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End Results and Starting Points: Expanding the Field of Disability Studies

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**End Results and Starting Points:
Expanding the Field of Disability Studies**

Edited by

**Elaine Makas
University of Southern Maine**

&

**Lynn Schlesinger
State University of New York--Plattsburgh**

A publication of

The Society for Disability Studies

&

The Edmund S. Muskie Institute of Public Affairs

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This book is dedicated to Irving Kenneth Zola, Ph.D., whose intellectual and personal inspiration permeate the volume. Irv brought us together, he encouraged us to share the products of our work, and he gave us the confidence to express our creativity.

The Society for Disability Studies

The chapters in this book are extended abstracts of some of the presentations given during the June 23-25, 1994, annual meeting of the Society for Disability Studies held in Rockville, MD.

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 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.

For further information on the Society or the Disability Studies Quarterly, contact The Society for Disability Studies, Suffolk University, Eight Ashburton Place, Boston, MA 02108-2770; (voice) 617/523-3429; (TTY) 617/523-3682. For further information on the Society's Annual Proceedings from 1986 to the present, contact Elaine Makas, Lewiston-Auburn College of the University of Southern Maine, 51 Westminster Street, Lewiston, ME 04240.

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Section I

Disabling and Nondisabling Images of Disability

This first section includes seven papers that examine how people with disabilities have been portrayed historically and cross-culturally. Written presentations and visual images of disability are not new phenomena, nor are they neutral. Rather, the ways in which people with disabilities are presented and the ways in which they present themselves are profoundly cultural and historical. They may reflect social norms and/or represent challenges to socially-prevalent understandings of disability. While an increasing number of films, commercials, and TV shows in the last 20 years have portrayed people with disabilities, it is important to ask what those images implicitly and explicitly convey about disability. Do they reinforce the "disabling" of people with disabilities (e.g., telethon debates, discussed in Bogdan and Biklen, 1993)? Do they emphasize stigma, pity, victimization? Or are they empowering--encouraging acceptance and recognition of difference, the promotion of social equality, and social change? Or, as several of the chapters point out, do presentations of disability often include images that are both abling and dis-abling, reminding us that social life is not linear or easily categorized, but rather complex and ambiguous?

In "Literary Representations of People with Physical Disabilities," Barbara Bergquist examines such representations historically, from Greek and Roman myths to contemporary works, such as those by Kovic (1990) and Connaughten and Sheridan (1989). She concludes that disability as a symbol of fear, pity, and shame will continue to be used in contemporary literature, including works by people with disabilities. In part, she believes this is positive because if "we can know and empathize with the feelings of each other, those with and those without physical disabilities, we have a better chance of overcoming these particular fears, angers, shame, and pity" (p. 7).

Like Bergquist, Maria Anastasopoulou reviews a range of literature in order to examine images of disability. In her chapter, "The Discourse of Disability in Novels by Women Writers," Anastasopoulou equates both gender and disability with "passivity, powerlessness, and dependency" (p. 11) and shows how they are used as literary tools to equalize relationships between female and male characters. In Bronte's (1847/1980) novel, only after Rochester has become blind can he and Jane Eyre marry as equal partners. In this and other novels outlined by Anastasopoulou, women are able to achieve independence and creativity only when men are rejected altogether, or when men begin to understand the experiences of being oppressed and invalidated. While disability becomes a liberating force for the women characters, it remains associated with negative images of dependence and incompleteness.

Beth Franks considers another form of literary representation in her chapter, "Disability and Fairy Tales: An Analysis." Applying content analysis to 20 of Grimm's fairy tales, Franks looks at the type of disability portrayed, gender, "sphere of action," ethical behavior, and the importance of disability to the plot. Franks found that characters with disabilities in her sample were just as likely to be "good" as "bad," and that paradoxical twists of fate might present disability as a strength just as much as a weakness. Similar to Bergquist ("we all are 'disabled' in some way") (p. 7), Franks emphasizes that disability "can happen to any character" in the fairy tales she analyzed (p. 21).

Visual representations of disability are James W. Trent's data in "Disability Images: Photographic Constructions of 'Feeble Minds' at Letchworth Village, New York." Trent's historical analysis illustrates how the changing presentation of the residents of Letchworth Village reflected social changes in American culture. Economic rises and falls, social policy revisions, and normative changes in the definition of "mental disability" contributed to and were affected by the changing photographic portraits of people at Letchworth. Trent's paper reminds us how important it is to ask who produces the image, and to what ends. As he notes, "the photographs provided images of 'mental disability' at Letchworth Village which the photographer constructed and which institutional officials, on the one hand, or institutional critics, on the other, wanted the public to see" (p.26).

In "Ability and Disability in the Ancient Greek Military Community," Martha Edwards reminds us that we ought to examine our own assumptions and cultural biases when engaging in research. Edwards expected that she would find negative images of disability and the exclusion of men with disabilities from ancient Greek military service. Like the work of Nora Groce (1985), Edwards' historical analysis reveals a subculture in which disability was defined very differently than it is in Western, mainstream conceptions. She writes: "The historical study of physical disability in any period, ancient or modern, emphasizes ability/disability as a cultural construction" (p. 31).

The next chapter, "Stigmatization of People-Who-Stutter: Some Reflections" by Miriam Hertz, illustrates that there are other variances in the images of disability in addition to those which are historical and cross-cultural. How different disabilities are portrayed may reflect both the experiences of people with disabilities and the expectations of the general public. Students in a course taught by Schlesinger (one of the editors of this book) reacted differently and strongly to the various essays in With the Power of Each Breath (Browne, Connors, & Stern, 1985). Through discussion, it became clear that some disabilities and some activities were viewed as "nicer" than others. Students felt comfortable with a blind woman's description of finding readers, but very uncomfortable with another woman's anger in trying to receive validation for environmental allergies. In Hertz's paper on stigmatizing images of stuttering, she reviews research that compared attitudes towards

people-who-stutter and those towards people with other disabilities. In the tradition of work by Bogdan (1992), Bogdan and Taylor (1987,1989), and Schwartz (1988), Hertz asks what it means to be viewed as more or less human.

