous participants in the Disabled Students' Residence Program. The purpose of this Residence Program is to teach youth who have never lived away from home how to use attendants so they can live independently.

Interviews were done mainly in person; however, some were done by phone. The questionnaire required the participants to think back to their experiences using personal assistance services. They also answered hypothetical questions on creating an ideal system for delivery of personal assistance services (PAS) to youth.

### Observations

Some of the participants had their own attendants. Two of the ten students had directed their own personal assistance services (provided by non-family members) starting at ages

**Table 1. Youth In Transition--A Breakdown of Participants by Age, Ethnicity, and Disability**

SCHOOL	AGE	ETHNICITY	DISABILITY
*	18	African American	Brain Injury
*	18	African American	Blind
*	18	African American	Spinal Cord Injury
*	19	Latino	Hard of Hearing
*	17	Latino	Muscular Dystrophy
*	21	Afghani	Blind
**	18	Lebanese	Cerebral Palsy
**	18	Caucasian	Cerebral Palsy
***	19	Caucasian	Cerebral Palsy
***	20	Caucasian	Muscular Dystrophy

\* student at Skyline High School, Oakland, CA

\*\* student in the Disabled Students' Residence Program at U.C. Berkeley

\*\*\* past participant in the Disabled Students' Residence Program at U.C. Berkeley

15 or 16. One student said that, in order for him to participate in Boy Scouts at age 11, he had to train his peers how to dress him and to attend to his daily living needs.

These two college-educated individuals had four things in common. First, they had their own attendants. Previously, their parents assisted them. On occasion, parents hired baby-sitters as attendants. Second, these two individuals could not get in and out of bed without assistance. Both paid their attendants from \$7-10 an hour to assure the attendants' reliability and to make it possible for them to get out of bed in the morning. Third, both were wealthy. They came from middle class to upper middle class families. Ultimately, it is clear these two students came from families that could pay for their attendant care. Most disabled youth are not so fortunate.

Fourth, they had similar experiences while their parents were their attendants. They said that having parents as attendants ranked high on the scale of worst experiences with an attendant. What is the reason for this negative reaction to having parents as attendants? It is extremely hard for youth to exercise their independence when their attendants are parents. Having one's own family members as attendants also causes additional stress and conflicts among family members.

Speaking from personal experience, at eighteen I started receiving In-Home Support Services (IHSS), California's program of personal assistance services. My county let me hire my mother as an attendant. Initially, this seemed like a good idea. My parents were my personal attendants for years. I thought, why not let them finally get paid for it? Prior to getting paid for PAS, my mother had spent 2/3 of her income on what I term a "glorified baby-sitter" to function as an attendant for me. What appeared to be a good idea turned out to be a catastrophe. My mother would often tell me to clean my room, just as any parent would tell his or her teenage child. But, as a slightly manipulative eighteen year old, I would say no. I would then remind my mother that she was my paid attendant and that she should clean my room. This led to many arguments. My mother did not last very long as an attendant. This example illustrates how having a parent as an attendant can upset the power dynamics of a family.

When interviewing the high school students about who attended to their needs, five out of six students said family members. Most high school students were unaware of programs such as IHSS. Most of the time it was parents or siblings who gave assistance to the person with a disability without ever getting paid for it.

Only one of the six high school students said that he did not receive personal assistance from his family. This student was hard of hearing and used an interpreter in school. His parents did not use sign language to communicate with him. They had taught him to communicate only by speaking. He did not consider an interpreter to be a personal assistant and felt he did not need an interpreter outside of school. He believed he did not need an interpreter because he repeated himself until he was understood.

The other five high school students said their personal assistance enabled them to function as independent young adults. Three of the students had conflicts in the family relating

to personal assistance needs. These conflicts occurred because the parent's role as caregiver was being challenged and threatened by the shift in roles. Not all high school students, however, were emotionally and psychologically ready to become independent.

Most students agreed that attendants should form a union. However, when asked about wages, the students did not know how much attendants should be paid. Some felt that people should just volunteer their time or get paid minimum wage, while others thought that attendants should be paid \$7-\$10 an hour. However, there was consensus that wages should depend on the experience an individual had in providing assistance and the tasks that needed to be completed.

The study's high school students did not have active social lives; they lived according to other people's schedules. They were dependent on their parents and siblings to take them places, so they did not go out alone. One student said she was afraid to go out alone. Only two of six had been on a date. I asked if they would feel more comfortable going out with friends or on a date if a personal assistant were to accompany them. Four out of five said yes. Four also said that they wanted that attendant to be a peer. College students responded that they wanted their attendants to be peers as well.

### Policy Implications

MacCreedy (1984) stated that negotiating relationships with attendants can be seen as part of creating "a new way of life" in response to a social movement (pp. 155-156). First, before "a new way of life" can be created, however, a number of policy issues need to be addressed:

- What are the possible implications when a minor is working for another minor? Are there liability issues if the attendant injures the person with a disability? Are the attendants' parents liable because the attendant is under the age of majority?
- What are the possible implications of an attendant working while the youth is on a date? One of the students asked an attendant to help him engage in sexual intercourse. The attendant agreed to do so, but not without signed consent from both individuals.
- What vernacular should be used when referring to the service delivery systems of personal assistance? Presently, students are familiar with only two service delivery systems terms. One is called personal care, meaning any intimate assistance when the body is nude, specifically one's sexual organs. The second is called non-personal care. This can mean anything where nudity is not involved at all. Although it is important to know the language of service delivery systems, it is also important not to make youth think in terms of the medical model approach. This is because the criteria for service eligibility are based on the medical model. Thinking in medical terms hinders youth from feeling open about speaking up for their needs.

- Lastly, any new system of PAS delivery should include freedom of choice. The system can utilize independent providers, management support services, or home care agencies. Consumers should be able to hire whomever they want at any time, including parents or immediate family members.

### Reference

MacCready, M. (1984). Young disabled and their care attendants. San Francisco, CA: University of California-San Francisco.