Section I concludes with "The 'Differently Able' as Symbols and Agents of Revolutionary Change in Latin American Fiction" by Victoria Cox. Using novels by José Donoso and Gabriel Garcia Márquez, Cox describes how characters with disabilities, like some of the characters in Grimm's fairy tales or in women's literature, may both reflect and actively bring about changes in society and social relationships. Unlike the characters described in Franks' essay, the changes portended or brought about in the novels analyzed by Cox transcend individual situations. And unlike the "male mutilation" about which Anastasopoulou writes, the novels that Cox discusses present disability as a positive force: "The body of the differently able character confronts the discourse and the ordered body of the hierarchical and class conscious society, while at the same time proposes an alternative society" (p. 41).

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Literary Representations of People with Physical Disabilities

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This paper takes a historical approach and focuses on the feelings nondisabled people have toward people with disabilities and the feelings those with disabilities have toward themselves and their disabilities. The feelings addressed here are fear, anger, pity, and shame.

For nondisabled people, when encountering a person who has a disability, fear usually derives from two sources: fear that a similar misfortune could happen to them, or fear that they do not know how to deal with the situation. Part of the fear that this could happen to them is the belief that a disability is a punishment for being bad, an outward sign of inner evil. This fear causes anger and shame, and a feeling that people with disabilities are different or contaminated, to be shunned or ridiculed lest they affect or infect the nondisabled people with whom they come in contact. Yet some nondisabled people also feel guilt or shame that they feel this way, wish they did not have to face people with disabilities and, hence, prefer to have them kept hidden or institutionalized or otherwise "warehoused." On the other hand, sentimental pity allows people to feel good about those with a disability without requiring any action except, perhaps, dropping a coin in a container.

Historically, people with disabilities are the butt of jokes or are considered morally weak. The lame Vulcan is ridiculed by the gods in Greek and Roman mythology (Cary, 1949), as are the hunchbacks Thersites in Shakespeare's (1601-1602/1974) Troilus and Cressida and Rigoletto in Verdi's (1851) opera. Oedipus' (Sophocles, 5th century B.C./1960) club-foot is a sign of an inner disability, and Shakespeare's (1592-1593/1974) Richard III uses his physical deformity to justify his moral evil.

With the rise of sentimentalism in the nineteenth century, pity vies with fear. Tiny Tim in Dickens' (1843/1977) A Christmas Carol and Quasimodo in Victor Hugo's (1831/1941) The Hunchback of Notre Dame both evoke pathos. In melodrama, giving a character a disability is a sure-fire way to evoke sympathy.

In the twentieth century, many of these same ideas continue. The fears of nondisabled people, their ridicule of those with disabilities, their pity and shame, and the beast-with-a-good-heart theme all appear in The Elephant Man (Lynch, 1980). Disabilities and, in particular, wheelchair use become standard symbols of inner weakness: the fragile, lame Laura who cannot face life in Tennessee William's (1945/1970) The Glass Menagerie; the castrated male in Edward Albee's (1960) The American Dream; the weak, dying king torn between reality and fantasy in Eugene

Ionesco's (1963) Exit the King; and the blind, paraplegic Hamm in Samuel Beckett's (1958) Endgame who is emotionally paralyzed and refuses to see reality.

There are, however, many admirable people with physical disabilities in modern books, plays, and movies. They are ordinary people who struggle to face their disabilities realistically and who seek to lead as normal a life as possible: Helen Keller (Penn, 1962; Keller, 1976); Ved Mehta (1972, 1979, 1982) in his autobiographical writings; Christy Brown in My Left Foot (Connaughten & Sheridan, 1989); Sarah Norman in Children of a Lesser God (Medoff, 1987); and Stephen Hawking in the biographical movie, A Brief History of Time (Morris, 1992).

The fears everyone has of pain, loss, sorrow, and death are common to those with disabilities, too. But the fear of rejection is perhaps more pronounced. Philip Carey, the hero in Somerset Maugham's (1950) Of Human Bondage, has a club-foot and continually feels isolated and ostracized because he is different. People stare at him, snub him, or taunt him when they are angry. When Sarah Norman, the deaf girl in Children of a Lesser God, admits that she was rejected by a previous teacher, James asks her, "Do you still hurt?" She answers, "No, I never hurt from other people." James asks, "What if you admitted that you do hurt?" She answers, "I would shrivel up and blow away" (Medoff, 1987, p. 30).

Someone with a disability may also have deeper feelings of shame than others. Franklin Roosevelt believed that people would not consider him to be a strong leader if his inability to walk were obvious. As a result, the press conspired with him not to mention his polio or to photograph him in a wheelchair or being carried (Gallagher, 1985). Philip Carey is ashamed of his club-foot, constantly hides it, and hates to run because it becomes more obvious then. This shame comes in part from the snubs and ridicule he receives, and in part from his own feeling that the disability is a punishment for being bad (Maugham, 1950). If children of divorce blame themselves for the breakup of the family, children with disabilities often blame themselves for their physical difficulties because they cannot find any other explanation. Those who have had contagious diseases, e.g., people with polio or AIDS, may also feel contaminated and exiled.

Part of the shame someone with a physical disability experiences may also be related to the belief, not uncommon among nondisabled people, that a physical disability reflects a mental deficiency. Until Dr. Treves showed them differently, people thought that John Merrick was an animal without speech or intelligence; they called him an elephant man, and they beat him to get his attention (Lynch, 1980). Except for his mother, Christy Brown's family and neighbors thought Christy had severe mental retardation, and neighbors thought he should be institutionalized (Connaughten & Sheridan, 1989). Sarah Norman's family also thought she had retardation (Medoff,

1987). My own experience was an attempt to deny me entry to an academic program in high school despite my good grades in elementary school.

This fear and shame can lead to anger and self-pity. Sometimes the anger is directed outward. The paraplegic hero of Born on the Fourth of July is angry at the government that led the U.S. into the Viet Nam War, and he is angry at the Veteran's Administration for the treatment wounded veterans received. At other times, the anger is directed inward and leads to self-hatred and self-pity (Kovic, 1990). Depression is self-directed anger. When Christy Brown is rejected by his doctor, with whom he has fallen in love, he is furious with the world and himself, sinks into despair and self-pity, and tries twice to kill himself (Connaughten & Sheridan, 1989).

The foregoing does not imply that people with disabilities are the only ones to have these feelings. That would be a distortion of reality. Moreover, the works cited examine the human spirit; they are not studies of those with disabilities per se, except to the extent that we all are "disabled" in some way. If we can know and empathize with the feelings of each other, those with and those without physical disabilities, we have a better chance of overcoming these particular fears, angers, shame, and pity.