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## Transition to College: Preliminary Findings of Four Case Studies

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Many individuals with disabilities are unsuccessful in completing transitions from high school to college and employment (Henderson, 1992; Wagner, Newman, D'Amico, Jay, Butler-Nalin, Marder, & Cox, 1991). This paper explores issues that can have an impact on youth in the process of making these transitions. The following research question guided the study: How do first-year post-high school transition processes among four youth who have disabilities compare with each other and with current transition research? Youth in the study graduated from high school the same year and participated in the DO-IT Scholars program. The DO-IT (Disabilities, Opportunities, Internetworking, and Technology) Scholars program at the University of Washington is primarily funded by the National Science Foundation. It uses computers, adaptive technology, and the Internet network to promote independent and efficient access to information, to other students, and to mentors. DO-IT helps students with disabilities develop skills for the transition into postsecondary activities. Participants in this study are described below:

	<u>Sex</u>	<u>Disability</u>	<u>H.S. GPA</u>	<u>SAT Scores</u>	<u>Productive Engagement First Year Post-H.S.</u>
Chris	F	Visually Impaired	3.75	V 610 M 600 nonstandard	Full-time enrollment: university Focus: molecular biology
Pat	M	Hearing Impaired	3.03	V 400 M 520 nonstandard	Full-time enrollment: two-year college Focus: electronics
Leslie	M	Orthoped. Impaired	2.79	no record	Part-time employment: university computer lab Focus: computers/networks
Terry	M	Orthoped. Impaired	3.33	V 640 M 500 nonstandard	Part-time enrollment: two-year college Focus: general studies

This study was a sub-study of a larger work. Data were collected from semi-structured interviews, observations, informal conversations, and high school records. Interview protocols incorporated open-ended probes related to four themes that emerged from the interviews: Disability Management, Transition Preparation, Non-Familial Relationships, and Computer Technology. Analyses involved comparing data from participants with each other and with current research in the area of transition.

## Results and Discussion

### Disability Management

Factors that may have an impact on transition processes include the perception of disability, the ability to manage assistive technology and various tasks associated with a specific disability, and personal resiliency (Gortmaker, Perrin, Weitzman, Homer, & Sobol, 1993; Resnick & Hutton, 1987; Wagner et al., 1991). All participants demonstrated good understandings of and high degrees of comfort in discussing their disabilities. Negative, positive, and neutral aspects of having a disability emerged from their reflections. Their explanations reveal personal resiliency as they identified and dealt with disability-related impacts.

Chris: I'm blind. What else do you call it? [I see] nothing, zero, zilch. Completely, totally, absolutely. . . . I am, however, a visual thinker. . . . Well, you have to get a new pair [of artificial eyes] like every, I think it's like three or four years. Um, and they like dump, you know, that stuff that they use to take molds of your teeth? . . . Basically all you do is you rinse them off, you dry them off with like, with like a paper towel or something . . . . I might say that I would have had more . . . friends, if I hadn't been blind. . . . Or would I have just been in the in crowd? . . . Looking back on it now, I'm really glad that I didn't end up in the middle of that group of people.

Pat: Umm, I have severe nerve damage in my ears and that. I was born that way. . . . I usually get new hearing aids every five or six years. . . . My classes [in high school] were difficult because of my hearing loss . . . I hear male teachers better than I do females, so my grades changed all the time. . . . I had to gain a lot of friends that adapted to my impairment.

Leslie: Arthrogryposis . . . means that I was gonna be a normal baby, you know, until about the second trimester, and then my mom caught this virus or something, and it caused my muscles to . . . to stop growing. And my joints to freeze in the position that they were in. [Leslie now uses an electric wheelchair.] I have enough problems that aren't even related to my disability. . . . I'm kind of stuck. I kind of depend on people for things that I need, you know. . . . Mostly my disability kept me from getting some of those roles [in high school plays].

Terry: Oh, OK, um, I, yeah, I have Duchenne's dystrophy. It's a genetic disease, muscle disease. So I mean like when I was real young I was normal and then, as I got to a certain age, I just started getting weaker and weaker until I couldn't stand up anymore. . . . I had a manual chair for a couple years . . . then I started using an electric wheelchair. . . . I think it's probably helped me a little bit actually, more than it's hurt me. . . . I think I had to look to other things in order to stay sane, you know. I think it helped me to develop my mind somewhat.

### Transition Preparation

Academic skills, an understanding of specific accommodations needed, and knowledge about rights to reasonable accommodations may affect decisions and success in pursuing postsecondary education (Wagner, Blackorby, Cameto, & Newman, 1993). Specific transition planning can be helpful. To gain insight into the nature of high school transition preparation, school records (transcripts, IEPs, psychological evaluations, and recommendations) of participants were reviewed. Chris' school record included an elaborate transition plan. The records of the other three participants documented minimal transition planning. Conversations with participants confirmed these differences in transition preparation.

### Non-Familial Relationships

Non-familial relationships include friends, counselors, teachers, and other mentors. The reciprocity implicit in a relationship between peers helps each person succeed and progress (Shapiro, Haseltine, & Rowe, 1978). Mentors also enhance academic and career success by providing counseling, confirmation, friendship, and a sense of identity (Kram & Isabella, 1985; MacLeod-Gallinger, 1992). Comments about friends constituted a substantial portion of participant interviews, as indicated by the following excerpts:

Chris: I didn't really have that many friends.

Pat: I was very lucky to have the friends I got . . . a lot of my classmates understood my disability. And cause of that they did stuff like speak up when I am around.

Leslie: Umm, I [was] just lonely a lot [in high school]. Just going through really, you know, sort of emotional, really trying times.

Terry: Socially, high school was kind of a zero for me most of the time. Mostly, I don't know. I had . . . a lot of acquaintances . . . but I didn't, I didn't have a lot of real close friends in high school.

Experiences of loneliness and isolation were especially prevalent in the conversations with Chris, Leslie, and Terry. They commented on the lack of reciprocity in past attempts at forming friendships and questioned the authenticity of friendships.

Mentors in high school played important roles, including role-modeling and friendship. Each participant told of at least one favorite teacher in high school who provided unique counseling, guidance, and/or confirmation. For Chris, the biology teacher opened up this field by being at ease and not becoming "worried about having a blind person in his class." For Pat, math and computer teachers presented challenging work and allowed Pat to "learn it before they taught me 'cause I always jumped ahead." For Leslie, the debate teacher coached and nurtured her team, "She just sort of treated everyone like they were, you know, her children." For Terry, the football coach offered encouragement and

support though Terry was not on the team: "I really liked the coach . . . he was like a P.E. teacher at the middle school that I'd known before, too."

Participants reported that attending college and participating in the DO-IT program increased opportunities to develop friendships and to diminish feelings of isolation. Chris reported, "I think that the DO-IT program time, especially the first year, was really cool because, um, I came here and I made a lot of friends, which was something that's really hard for me to do. Um, and I made them quickly, and I feel I got to spend two weeks together, and it was really, really fun."

### Computer Technology

Computers help students who have disabilities participate more fully and independently in postsecondary educational activities (Burgstahler, 1993). Participants in this study made significant use of computer technology for information access and communication. All had access to computers and the Internet in their homes, most made available through the DO-IT Scholars program. Participants used computers to take notes, prepare class assignments, access information, and interact with peers and adults over the Internet. The benefits of using computers do not come without cost, however; participants reported that new skills must be developed to maximize the full potential of computer and network technologies.

### Conclusions and Implications for Future Research

This sub-study explored the first year of post-high school transition of four individuals who had disabilities and who participated in the DO-IT Scholars program. The experiences shared by the participants concerning their transition processes were compared with each other and with current transition literature. Preliminary results of the case studies suggest that transition preparation, friends and mentors, and technology had an impact on the lives of participants. Additionally, participants projected candidness regarding descriptions of their disabilities and resiliency in dealing with the impacts of their disabilities. The preliminary findings of this sub-study elicited the following questions that might be addressed in future research:

- How do candidness and resiliency regarding disability relate to success in postsecondary activities? How do these characteristics affect a person's ability to self-advocate and manage the diverse aspects of having a disability?
- How does specific high school transition preparation affect success in postsecondary activities?
- How do peer and mentor relationships influence the lives of people with disabilities after high school?
- How can technology best be utilized to promote success in the postsecondary activities of people with disabilities?

## References

- Burgstahler, S. (1993). Computing services for disabled students in institutions of higher education. (Doctoral dissertation, University of Washington, 1992). Dissertation Abstracts International, 54, 102A.
- Gortmaker, S.L., Perrin, J.M., Weitzman, M., Homer, C.J., & Sobol, A.M. (1993). An unexpected success story: Transition to adulthood in youth with chronic physical health conditions. Journal of Research on Adolescence, 3(3), 317-336.
- Henderson, C. (1992). College freshmen with disabilities: A statistical profile. Washington, DC: HEATH Resource Center.
- Kram, K., & Isabella, L. (1985). Alternatives to mentoring: The role of peer relationships in career development. Academy of Management Journal, 28(1), 110-132.
- MacLeod-Gallinger, J. (1992). The career status of deaf women. American Annals of the Deaf, 137(4), 315-325.
- Resnick, M.D., & Hutton, L. (1987). Resiliency among physically disabled adolescents. Journal of Adolescent Health Care, 17(12), 215-225.
- Shapiro, E., Haseltine, F., & Rowe, M. (1978). Moving up: Role models, mentors, and the "patron system." Sloan Management Review, 19(3), 51-58.
- Wagner, M., Blackorby, J., Cameto, R., & Newman, L. (1993). What makes a difference? Influences on postschool outcomes of youth with disabilities. Menlo Park, CA: SRI International.
- Wagner, M., Newman, L., D'Amico, R., Jay, E.D., Butler-Nalin, P., Marder, C., & Cox, R. (1991). Youth with disabilities: How are they doing? Menlo Park, CA: SRI International.

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## Section XIV

### Group Empowerment

As members of society we often seek out those most like us, those people who share our values, who can empathize with our experiences, and who can provide peer support. What is perhaps more difficult is uniting across differences to reach mutual goals. This last section of papers discusses how groups of people, those who have disabilities, can be empowered, not only as individuals, but as members of those groups.

The first chapter looks at one example of group membership and empowerment: people who use service animals. Ed Eames and Toni Eames write in "Coalition Building: The International Association of Assistance Dog Partners" that the governing board of the newly-founded group is made up of blind and visually impaired people, those who are deaf and hard of hearing, and people with physical disabilities. The authors look at the difficulties in building a cross-disability coalition and at the benefits of mutual support and advocacy.

Robert Metts writes about applying a research approach to empower people with disabilities in his chapter, "The Outlook for Participatory Action Research in Disability Studies." While specifying that PAR is not a methodology, Metts acknowledges that it is a logical way to extend the disability rights/independent living tenets of empowerment and consumer control. As a member of the original Physically Disabled Students Program at the University of California at Berkeley, Metts is able to describe empowerment from a group perspective. He explains how disabled people can contribute to formulating research agendas and the implementation of disability friendly research that is not based on tokenism, but on true respect for the expertise of consumers and their families.

Using a PAR model to conduct their research, Devva Kasnitz and Tanis Doe show how people with disabilities can be empowered by contact with other people with disabilities. In their chapter, "Leadership and Peer Support in the Independent Living Movement," the authors present a "model in progress" to trace the factors in the life course histories of 30 leaders with disabilities. The investigation led to the identification of several key factors leading to the development of leadership skills and opportunities. In this paper, having a disability can be considered a positive factor that motivates a focus or incites an interest in political and social movements. The authors also look at the cross-disability perspective of leadership and how people with some disabilities are able to find roles that suit both their personal qualities and their disabilities.

Lastly, a chapter on exemplary programs for people with disabilities is presented by Valerie Vivona. "Best Practices for People with Mental Retardation or Physical Disabilities" looks at how policy and funding decisions can directly affect empowerment by denying or providing services. The paper identifies "best practices" among programs that provide attendant care to persons with disabilities. These programs were nominated

and selected based on criteria developed by users of PAS. Consumer choice and input, adequacy of services, and consumer satisfaction were used as criteria. Services provided to people with mental retardation are often referred to as individualized supports or supportive services rather than PAS, yet the services are similar, despite the differences in physical needs. In this case, the empowering factor is "choice," and that includes being able to hire, train, and direct assistants, and having a range of options for management, such as having an agency deal with financial matters.

Whether it is through working with other people with disabilities who share common experiences, achieving choice and personal supports, or getting consumer voices heard at the research table, group empowerment will only be achieved when barriers are removed and supports are available and appropriate in every community.

## **Coalition Building: The International Association of Assistance Dog Partners**

**Ed Eames, Ph.D.  
Toni Eames, M.S.  
California State University, Fresno**

In 1993 a number of people with disabilities who were partnered with guide, hearing, or service dogs met in St. Louis to create the first consumer-driven organization that focuses on partnership with assistance dogs. A governing board was elected that consisted of individuals drawn from the blind and visually-impaired, deaf and hard-of-hearing, and physically disabled and mobility-impaired communities. The goals established at this inaugural meeting were education, legislation, advocacy, and mutual support.