In my crystal ball, I do not foresee writers giving up disability as a symbol of inner weakness. It is too useful, and it covers too broad a spectrum of the human condition. There are, however, quite a few books, plays, and movies, such as The Elephant Man (Lynch, 1980), which cause discussion of disability issues and which are positive and realistic. My Left Foot (Connaughten & Sheridan, 1989) portrays the physical and emotional experiences of someone with cerebral palsy realistically, although the movie version has a romantic happy ending. Christy has been honored, he has met the woman he will marry, and, as the movie concludes, they are on a hill overlooking Dublin at sunset.

Children of a Lesser God (Medoff, 1987) carries realism further. Sarah Norman alienates many people at the beginning because of her all-too-justified anger at the speaking world. But, gradually, we come to admire her courage and to support her desire to be herself. Sarah and her teacher do marry, she enters the hearing world, and she becomes a star bridge player to show her mental acuity and her ability to fit into the speaking world. But she refuses to learn to speak, and this becomes the source of tension in Act II. Sarah asks James why she has to enter his world, and why he does not have to enter hers. By the end of the drama, they separate, and Sarah, à la Nora in A Doll's House (Ibsen, 1879/1978), goes off to find herself and to be herself.

Let us hope for more works like Children of a Lesser God (Medoff, 1987) which show that a person with a disability has the right to be, and wants to be, an individual, someone who has a life in the real world, just like everybody else.

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The Discourse of Disability in Novels by 19th Century Women Writers

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Helen Waite Papashvily (1956), in her study of the American domestic novel, entitled All Happy Endings, sees the first efforts by women writers to explore the man-woman relationship in feminist terms, terms that would allow for a more egalitarian symbiosis, as signs of aggression against men. She interprets the female protagonist's quest for shaping her subjectivity beyond socially-prescribed gender roles as a strategy for maiming the male and an effort to undermine his male hegemony.

It is obvious that Papashvily judges mid-nineteenth century women's novels by applying criteria, as Susan K. Harris (1990) observes, "shaped by the sexual perceptions of her own decade" (p. 6), a decade in which sexual definitions stimulated, as is widely known, Betty Friedan to write The Feminine Mystique (1963). It is also obvious that Papashvily is influenced by the critical tradition established by the pioneer studies on the subject by Fred Lewis Pattee (The Feminine Fifties, 1936/1940) and Herbert Ross Brown (The Sentimental Novel in America, 1789-1860, 1940). Unlike Papashvily, Elaine Showalter (1977), writing from the perspective of the feminist 1970's, brings a different interpretation to the phenomenon of the "mutilated male" in women's fiction. In A Literature of Their Own, Showalter considers the wounding of male heroes to be a way of making them experience the passivity, powerlessness, and dependency associated with women's experience of gender (p. 152).

Charlotte Bronte's (1847/1980) Jane Eyre belongs to the convention of the *bildungsroman*. The discrepancy between the aspirations of the young heroine, to exercise her intellect and to realize her potentialities, and the gender-defined identity she is expected, and often forced, to assume characterizes the female *bildungsroman*. For the heroine, it means indoctrination into the norms of womanhood as prescribed by patriarchal sexual politics. As Annis Pratt and her colleagues observe, "The supreme goal of these novels of development is to groom the young hero[ine] for marriage" (Pratt, White, Loewenstein, & Wyer, 1981, p. 14). Rachel Blau DuPlessis (1985), in Writing Beyond the Ending, points out the contradiction between love and quest plots in nineteenth-century fiction, a contradiction usually resolved by suppressing the quest or *bildung* plot, whether by marriage or by death (pp. 3-4). Writing within the conventions of the nineteenth century, Charlotte Bronte felt uncomfortable with both choices: to either condemn her heroine to a marriage that would silence her like death or to exact physical death because she refused to comply with the traditional gender roles prescribed by patriarchy. Instead, Bronte (1847/1980) tried to work out a compromise between the two possibilities. Jane's marriage to

Rochester becomes possible only when he is maimed and blind; in other words, when he himself has experienced what it means to be powerless and dependent and, therefore, becomes capable of accepting Jane as a partner in equality rather than as a subservient mate. Bronte has chosen the strategy of mutilation to feminize, so to speak, Rochester, and thus bring him closer to Jane. On the other hand, as is natural, his weakness allows Jane a wider range of power and authority in their relationship. Seen from this perspective, it becomes obvious that, rather than mutilating the male hero in the novel out of hatred, Charlotte Bronte devised the technique to be able to effect a more egalitarian relationship in marriage and, thus, offered a different model of marriage.

Elizabeth Barrett Browning's (1854/1992) poem-novel, Aurora Leigh, bears similarities to and possible influences by Charlotte Bronte's Jane Eyre, as several critics have pointed out. Browning's Aurora, who aspires to a career as a poetess, rejects Romney's proposal of marriage because of his conventional notions about women. Romney can offer Aurora the only choices that Victorian society approved for a woman: that of a charity worker under the lead of her husband or that of "the angel in the house." Like Jane, Aurora chooses to reject the abdication of power implicit in both roles and opts wholeheartedly for an authentic life. Like Rochester, Romney is blinded as a result of the fire that destroys his ancestral mansion; and like him, he is finally accepted by Aurora after a long separation. In a work which set out to explore the position of the educated woman in society, Elizabeth Barrett Browning finds the opportunity to castigate the limitations society presses upon the development of women. And yet, indoctrinated herself by her society's notions about what was considered to be appropriate female behavior and unwilling to portray her heroine as an unnatural woman and a freak--the common portrayal of the woman-artist in the nineteenth century--Barrett had to find a compromise between her heroine's aspirations and what was socially acceptable so that a new model of a more egalitarian relationship in marriage for Victorian educated women could be proposed. Thus, after years of artistic accomplishment, Aurora seems to feel that her success as an artist is incomplete if not attended by emotional fulfillment as a woman through a heterosexual love relationship. As she is growing into maturity, Aurora draws nearer to her society's beliefs that love is central to human development, especially for a woman. Similarly, Romney has matured through his socialistic adventure that cost him his sight, and he has come to accept the centrality of Aurora's vocation and her right to practice it. His mutilation has curbed his arrogant authority and gives Aurora more space for self-assertion in the relationship.