### **Goals**

#### **1. Education**

- a. educate members of the public about the role of assistance dogs in the lives of people who have disabilities
- b. educate members of the disability community about the benefits of partnership with assistance dogs
- c. educate and sensitize assistance dog training programs and trainers about disability issues and the needs of their students
- d. educate and sensitize those partnered with hearing, service, or guide dogs about the needs of those with other disabilities and about the work of one another's assistance dogs

#### **2. Legislation**

- a. foster legislation strengthening the rights of people who have disabilities to be accompanied by their assistance dogs
- b. work against legislation that would limit or weaken the already secured rights of people with disabilities who are partnered with assistance dogs

#### **3. Advocacy**

- a. share information about access rights
- b. support one another in cases of access denial

- c. work with veterinarians, dog food manufacturers, assistance dog training programs, etc., to develop methods to foster and maintain the partnership between people who have disabilities and their assistance dogs
  - d. work for consumer empowerment
4. Mutual support
- a. share information about dog care, training, and equipment
  - b. share information at the local, state, and national level about veterinary care, disease control, etc.
  - c. provide support when the partnership ends
  - d. develop an information network to increase the choices of those seeking partnership with assistance dogs

#### Recruitment

With an estimated 15,000 assistance dog partners dispersed throughout the United States, an effort was made to reach as many constituents as possible. Notices were placed in mainstream and specialized disability-related publications. At this time more than 1,000 individuals subscribe to Partners' Forum, the quarterly newsletter published by International Association of Assistance Dog Partners (IAADP).

From the beginning, this newsletter was viewed as the core element in the organization's drive to provide a voice for people with disabilities who are partnered with canine assistants. Partners' Forum has been the vehicle for many writers to have their work published. Regular features include columns devoted to access denial cases, quality of training, canine behavioral problems, etc.

IAADP's first conference was held in conjunction with the annual conference of Assistance Dogs International, an organization of assistance dog training programs. The initial goals developed a year earlier were reaffirmed, and a number of committees were established to pursue these efforts. Recognizing that the most widespread national and international access problem has been the refusal of taxi drivers to transport people who have disabilities and their canine assistants, the group set forth the goal of educating drivers and companies about municipal, state, and federal laws guaranteeing the rights of Americans who have disabilities to travel with their working partners. A longer term effort to reduce the financial burden of canine partnership by working with veterinarians, drug and vaccine manufacturers, and dog food producers was endorsed at the meeting.

Building a cross-disability coalition in which different disabilities are given equal weight and power is difficult. The original Board, which consisted of two individuals partnered with guide dogs, two partnered with hearing dogs, and two partnered with service dogs,

has undergone change. More than half of the 15,000 assistance dog teams are represented by guide dog handlers who already have two consumer-driven groups, one affiliated with the American Council of the Blind, and the other with the National Federation of the Blind. Therefore, their participation in the coalition has been limited. Like other special interest groups, the most pervasive problem is informing those partnered with assistance dogs about IAADP's existence and mission.

### Accomplishments

- \* published seven outstanding quarterly newsletters
- \* Partners' Forum, IAADP's newsletter, received an award from the Dog Writers Association of America
- \* obtained not-for-profit status
- \* answered more than 500 queries about access rights, training programs, equipment, etc.
- \* conducted panels at the 1994 and 1995 Assistance Dogs International conferences
- \* held 1994 and 1995 conferences in which committees and priorities were established
- \* published a brochure describing IAADP
- \* published a brochure in seven languages focused on access rights
- \* in conjunction with the American Kennel Club, developed a registry procedure for all assistance dogs at no cost to the human partner

### IAADP's Future

In addition to the challenge of expanding its membership and developing a core of committed volunteers, the organization's major challenge will be establishing a solid financial base. At a \$10 a year subscriber/membership rate, current income is barely sufficient to pay for the publication of the quarterly newsletter. To underwrite an expanded set of goals, additional resources will be needed. However, the current financial scene reflects a decrease in government support and an increasing number of nonprofit organizations competing for limited private philanthropic dollars.

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## The Outlook for Participatory Action Research in Disability Studies

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A panel was convened at the Society for Disability Studies 1995 Annual Meeting to discuss an approach to research that has come to be known as participatory action research, or PAR; and to consider its relevance to research in the field of disability studies. As the lead-off speaker on this topic, it seemed appropriate, therefore, that I began my talk and will begin this chapter by presenting a working definition of PAR.

I am currently working with the staff of NIDRR and a distinguished group of disability scholars and professionals to explore the possibilities for the use of PAR in the context of disability-related research. In this exercise, we have been working with the following definition:

PAR recognizes the need for persons being studied to participate in the design and conduct of all phases (i.e., design, execution, and dissemination) of the research that affects them. PAR is an approach to, or a strategy for, research, not a methodology.

In many ways, PAR is a logical extension of the disability rights/independent living movement, which, in turn, is a response to the seriously flawed societal perception of people with disabilities and to the inappropriate, inadequate, and downright discriminatory treatment forced on people who have disabilities by the so-called disability professionals of the past and present. Those of us with disabilities can all recount horror stories of the inappropriate and damaging treatment that we encountered as a result of disability policies and customs that are based, at least in part, on the misinformed recommendations of so-called disability professionals.

My own personal highlights in this regard begin with the pressure that my parents received to institutionalize me when I contracted polio at the age of eighteen months, simply because the professionals believed that I would "never be able to walk again." Then, throughout my childhood, my parents were forced to fight nearly constant battles to keep me in public schools instead of in the scholastically inferior (to put it mildly) handicapped programs recommended by the so-called experts of the time.

My parents lost that battle for the first three years of my schooling, and, as a result, I spent eight hours a day in a baby-sitting warehouse for all of the children with disabilities in my part of Hayward, California. My parents ultimately prevailed, and I was able to attend the public schools from the fourth grade through the end of elementary school.

In the seventh grade, however, I was challenged again by those in the system who wanted to place me in a program for developmentally disabled students (then referred to as "the

mentally retarded") simply because the program took place in one classroom and, therefore, did not involve my walking from class to class. The experts, you see, thought that it would be wise for me to sacrifice my intellectual development to reduce the risk of occasionally being knocked over by my classmates while traveling from class to class.

To make matters worse, the so-called experts from the medical community invariably used their near god-like status to come in and buttress these stupid policies. The medical community also plagued us with weird medical suggestions, such as the recommended amputation of my left arm so that it would not "get in my way."

Most disabled people, at least of my generation, feel that the disability professionals have inexcusably ignored our wishes and suggestions and that, as a result, we have had to function in the context of inappropriate disability programs and policies. Those of us who initiated the movement in the late sixties and early seventies clearly viewed the established community of nondisabled disability experts and professionals as the enemy.

When we designed the first independent living center in Berkeley in 1972, and when we designed its prototype, U.C. Berkeley's Physically Disabled Students' Program in 1970, we also wanted to force the existing disability service systems to abandon their false belief in the expensive and demeaning medical model of rehabilitation and, instead, to increase their provision of cheaper and more appropriate non-medical services that foster independent and dignified living for people with disabilities. The professionals fought us like dogs.