Elizabeth Stuart Phelps' The Story of Avis (1877/1985) was clearly modeled on Aurora Leigh. But, whereas Barrett emphasized the feasibility of an egalitarian marriage for an educated woman and made it seem a welcome possibility, Phelps chooses to explore the effect of what Pratt et al., (1981) call the "archetypal enclosure" on talented women (pp. 45-48). Thus, Phelps (1877/1985) is more concerned with how the institutions of marriage and motherhood deter women from developing their creative

talents to their fullest potential. Avis, haunted by her mother's unhappiness at having given up her artistic aspirations, soon becomes aware of the incompatibility between marriage and career for a woman. When Philip Ostrander confesses his love for her, Avis, against her inclination, denies her love for him. She knew, in her heart, that "she was not meant to marry" (p. 55), and she was determined not to yield to what Rachel Blau DuPlessis (1985) termed the "romantic thralldom," which entails a state of dependency for the woman in love. Avis is not willing to accept "the consequences of love as other women do" (Phelps, 1877/1985, p. 68). Yet, when Philip recklessly enlists in the Civil War and returns physically wounded, Avis is overcome. Persuaded by promises of independence to practice her art and develop her individuality, she accepts his proposal, but not without a struggle between her "two warring natures." So far, The Story of Avis closely follows the pattern of Aurora Leigh. Phelps, however, goes further to explore a new situation: how the everyday drudgery of marriage and motherhood, compounded by a husband's poor health, stifles the artistic creativity in a woman. When Philip finally dies, it is too late for Avis to continue from where she had left off. Her pictures are as if done by "a rheumatic hand," as if her "fingers were stiff," art critics observe (p. 244). And Avis admits to her father that "the stiffness runs deeper than the fingers" (p. 244).

Fanny Fern's (1854/1986) Ruth Hall delineates the conditions of a woman's success in pursuing an artistic career as well as her capacity for self-determination and economic independence. As long as she was under the protection of her father and, later, of her husband, Ruth had little say in the direction her life takes. It was only after her husband's death that Ruth was forced, by circumstances, to muster all her ingenuity and emerge as a powerful person who managed to attain literary fame and economic success, enough to support herself and her two daughters. Unlike Phelps, who utilized the "mutilation of the male" as a deterrent to the heroine's success, Fern (1986) uses another strategy, common in women's novels, which Susan K. Harris (1990), in her discussion of what she calls "exploratory novels," has termed "the phenomenon of the disappearing male" (p. 206). Sickness or accident, which results in the death of the heroine's husband or any male that demands her attention, is a circumvential trope to remove male domination and, thus, enable the heroine to develop into an independent, self-reliant human being.

Later novels confront the problem of male dominance in a more direct way. They do not try to compromise the problem by mutilating the male so that a more egalitarian relationship can result. Neither do they use the *deus ex machina* device of "the disappearing male" in order to allow their heroines space to realize themselves. Instead, they propose what I would like to call "the strategy of the absent male." In these novels, the heroine, who nurtures aspirations of self-realization through art or other social activities, simply rejects marriage altogether, as did Christie Devon in Louisa May Alcott's Work: A Story of Experience (1873/1977), Perley Kelso and Sip Garth in Elizabeth Stuart Phelps's The Silent Partner (1871/1967), or the more well-known Thea Kronborg in Willa Cather's The Song of the Lark (1915).

Another form of disability which women writers have used as a strategy to defeat the socially-prescribed roles for them is madness. Charlotte Perkins Gilman's heroine of "The Yellow Wallpaper" (1892/1992) resorts to madness as a way of escape from the confining role society forces upon her.

Male disability, therefore, in its various manifestations, and female madness are strategies women novelists often used in the nineteenth century to cope with the problem of female development beyond socially-prescribed gender roles prevalent at the time.

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Disability and Fairy Tales: An Analysis

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Fairy tales have been examined for their psychological content (Bettelheim, 1989), their portrayal of women (Kolbenschlag, 1988; Tatar, 1987), and their political messages (Zipes, 1983). Given their extensive presence in our culture and their potential impact on their audience, there are surprisingly few discussions of how disability is portrayed in fairy tales. In this preliminary study, a sample of tales taken from the Grimms' collection is analyzed for its rendition of disability. The tales were selected from Pantheon Books' 1944 edition of The Complete Grimm's Fairy Tales (Grimm & Grimm, 1944). This edition contains a total of 210 tales, 200 fairy tales and 10 children's legends.

A tale was chosen for inclusion in the study using the following criteria: (1) all animal tales were excluded; (2) tales in which disability was not present were omitted; and (3) the sample size was limited to 20 tales. The first 45 tales in the collection were examined to make up the sample size of 20. According to this sample, disability is present in nearly half the Grimms' tales. Table 1 lists each of the tales used in the analysis. In this table, each tale is listed by name and by number as it appears in the Pantheon edition. In some cases, the title has been shortened. After the title, the category of disability is recorded as well as the description used in the text.

Table 1
Tales by Number and Disability

<u>No.</u>	<u>Tale</u>	<u>Disability</u>	<u>Description</u>
3	Our Lady's Child	Speech Imp.	no sound
4	The Story of the Youth ...	Mentally Imp.	stupid
9	The Twelve Brothers	Speech Imp.	dumb (mute)
11	Brother and Sister	Visual Imp.	one eye
12	Rapunzel	Blind	blind
13	The Three Little Men ...	Physical Imp.	little
14	The Three Spinners	Physical Imp.	strange
15	Hansel and Gretel	Visual Imp./ Physical Imp.	cannot see far/ on crutches
20	The Valiant Little ...	Physical Imp.	giant
21	Cinderella	Blind	blindness

Table 1 (Continued)

<u>No.</u>	<u>Tale</u>	<u>Disability</u>	<u>Description</u>
25	The Seven Ravens	Physical Imp./ Physical Imp.	cut-off finger/ dwarf
31	The Girl without Hands	Physical Imp.	cut-off hands
32	Clever Hans	Mentally Imp.	behavior
33	The Three Languages	Mentally Imp.	stupid
34	Clever Elsie	Emotional	obsessive
35	The Tailor in Heaven	Physical Imp.	lame
37	Thumbling	Physical Imp.	quite small
39	The Elves	Physical Imp./ Autism	little men/ staring eyes
44	Godfather Death	Physical Imp./ Visual Imp.	withered legs/ lost sight
45	Thumbling's Travels	Physical Imp.	small

Content analysis, "a research method that uses a set of procedures to make valid inferences from text " (Weber, 1990, p. 9), was the primary method employed to analyze the tales. Tales were examined for: (1) type of disability; (2) gender of character who had a disability; (3) character's sphere of action, as described by Vladimir Propp (1968); (4) ethical behavior of the character; and (5) the function of the disability in the plot.

Type of disability

New York State's guidelines for classification of pupils with special educational needs was used to categorize disabilities. In this classification system, there are 13 different types of disability, of which six were found to be present in the 20 tales.

Table 2
Types of Disability Present

<u>Type of Disability</u>	<u>Frequency</u>
Autism	1
Emotional Disturbance	1
Mental Retardation	3
Physically Impaired	12
Speech and Language Impaired	2
Visually Impaired	5

The total, 24, is greater than the number of tales because in three tales one character had more than one disability, and, in one, more than one character had a disability.

Gender distribution

Both male and female characters had disabilities. In the stories, twelve males and nine females had disabilities. In the category of Physically Disabled, an interesting distribution was found. This category was broken down into two sub-types: stature (dwarves, elves, and giants) and orthopedic disabilities, which included missing or deformed limbs and lameness. Twelve characters, eight men and four women, had physical disabilities; however, the specific type of disability appeared to be closely correlated with the gender of the character. No women and six men were either exceptionally small or exceptionally large, while four women and two men had orthopedic disabilities.

Table 3
Physical Disability and Gender

<u>Gender</u>	<u>Stature</u>	<u>Other</u>
Male	6	2
Female	0	4

Propp Sphere of Action

As described by Propp (1968), there are seven spheres of action which roughly correspond to a character's role. A one to one correspondence between character and sphere of action is not always the case, since a character may serve one or more roles in a tale.

Table 4
Propp Sphere of Action of Characters with Disabilities

<u>Role</u>	<u># of Characters</u>
Villain or villainess	3
Donor of magical agent	1
Helper	5
Sought-for person	2
Dispatcher	1
Hero or heroine	10
False hero or heroine	3

In the 20 tales, all seven of Propp's spheres of action were fulfilled by characters with disabilities; however, these were not equally distributed. In addition, some characters who had disabilities fulfilled more than one role.

Ethical Quality of Characters with Disabilities

The Propp (1968) sphere of action does not always disclose whether or not the character behaves ethically; therefore a further analysis was made to examine the ethical role the character with a disability played. The results are as follows: 15 characters played predominately "good" roles (hero, heroine, helper, donor), while four played "bad" roles (villain, villainess). Two characters played roles that were ambiguous, both good and bad.

Function of Disability in the Plot

Tales were examined to determine the importance of disability to the plot. The role of the disability was categorized as integral, important, or incidental. Disability was judged to be integral to the plot if the action of the tale revolved around it. In the tale "The Three Spinners," physical deformity produced by spinning is the pivotal point of the tale. Because certain features were exaggerated by spinning, the heroine is prohibited from engaging in a task which she hates. Secondly, disability, such as the small stature of dwarves and elves, was often considered to be important to the plot, but not absolutely necessary to it. Finally, disability could be incidental to the story. The blinding of Cinderella's stepsisters at the end of the Grimms' version of this tale is a detail left out of many versions. Disability played an integral role in seven tales, was important in six, and was incidental in eight.

Analysis of the function of disability to the plot was carried one step further. Disability was also categorized as punishment (e.g., the blinding of Cinderella's stepsisters), as a trial or a test (e.g., being mute for seven years), or as descriptive (e.g., Godfather Death having withered limbs). A fourth category emerged when it became clear that not all of the 20 tales fell into these three categories. In seven cases, disability provided a reversal in the plot. For example, the "simple" son goes into the world and, because of his simplicity, behaves correctly (shows compassion), thus reversing his fortunes.

Table 5

Function of the Disability

<u>Function of Disability</u>	<u>Frequency</u>
Punishment	1
Trial	5
Descriptive	8
Reversal	7

If the sample used for this analysis is typical of the rest of the Grimms' tales, then it can be concluded that disability is used neither as the marker of the villain nor as punishment of the villainous character. In fact, it is quite the opposite. In the 45 tales that were analyzed, almost half had characters with disabilities in them. Of these, disability was used as a form of punishment in only one.

Disability was used as a "test" or a "trial" in five cases. In "Rapunzel," the prince who climbs up Rapunzel's hair to get into the tower is thrown into thorn bushes and blinded, but, after wandering in the wilderness, he is reunited with Rapunzel whose tears give him back his vision. Even if disability-as-trial and disability-as-punishment are added together, less than one third of the stories use disability in this way.

In eight cases, disability was part of the character's description, but only three of these characters were "bad"; one character was mixed, and four characters played "good" roles. Thus, disability cannot be said to be the descriptor of a "bad" character.

Disability acts pivotally in seven of the stories, that is, the fortunes of the hero or heroine are reversed through disability. This is a far more subtle and powerful action than the simple one of a character being "tested" by disability, for in each of these cases the disability is integral to the plot. In almost a Zen way, in the tradition of the wise fool, the message of the tale hinges on a paradox. The fool, because of his simpler vision, acts compassionately. It is the act of compassion by someone who in his/her own right is considered to deserve compassion, that carries the moral burden of the story, teaching the audience that wisdom can be found in fools, and strength in those who are physically weak.

To complicate matters, however, reversals in the plot are not always in the direction of disability-as-strength. In two cases ("Clever Elsie" and "The Elves"), the audience is encouraged to think positively of the character who has a disability, but they end up with a more negative picture. For example, the elves, who are helpful and kind initially, substitute one of their own children for a human child, leaving an autistic-like changeling in its place. Again, when disability is pivotal to the narrative, it delivers a paradoxical message about the way the world initially appears. Disability is not portrayed as either negative or positive but, within this sample, the message is that it can happen to any character whether he/she is good or bad, villain(ess) or hero(ine), rich or poor, or playing a main or secondary role.

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Disability Images: Photographic Constructions of "Feeble Minds" at Letchworth Village, New York

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When New York state officials founded Letchworth Village in 1911, New Yorkers believed the new public residential facility for "the feeble-minded" would be the best of its kind in the nation. Modern construction, new principles of scientific management, methods of institutional self-sufficiency, and, for a time, a generous appropriation from the New York legislature--all gave planners and ordinary citizens confidence in the new facility. For nearly two decades Letchworth Village seemed to fulfill its progressive image as "feebleminded inmates" lived, worked, and cared for each other under the custody of prominent and respected institutional officials.