But we won, at least politically. In the United States, the disabled community, particularly the physically disabled community, has made significant political progress. Sufficient political and bureaucratic mandates are now in place to give us a significant voice in government policies related to our disabilities. We also have the proper people in the most powerful positions (e.g., Judy Heuman, Howard Moses, Fred Schroeder, Kate Seelman). We have not even come close, however, to achieving our legitimate goals of equity, independence, and dignity for people with disabilities.

This is because political power alone is not all that is required for us to reach these goals. I believe that the disability rights movement's future progress in these areas is going to depend to a very large extent on our abilities in two areas: 1) our ability to hold onto and to expand our political gains, and 2) our ability to identify and solve the myriad social and technical problems associated with our move toward independence.

Our collective competencies in both of these areas, in turn, will depend on the levels of expertise and knowledge that we will be able to bring to bear. In other words, our movement's future progress will be largely influenced by our ability to gain access to the resources required for research and by our ability to use those resources wisely. This is where PAR comes in, because PAR is extremely compatible with the politics of disability. The type of consumer involvement that has been the centerpiece of the disability rights/independent living movement from the beginning also lies at the very heart of PAR.

It is important for those of us associated with the disability rights movement to understand that the current and ongoing institutionalization of PAR in the United States rehabilitation system affords us extremely valuable access to the research resources we need, and that it is up to us to determine how best to capitalize on this new-found access. I believe that the decisions we make now regarding the definition of PAR and the uses for PAR will influence the activity of our movement for decades to come. So let us discuss for a moment the best ways to use PAR.

First of all, in this era of tight research budgets, I believe that the traditional academic approach to research, which allows scholars to independently follow their whims, is an arrogant and unacceptably inefficient substitute for a research agenda. Many academic researchers support their arguments in favor of the traditional approach by associating a research agenda with a tendency for research bias. I believe that the two are not necessarily causally associated, and I further believe that a coherent research agenda is essential to efficient policy-related science.

I see PAR as being at the logical center of the process of formulating such an agenda, and I am encouraged that PAR approaches are being mandated at nearly all levels of disability research and policy. The institutional infrastructure is rapidly developing that will allow us to formulate an informed research and policy agenda.

However, the clarity and strength of the research agenda that emerges over the next few years will depend on the level of expertise that we are able to bring to bear on it. In other words, it will depend on: 1) the ability of the disabled community to organize to accomplish the task, 2) the level of expertise of the disabled people involved in the process, and 3) the ability of the disabled community to educate and utilize the expertise of our nondisabled colleagues.

There is nothing that I can presume to teach the disability rights movement about politics. I am constantly amazed at our movement's political savvy. Though we have lost both Ed Roberts and Irv Zola recently, we still have more than our fair share of absolutely superb politicians. The PAR mandates will give these able people an opportunity to organize the disabled community around the need for an informed and focused research agenda. This will not happen, however, unless our political leaders understand the importance of the exercise and begin to dedicate the necessary resources to the effort.

The effort will also depend on the ability of the established disability-directed and informed research organizations (organizations such as the Society for Disability Studies and the World Institute on Disability) to reach out and attract the interest of a greater number of scholars, whether disabled or not. This task, of course, is made all the more difficult by the coincidental passing of two of the movement's great leaders, but anyone who knew either of these men understand that they would have more than agreed on its importance.

As you can probably see from my remarks so far, I truly believe that, properly understood and applied, PAR and the PAR mandates together represent a terrific tool for the creation

and evolution of a very right-on and empowering research agenda. However, my experience as a person with a disability since early childhood, and my experience for the last ten years as a research scholar, have each enlightened me about pitfalls that could derail our efforts. I would like to conclude with a discussion of these pitfalls.

My experience as a disabled person has shown me that the established disability professions have a tendency, to put it mildly, to ignore and diminish the views of people with disabilities. Therefore, I believe that it is important for people with disabilities to create a rigorous PAR system in which token input from the disabled community is not tolerated. Though official participation by people with disabilities on all relevant advisory boards is crucial, such participation is by no means sufficient. In creating the new PAR-based system of research, we must insure that mechanisms are put in place to ensure that disabled people and their families and friends are heavily represented in the design, execution, evaluation, and dissemination of all disability-related research.

My experience as a disabled person also tells me that disability professionals have a tendency to create stupid policies based on ignorant assumptions about disability (e.g., their tenacious belief in our need for services associated with the medical model, despite the mountain of evidence indicating that these services tend to be expensive and inappropriate). Therefore, I believe that a key role for the disabled community in PAR must be to inform the research process.

Much discussion on the topic of PAR is centered on the issue of how best to use consumer input. In a recent NIDRR-sponsored meeting on PAR in Washington, DC, we spent some time sitting around, trying to imagine situations in which PAR will work and situations in which it will not work. Though I enjoyed the exercise, and though I see it as a logical part of the process, after some reflection I believe that it is not necessary for us to answer these kind of applicability questions up front. I believe that the systematic inclusion of disabled people and their families and friends in the design and evaluation phases of research policies and projects, by itself, will answer most applicability questions because the disabled participants will tend to know what they bring to the discussions, and because they will be quite capable, generally, of collaborating with competent technical experts and researchers to determine the best places for consumer involvement.

Now for the alleged insights of Bob, the researcher. As a professional researcher, I have been forced to overcome my tree-hugging liberal instincts and accept that a research approach does not become valid simply because it happens to empower a constituency. I believe that much of the research associated with the women's movement and with various ethnic minority movements has shown us that the constituents of interest groups are not well served when dogma is substituted for rigor. To be scientifically valid, research must reveal hidden truths. This requires methodological rigor.

In the conventional model of research, researchers identify their hypotheses, develop and implement methodologies for testing them, and then interpret the results. However, many researchers, particularly in the social sciences, have come to the collective realization that researchers in unfamiliar environments may require assistance, as they develop their

hypotheses and interpret their results, from people who are more familiar with the environments in question than they are. My own experience as an institutional economist in the Third World made me a firm believer in this approach. My subsequent return to the study of disability-related issues then caused me to see the necessity for this type of assistance from disabled people when disability studies are undertaken, wherever they take place.

I believe that the institutionalization of PAR can fulfill this function and, thus, vastly improve our research. However, this will not come without generating significant angst within the disability-related professions because it will fundamentally alter the relationships between researchers and their subjects. Rather than being considered all-knowing and all-powerful, disability researchers, essentially, will be employed by their subjects as a class, and by society as a whole; and their assignment will be to contribute their technical expertise to the collaborative pursuit of an agreed-upon research and policy agenda.

This will enhance the position of those professionals, whether they have disabilities or not, who can contribute necessary and valuable technical skills to the collective effort, and it will diminish the position of those who have been simply passing themselves off as experts, while promoting and perpetuating the failed conventional wisdoms of the past.

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## Leadership and Peer Support in the Independent Living Disability Rights Movement

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[Peer support] means, it means my life--everything, it's everything that's meaningful to me, it's everything that's given me anything. Before I was involved in our movement I was in the worst pain and enduring abuse and oppression, and terrible treatment and loneliness--and homelessness and moneylessness and friendlessness; and being involved in the movement, both the mental patients, consumer survivor, disability rights, independent living movements, civil rights movements, since being involved in that I've had everything that's meaningful in life, or almost everything except my Lear jet--a home, a job, friends, you know. And a purpose in life. (Howie the Harp, 1953-1995)

### The Problem

Over the last five years the World Institute on Disability (WID) has conducted research on the relationship of peer support to leadership by utilizing focus groups, key informant interviews, expert review of reports, pilot sample case studies, and, now, intensive life history interviews. We know that effective group leadership and effective individual strategies are not two separate processes; rather, they lie on a continuum from self-advocacy to systems advocacy. Any individual's position on or transition along this continuum is mediated by his or her social and cultural context, beliefs, attitudes, and experiences. Borrowing from marketing theory (Mayer & Tuma, 1990), this study seeks to analyze the occurrence of significant events or changes in people's lives by constructing "event histories."

From the beginning, the founders of the independent living movement drew upon their own experiences as people with disabilities to determine what was needed to live independently. Independence is defined in terms of the control a person with a disability has over his or her own life (Shapiro, 1993). The experience of discrimination is a part of this historical process. Disability is a tremendous stigma in our society (Goffman, 1963), a discrediting attribute (French, 1984). Most disability rights leaders experience discrimination directly. All have witnessed it. Meeting other people with disabilities and having people with disabilities as role models are important in overcoming the demeaning effects of stigma. These experiences contribute to the process of self-acceptance and personal integration for a person with a disability (DeLoach & Greer, 1981; Vash, 1981). As people with disabilities begin to feel and be more self-sufficient, they shift from the role of recipient to that of actor (Johnson, 1983). Becoming empowered and successful as individuals has enabled people with disabilities to connect with others and to form a

sociopolitical movement. Like members of the women's movement, members of the disability rights movement have recognized that the personal is political.

### Design

We approach these ideas using a model drawn from Life Course and Event History Analysis research methodology. Examples of the power of this methodology can be found in Mayer and Tuma's (1990) edited volume, *Event History Analysis in Life Course*. This approach identifies and chronologically maps key "events" in people's lives, thus creating an "event history." It then examines the sequencing of these events and how they relate to "transformations of status" and "roles" in someone's life. This model describes how changes in someone's life are step-like. We hold a certain status and role for a period of time, then go through a fast or gradual transition to a new status and role with all of the attendant rights and responsibilities incumbent on that status or role. Using life course event history analysis, we select specific key transitional events, their sequencing, and their inherent role incumbencies.

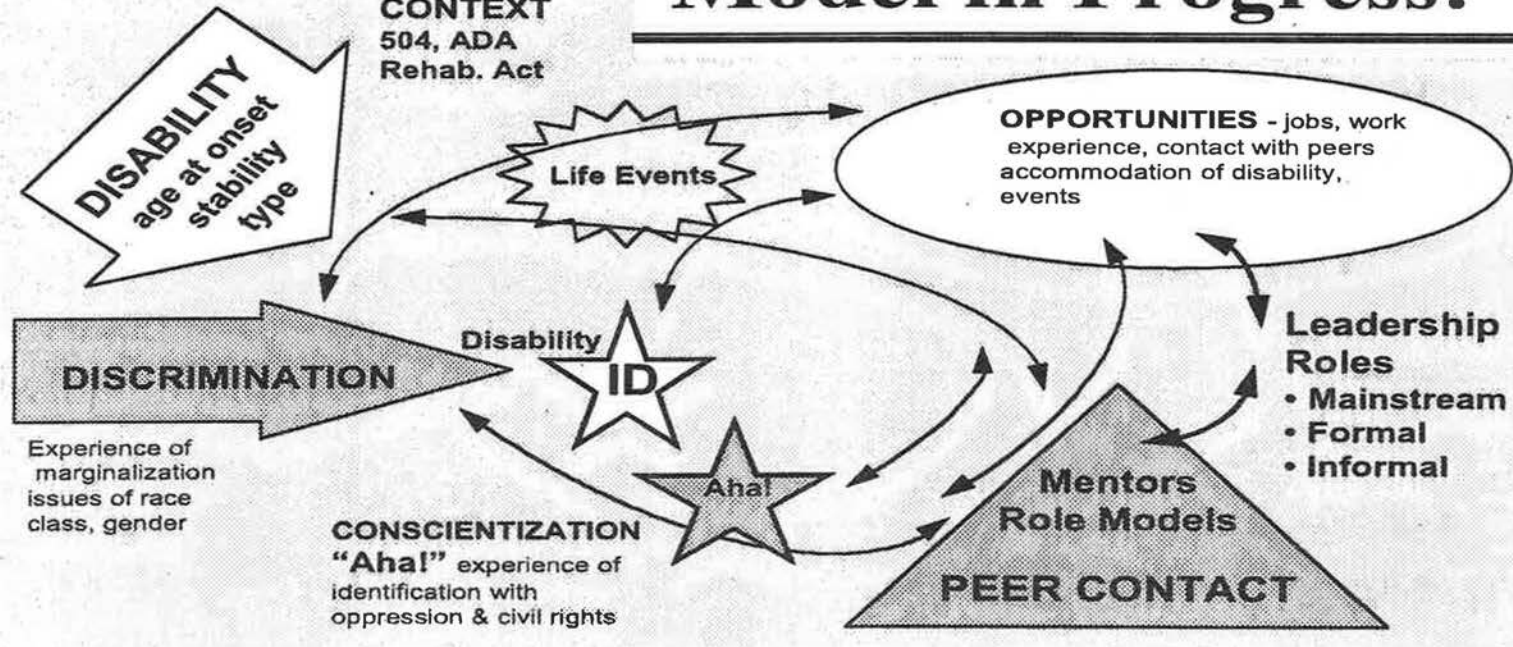
To capture a wide range of variation, the study respondent sample selection design includes four sets of filtering criteria: cohort group membership, attributes of leadership, the results of a nomination process, and a focused recruitment for diversity. It is significant that age at onset of disability for all of our participants is relatively young, an average of under 15 years of age. Only 20% of the sample report an age at onset over the age of 23, although the average current age of respondents is over 45. This may be part of a general trend in our society that leaders emerge young. These data also suggest that people with an early onset of disability are more likely to take on leadership roles in the disability rights movement. The leaders selected in this project were chosen because they were recognized leaders in disability rights organizations or activities, rather than professional or business organizations, and there may be some differences from the general population of leaders with disabilities. It may also be an historical artifact of the development of the movement by young post-polio men and women. Alternatively, this trend may reflect an epidemiological bimodal pattern for onset of disability that genetic, developmental, and accident-caused disabilities are more common among the young, while chronic illness-related disabilities are more common among the elderly. It may also be that people with an older age at onset who are predisposed to leadership have already assumed these roles in other arenas. One final possibility is that the time elapsed since onset is critical, and the majority of the leaders we interviewed have been disabled for over thirty years.