By 1932, after nearly three years of economic depression, Letchworth Village was already experiencing the effects of hard times. Like all other public residential facilities in the nation, the New York institution was incarcerating more and more "inmates," but without new state appropriations. In 1941, on the eve of war, the over-crowding at Letchworth Village was no better; by the end of the war, matters had gotten even worse. Exposés of these conditions in the late 1940's added new state funds for new buildings and new programs. Yet throughout the 1950's and even into the early 1970's, the new buildings and programs could not keep up with the new "patients" now being admitted to New York state schools at a faster rate than ever before.

From the nation's premier "state school" in 1911 to an institution compared to a death camp in the early 1970's, the image of Letchworth Village reflected changing American constructions of so-called "mental disability." These changes mirrored not only social and economic exigencies of problem and policy interpretation, but also radical changes in the very image of "mental disability." From the "menacing moron" at the time of Letchworth Village's founding, to the "adaptable and adjustable mentally deficient" of the 1920's, to the victim of neglect in the late 1940's, to the "angel unaware" of the 1950's and 1960's, to the victimized "person with developmental disabilities" of the 1970's, so-called "mental disability" reflected varied, curious, and always socially-constructed images (Trent, 1994).

The Photographs of Bourke-White and Genthe

Shortly before her death in 1932, Mary Averell Harriman hired Margaret Bourke-White to take photographs of Letchworth Village (New York State, Department of Mental Hygiene, 1937, 1948). Harriman, a wealthy philanthropist, had

been a trustee of the village since it opened in 1911. Nineteen thirty-two was a very different year from 1914 when she began financing the Committee on Provision of the Feeble-Minded. In 1914 "the menace of the feeble-minded" rhetoric had reached its peak. By 1932, in the depth of the Great Depression, residents were sleeping two-to-a-bed and in hallways, and the demand to admit more needy "feeble minds" was greater than ever. Yet, funding was at best stable and at worst decreasing. As the depression lingered, public officials found few reasons to provide more resources to public facilities.

In this context, parole and discharge from the institution became an attractive way of making room for new clientele, especially so called "low-grades" and "juvenile defective-delinquents." Careful to parole well-behaving "inmates," Letchworth's superintendent, Charles Little, was eager to find ways of convincing politicians and the public that parole and discharge worked. Harriman's funding of an up-and-coming photographer fit this new public interest.

Margaret Bourke-White knew little, if anything, about what officials at the time were calling "mental deficiency," and there is no indication she thought much of her Letchworth series. Yet the photographs reflected both her particular style and the new vision superintendents were attempting to create. Most of the photographs were close-ups of "patients," the name institutional officials were now likely to call inmates. A few were not posed, but most showed the hand of the photographer. In several photographs, patients appeared in uniform-like clothing. They looked alike. Most were working--in the laundry, ironing clothes, at the loom, or in the classroom. Most looked too neat and attractive to be at work, as if their work were contrived, more real in the meaning created by the photographer than in the daily lives of the workers. None showed the "stigmata of degeneracy," nor were they produced to show examples of flawed pedigree so common to photographs of earlier times. Bourke-White portrayed children and teenagers any American community would welcome.

In November 1941, Arnold Genthe published photographs of Letchworth Village, probably the last series of his long and distinguished career (Genthe 1941; New York State, Department of Mental Hygiene, 1948). Quite different than Bourke-White's, most of Genthe's images show patients who appear in day-to-day clothing. Their appearances were hardly uniform. The work they did looked real and rough. Unlike Bourke-White's crisp photographs, Genthe's looked more like snapshots capturing moments than themes or ideas.

If Bourke-White tried to project a theme designed by Letchworth officials, Genthe attempted to see Letchworth Villagers as workers in a moment, real for that instant. There was little in Genthe's photographs that suggested a world outside the institution. Genthe's patients were peasant-like, rooted in a community (albeit, an

institutional community) they were not likely to leave. In less than a decade, an economic depression had profoundly changed the image of "mental deficiency."

The Exposés of Haberman and Rivera

At the end of the decade, Irving Haberman did a third set of photographs of Letchworth Village. First appearing in the New York daily, PM, and reproduced in Albert Deutsch's Shame of the States (1948), Haberman's photographs departed from both Bourke-White's and Genthe's gazes. For Haberman, photographs of Letchworth Village were exposés of wretched conditions. Exposed were naked residents huddled in sterile dayrooms, unkempt and unclean. Neither Bourke-White's crisp teenagers nor Genthe's "happy and carefree" but hard-working laborers, Haberman's patients were helpless quasi-human beings, exploited and victimized by inhuman neglect. The focus and message of Haberman's photographs pushed the viewer not to the patient but to the inferno. Faces and activities were not important. Important was the hell made by the institution; important, too, was the need to do something about the conditions.

These victims, the photographs made clear, needed greater comfort, more amenities, and kind treatment. They did not, in post-war America, need to be outside the institution, as bad as the institution might be. Deutsch's words shaped the photographs to tell Americans--better to fix the facility.

In January 1972, Letchworth Village would be, for a fourth time, before a camera. This time Geraldo Rivera's television reports of Willowbrook State School and Letchworth Village, would give New Yorkers first, but eventually a national audience, a view of a new state-sponsored hell (Rivera, 1972). The New York station that aired the footage received more calls than ever in its history. Its "Willowbrook: The Last Great Disgrace" airing at prime time in early February had two and one-half million viewers, the highest rating of any local news special in the history of American television. What New Yorkers first and, then, all Americans learned was that Willowbrook and Letchworth were not unlike death camps of the Nazi era. At Willowbrook, Rivera told his viewers, one hundred percent of all residents contracted hepatitis within six months of entering the institution. In buildings with residents who had severe disabilities, most were naked or only partially clothed. Many, too, lay on dayroom floors in their own feces. To build the \$1.5 billion Albany Mall Project, Governor Rockefeller and the legislature had forced the Department of Mental Hygiene to freeze hiring. Between 1968 and November 1970, Willowbrook had lost 912 of its 3,383 employees, most of whom were direct patient-care staff. To trim the mental hygiene budget even more, state officials had scheduled Willowbrook to lose another 300 employees. As bad as Willowbrook was, Rivera found Letchworth worse. For many years the premier New York and even American institution, Letchworth Village had become a place hardly fit for human habitation. By 1972, it

no longer seemed possible that Letchworth or any other institution could be improved.