This paper proposes a *Model in Progress* that traces the various ways in which knowledge of, contact with, and identification with others with disabilities have an impact on leadership development. In this model people begin in an *historical context*, with ability, potential, or *predisposition* towards leadership regardless of their disability. Communication skills, self-esteem, family support, personality, pre-disability experience and expectations, and the drive to achieve are among some of the factors identified. The model then looks at *disability onset* directly--the type, onset, extent, and stability of

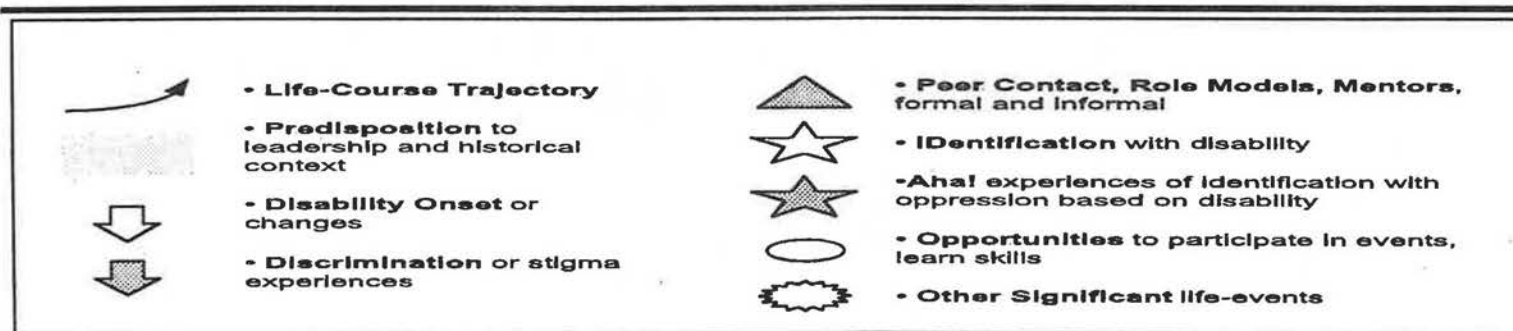
## PREDISPOSITION to Leadership

**HISTORICAL  
CONTEXT**  
504, ADA  
Rehab. Act

## Model in Progress:



## Model Key:



disability. Peer contact, contact with other people with disabilities, affects individuals' *identity* as disabled. The nature of a disability also affects the social stigma cast upon it. Stigma and the experience of *discrimination* in school, family, work, or generally in society seem to be critical factors in the development of leaders. Exposures to injustice based on race, class, and gender are also identified as significant life events leading to the "conscientization" or the awareness that disability is grounds for oppression. The "*Aha!*" experience is that of connecting one's disability to a collective status of shared issues within a civil rights movement. Identification as disabled and identification with a group of people who also have disabilities are part of the ongoing process of "constituent identity." The model also includes *opportunity*, that is, opportunities to meet peers, to see advocacy at work, and to learn new skills. The other area the model identifies as significant is "role models," which includes contact with people with disabilities at a peer level, from a distance, or even in books and media. Opportunities and role models interact, and occur repeatedly and in combinations to provide support and skills that lead to "roles" in the formal or informal disability network, or to university or government jobs/appointments or other mainstream leadership positions.

### Findings

One initial premise of this work is an intuitive feeling on the part of WID's founders that individuals who are leaders in the disability rights movement moved on a motivational continuum in a natural progression from a sense of personal empowerment, gained through self-advocacy, to group leadership roles. The data do largely bear out this view. Individuals who have exercised effective self-advocacy do tend to move into group advocacy roles. However, this view is too unidimensional. Some participants described how self-advocacy activities can be harder than group advocacy. For someone with low self-esteem or for someone who is buried in the experience of stigma, self-worth is questioned, while the value of others is not. If self-advocacy comes first, then the lessons learned in the individual struggle prepare one for group leadership. Most did not dwell on self-advocacy. Rather, they talked about the circumstances that brought them to an identification with others with disabilities and of their realization of a commonality of stigmatized status.

One unexpected finding is the direct way in which disabilities themselves can provide individuals with an opportunity to be in a visible community role leading to leadership. When asked "Has your disability affected your leadership role? Is your disability an advantage or disadvantage?" answers are striking. Annette's inability to fulfill expected social roles freed her to look elsewhere for direction.

ANNETTE: If I have leadership abilities it's because I have a disability. . . . I can't imagine what would have happened to me, what direction I would have gone in if . . . I lived in a southern, racist town, you know, and I was expected to come out, get married, and grace somebody's home.

Darla described how she was offered opportunities to take on visible roles in the Canadian disability rights movement precisely because of her deafness. Ronald talked of invitations he receives to sit on committees because he is disabled and Japanese-American. As disability rights movements grow and become increasingly diverse, individuals with under-represented disabilities and persons who are ethnic minorities may have unusual opportunities to represent their constituencies.

KATIA: I wouldn't be a leader of anything much if I didn't have this disability because I wouldn't have been as needed. Because there are many, many skilled organizers with other disabilities who can do planning and strategizing and lobbying and get the work done. Since people with environmental and chemical disabilities are so horribly desperate, even what I have to offer came in handy, it was usable. And it actually provided me with an opportunity to get our bearings and see where we fit in and get to know people who had better skills and so forth, who had other disabilities. I don't think I would have been forced into the role into which I have been active if I had a different primary disability, or none.