Beginning in the mid-1960's, new federal dollars had provided for facility construction, but new state dollars for upkeep were not forthcoming. This failure of new state monies occurred after two decades of sporadic funding increases, but constant dumping of new clientele into institutions. Until 1968, public institutional populations of people with mental retardation would increase, despite little or no additional state funding. With the exposés that continued to emerge in the late 1960's and early 1970's, the state school joined the state hospital as being increasingly out of favor. Though there was never unanimity, by 1972 more and more advocates seemed to be echoing Rivera's sentiment, "We've got to close that goddamned place down" (Rivera 1972, p. 147).

Before 1930, most photographs of Letchworth Village showed the "stigmata of degeneracy," the particular examples of disability that superintendents portrayed to the public as examples of flawed pedigree. In 1932, the wealthy socialite, Mary Averell Harriman hired Margaret Bourke-White to photograph "inmates" at Letchworth Village. In 1941, Arnold Genthe, the prominent California photographer, also did a series of photographs at the village, the last of his long career. After the war, Irving Haberman produced photographs for Albert Deutsch's Shame of the States, an exposé of public institutions, including Letchworth Village. Finally, Geraldo Rivera in 1972 published photographs of Letchworth Village, along with the more publicized photographs and film footage of Willowbrook State School. Bourke-White and Genthe are well-known photographers in the history of American photography; Haberman and the photographer accompanying Rivera's exposés are not so prominent. In each case, however, the photographs provided images of "mental disability" at Letchworth Village which the photographer constructed and which institutional officials, on the one hand, or institutional critics, on the other, wanted the public to see. Out of what they saw came changing meanings and policies. "Essence" became the constructed images.

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Ability and Disability in the Ancient Greek Military Community

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Ancient Greek civilization provides the foundation for much of modern, western culture. While many aspects of this heritage have been examined, little attention has been paid to the study of people with physical disabilities in ancient Greece. My doctoral research focuses on the degree to which a physical disability affected one's integration into the community, a matter of profound importance in the ancient world. When I began my investigation several years ago, I expected to find that people with visible physical disabilities were despised, given the pervasive ideal of symmetrical proportion that we see in Greek art, architecture, science, and philosophy. The military provides an excellent window through which to observe Greek attitudes about physical disability, as the army was an integral part of community and daily life (Hanson, 1989). The army was an exclusively male institution. I purposely exclude women from this discussion, as women with disabilities in the ancient Greek world lived in a different sphere and comprise a separate topic.

To be a Greek man was to be a soldier. The armies of each of the several hundred small, ancient Greek communities were citizen armies. Each Greek geographic area was dominated by its main city-state, or *polis*. The citizens of each *polis* fought together, trained together, drank together, and made political decisions together. I expected to find that a man whose physical disability interfered with his role as a soldier would be considered less than a full citizen, an awkward cog that impaired the military machine. Furthermore, I was quite sure that men with physical disabilities that kept them away from the battlefield altogether must have been considered less than full men.

My hypotheses, because they were based on three anachronistic perceptions of disability, were incorrect. First, the idea of what constituted physical ability was more flexible in the ancient Greek world. Second, the military community was broad enough to include a variety of abilities. Finally, the perception of physical ability was not in terms of an able/disabled dichotomy, nor was ability or disability seen as a permanent condition.

First, then, what constituted physical disability in Greek terms? In ancient Greece, there was no all-inclusive word for "disability" until the Athenian political institution of the fifth century B.C.E., democracy, necessitated it. Even then, a blind person and a person with one leg--for example--would not have perceived themselves to be in the same category. The fifth-century word for disability was *adunatos*, literally, "unable" or "powerless."

A physical disability, in itself, never constituted a state of *adunatos*. The biographer Plutarch relates a story of a Spartan with a limp who defends his role as a soldier: "A man does not need to run away when he fights the enemy, but to stay where he is and hold his ground" (Plutarch, 1st century C.E./1927-1976). This Spartan was not *adunatos* by any means. Neither was Philip II, the father of Alexander the Great, about whom the Athenian orator Demosthenes warns the Athenians. Philip II "had endured the loss of an eye, the fracture of his collar-bone, the mutilation of his hand and leg, and was ready to sacrifice to the fortune of war every part of his body" (Demosthenes, 4th century B.C.E./1984). Today, most people would describe such a man as "physically disabled." In the Greek view, however, the physical signs that a man was willing to sacrifice his body and keep fighting made him a dangerous foe.

The boundaries of physical ability, then, were less well-defined by the ancient Greeks than they are today. But was the definition of disability different in degree, or in kind? A limp in battle is one thing; an inability to walk at all is another. Men who were unable to serve on the battlefield must also be considered.

This brings me to my second point, that the military community was broad enough to include even extreme physical variation. Active fighting was only part of the military. We can see an example of a person with a physical disability serving in the role of advisor in a man named Artemon, who designed siege-engines, and who was nick-named "Periphoretus," which translates to "Carried-Around." He was known by this name because he could not walk and had to be carried to all of his projects. He accompanied the fifth-century Athenian general and political leader, Pericles, on all his military campaigns (Plutarch, 1st century C.E./1967-1982). Artemon was not considered less than a man because he was not on the front lines; he was certainly not *adunatos*; in fact, he was a man of ability and high prestige.

Garrison duty by men who were unable to participate in active fighting (e.g., Thucydides, 5th century B.C.E./1991) was also a part of the range of military duties. So many men of military age were physically incapable of active fighting in the field that there may have been an official class of men in Athens designated to guard the city's walls (Baldwin, 1967). Weapon-craft was also an obvious need. It is interesting to note that the archetype of craftsmen, the god Hephaestus, who forged the Greek weaponry for the Trojan war, had the epithet "lame" (e.g., Homer, ca. 8th century B.C.E./1924-1925). Other military crafts were also essential, such as composing the poetry of war, necessary on the march. The Spartan military poet Tyrtaeus was believed to be "lame," and the greatest war poet ever, Homer, was, by tradition, blind (e.g., Homeric Hymn to Apollo, ca. 7th/6th centuries B.C.E./1914).

This concept of inclusiveness in the military community should not suggest that the Greeks did not notice physical disability, or that they were not afraid of it. On the contrary, the father of history, Herodotus (5th century B.C.E./1990), puts "freedom from deformity" at the top of his list of criteria for happiness. I was unable to make sense

of this apparent contradiction--an inclusion of men with physical disabilities in the military community on the one hand, and a fear of disability on the other--until I saw what underlay the ancient Greek concept of ability and disability, which brings me to my third point: the continuum of ability.