The data suggest that the leaders interviewed fit into two broad categories. One group consisted of those predisposed to leadership roles. These are people who would probably have become leaders in any case, and for whom their disability provided a focus for their leadership activities. The other group are those for whom their disability itself propelled them into a leadership position. This admittedly overly-simple, but useful, distinction held true, even among people with a young age at onset of disability. Some demonstrated a propensity for leadership roles in arenas unrelated to their disabilities, and despite any stigma or discrimination attached to those disabilities. Only later did they come to a leadership role in the disability movement. Others, by contrast, described how the nature of the disability itself kept them from being wallflowers--there was no wall into which they could blend, no fence on which they could sit. Disability itself can make a leadership role very compelling.

Starting with the onset of disability and experiences of discrimination, people with disabilities need a strong sense of identification with other people with disabilities to understand the many issues they will face as leaders in the community. As a result of exclusion from the mainstream and inclusion in disability-specific experiences, including disability culture and disability industry employment, people with disabilities may come to recognize, defend, and efficiently extend their rights as people with disabilities in society. This explorative research project leads to specific recommendations about exposing young people with disabilities to role models with disabilities, and about policy changes that would ensure access to work, educational experiences, and leadership opportunities.

#### References

- DeLoach, C., & Greer, B. (1981). Adjustment to severe physical disability. New York, NY: McGraw-Hill.

- French, R. (1984). The long term relationships of marked people. In E. Jones, A. Farina, A. Hastorf, H. Markus, D. Miller, & R. Scott (Eds.), Social stigma: The psychology of marked relationships (pp. 171-193). New York, NY: Freeman.
- Goffman, E. (1963). Stigma: Notes on the management of spoiled identity. Englewood Cliffs, NJ: Prentice Hall.
- Johnson, R. (1983). Mobilizing the disabled. In J. Freeman (Ed.), Social movements of the sixties and seventies (pp. 82-100). New York, NY: Longman.
- Mayer, K., & Tuma, N. (Eds.). (1990). Event history analysis in life course research. Madison, WI: University of Wisconsin Press.
- Shapiro, J. (1993). No pity. New York, NY: Times Books.
- Vash, C. (1981). The psychology of disability. New York, NY: Springer.

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## Best Practices for People with Mental Retardation or Physical Disabilities

Valerie Vivona  
World Institute on Disability

Recognition for "Exemplary Practices" carries with it the benefit of increased public awareness for the recognized program and services offered, evidence of the program's effectiveness that can positively influence funding mechanisms, and an opportunity to network with other similar programs and those seeking information on how to facilitate positive change within their own programs.

This study identified exemplary Personal Assistance Service programs (PAS) for people with mental retardation or physical disability living in the community. Programs providing PAS have been in existence for both populations for decades, yet consumers' views about effectiveness have not been articulated, and there is no clear information on models to replicate. This project has identified and will document ten exemplary practice programs for providing PAS serving people with physical disabilities, including elderly people, and people with mental retardation.

Evaluation of the programs was based on effectiveness from a consumer viewpoint synthesized at the World Institute on Disability (WID) from criteria proposed by consumer groups across the country (which represent people with physical disabilities, individuals with mental retardation, and senior populations).

The three central effectiveness criteria are:

1. Adequacy of services
  - a. being part of a system which provides services cross disability, to people of various ages, and to minority populations
  - b. availability of comprehensive needs assessment
  - c. provision of coverage for overnight, weekends, emergencies, and respite
  - d. comprehensive menu of services (for example, provision of personal care, household chores, support for social/recreational activities, facilitation for appointments, such as physician visits)
  - e. sufficient hours to meet personal goals
  - f. optional ancillary services, such as payment processing or providing assistant registry

2. Consumer choice/input
  - a. choice related to who, what, where, and when services are delivered
  - b. clarifying consumer rights (development of self-advocacy skills)
  - c. training consumers in assistant management
  - d. consumer input into developing individual Personal Assistant Service plans
  - e. consumer input into program policies
3. Consumer satisfaction
  - a. consumer satisfaction with assistants
  - b. consumer satisfaction with life activities support

### Methodology

Program nominations were identified through a national search using a mailing of 1,835 announcements as well as notices on a variety of on-line electronic services. Nominations were sought from a wide variety of people, organizations, and programs nationwide. Nominations were based on the consumer effectiveness criteria. Nominations were limited to PAS models that foster independence for people with mental retardation or physical disabilities who live in their own or their family's home.

Literature on a range of PAS models that foster independence for people with mental retardation or physical disabilities and on best practice methodology in related fields was reviewed to determine a process for identifying exemplary programs.

Experts in the field of physical disabilities or mental retardation, including consumers, researchers, program administrators, and policy analysts, participated in a two-step interview process. In the first interview, experts were asked to identify best practice PAS programs in their area of expertise based on their own criteria.

The same experts were then mailed the consumer effectiveness criteria and information sheets completed by the program nominees describing the program in the context of the three central criteria. Lastly, we included the names (with available documentation) of additional programs nominated throughout WID's national search. During the second interview the same experts were asked to identify the top five programs from among all of those nominated and state the reasons why they were selected as best practice programs.

NOTE: In the area of physical disabilities programs, three top programs were identified, and the remaining nominees were tied. Thus, a tie-breaker committee composed of

researchers and consumers was established to identify the two remaining physical disabilities programs and asked to reach consensus on the reasons for the selection of the two programs.

### Validation of Selections

The chosen method for validation of selected programs was interviews with Consumer Advocacy Organizations that were familiar with the selected programs and with agencies that referred consumers to these programs for services. The consumer effectiveness criteria were used as the basis for the question format as well as specific questions pertaining to the "exemplary features" for which the programs were selected.

### Results

We learned that programs for persons with mental retardation have a degree of difference from programs providing services for persons with physical disabilities. First, the language is different; they are not referred to as PAS but, rather, as individualized supports or supportive services. A more significant difference is that most programs for people with mental retardation serve 20 to 30 persons, with a maximum of about 200 people. The reason is that the provision of services is more intensive, providing advocacy, service coordination, facilitation (translation of verbal and written information), and similar services, which take more time and are labor intensive. The emphasis is on "person centered planning," basing services on an individual's expressed goals and on planning for those goals with the person and other significant individuals in the person's life (family, friends, attendants, roommates, neighbors).

Programs serving people with physical disabilities have been around longer (at least a decade or more) and, thus, have been researched to a greater extent. More dollars exist to serve large numbers of people, and statewide systems exist, which were our targets for identifying exemplary practices.

We learned that "choice" is defined as the type and number of services available; the option to hire, direct, train, and fire personal assistants; a choice in managing the fiscal responsibilities of employing a PA or having an agency take on that role; and an option for the payment of family providers. Also, the importance of consumers' participation in program policy was a critical piece.

Similarities between PAS programs for both populations demonstrate that choice is an essential factor. However, for people with cognitive disabilities, achieving truth in their supports is an even greater challenge.

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