Modern rationality aside, the Greeks believed that even the most remarkable physical characteristics were reversible. Not only were able-bodied people only temporarily-able, but the continuum went the other way as well: people with physical disabilities were potentially able-bodied. The prospect of "deformity," as Herodotus points out, was always near. A man who had no disability during his entire life was considered exceptionally lucky. This was a world in which a simple broken ankle resulted in a permanent impairment of mobility, one in which a cut could easily result in gangrene and subsequent amputation. Every bacterial disease, not hampered by vaccination or antibiotics, took its full toll. In other words, there were many more people with physical disabilities in the ancient world than there are today. Able-bodied people were temporarily-able in a sense that could never be applied to the modern cliché (Gill, 1994).

This continuum of ability reached both ways. The Greeks went to the healing shrines of the god Asclepius to recover from a variety of what they considered ills, including ills that modern, western medicine considers permanent and irreversible (e.g., Edelstein & Edelstein, 1945).

I should emphasize that ancient Greece was no utopia for people with--or without --disabilities. Babies whose physical disabilities could be detected were probably exposed--abandoned to die--at birth (Garland, 1992); deaf people were considered "dumb" in every sense of the word (e.g., Herodotus, 5th century B.C.E./1990), and I detect in the ubiquitous Greek blind prophets the origins of the modern conviction that blind people are naturally compensated with extraordinary gifts (Bernidaki-Aldous, 1990).

I offer two conclusions in closing: first, the legacy of the Classical Greek military community regarding physical disability is not the intolerance I hypothesized. Ideals, by their very nature, do not directly represent the realities of any culture. The legacy of the Classical Greek military community is an acknowledgment of human physical variety and ability. Physical variation did not, in itself, automatically exclude men from the military. Second, and finally, the historical study of physical disability in any period, ancient or modern, emphasizes ability/disability as a cultural construction.

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Stigmatization of People-Who-Stutter: Some Reflections

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In 1991, I undertook doctoral research on the extent to which and the ways in which people who have a chronic stutter advocate for better regard from non-stuttering people and for equal rights and participation in American life. I examined the degree to which people-who-stutter perceive and act upon stuttering as a sociopolitical issue, following in the path of people with other disabilities who have formed the disability rights movement. I have chosen to share with you here some ideas from my dissertation, specifically, current ideas on the stigmatization of people-who-stutter.

Stigmatization and prejudice are widespread. Various studies have shown that, when compared to people who do not stutter, people-who-stutter are seen as having a variety of negative traits and characteristics, even though the actual comprehension of their message content does not seem to be affected (Duffy, Hunt, & Giolas, 1975). The adjectives ascribed to people-who-stutter have generally included anxious and tense, shy and socially withdrawn, lacking in self-confidence, or variations of these (Fowlie & Cooper, 1978; Ham, 1990; Lay & Burron, 1968; White & Collins, 1984; Woods, 1978; Woods & Williams, 1976).

However, findings have been sketchy, at best, of any real cognitive or personality differences between people-who-stutter and those who do not (Van Riper, 1982). Even though some studies have found people-who-stutter to be somewhat lacking in social skills or adjustment and also in self-confidence (Bloodstein, 1987; Woods, 1978), these studies have been neither conclusive nor of the magnitude to justify the stereotype (Bloch & Goodstein, 1971; Woods, 1978; Woods & Williams, 1976). Indeed, research on people-who-stutter has shown them to be more like everyone else in personality and emotional health than they are different. Moreover, it is in those situations in which stuttering is likely to, or is perceived to be likely to, interfere with personal interaction that people-who-stutter have been measured to have feelings of distress. Such findings are hardly a comprehensive measurement of total personality. As Bloodstein (1993) says, "some studies in effect penalized stutterers [sic] for stuttering" (p. 23). What, in fact, is being examined is how anyone might feel in situations where he or she anticipates and fears being judged wanting in character and misunderstood in verbal communication.

The stereotype of the person who stutters as lacking in social adjustment and self-confidence in comparison to the person who does not stutter has evoked some discussion in the speech and language literature. Woods and Williams (1976) believe that listeners perceive the feelings, such as anxiety, of the person who stutters at the

moment of stuttering to be those which he or she has all the time. Thus, "state anxiety" in a given situation, originating from the stress of stuttering, is seen despite a lack of supporting evidence to spread as "trait anxiety" throughout the personality of the person who stutters. That these stereotypes may be perpetuated despite contact with people-who-stutter suggests what White and Collins (1984) call the model of confirmatory testing. Here, listeners take into account the behavior of the person who stutters that supports the stereotype, but they disregard behavior that does not. To explain how the stereotype is maintained by people who have had little or no contact with people-who-stutter, White and Collins propose that the listener imagines that how he or she feels when stuttering is how the person who chronically stutters feels, not just at the moment of stuttering, but all the time (Ham, 1990).

These theories, especially the last one, are supported by the fact that many people view chronic stuttering as a pathological extension of what everyone does at least sometimes. It is not surprising, then, that Ham (1990) found from telephone interviews with 563 people that 21% of all respondents claimed to have stuttered at one time. Furthermore, 40% of their definitions given for stuttering were not at all rigorous; respondents gave circular descriptions such as "Stuttering? . . . that's when people have a stutter in their speech" (Ham, p. 263). Not being able to differentiate chronic stuttering from what they themselves might do in certain situations, these same subjects provided somewhat more responses recommending uninformed remedies for stuttering (271 responses), such as to calm down or slow down, than they did recommendations to seek outside help (240 responses) (Ham, p. 269). Their answers did not reflect an understanding that stuttering is an authentic disability for a large minority of the population, but instead reflected their belief that stuttering is a trait of isolated individuals which is easy to explain.

The standard stereotype of the person who stutters as inferior in social adjustment and self-esteem has also been revealed in studies that compare attitudes toward people with communication impairments and, specifically, people-who-stutter, with attitudes toward people with other disabilities. However, these studies have also revealed more extreme stereotypes as well.

In one study, by Schmelkin (1985), people whose disabilities were perceived to be less physical were found to be regarded as more intellectually impaired, less educable, and less competent than people whose disabilities were considered more physical. Stuttering, and speech and communication disorders generally, were perceived to be only as physical in nature as the broad categories of mental retardation, mental illness, and schizophrenia. They were regarded as much less physical than blindness, deafness, and the general category of "crippled/orthopedic handicap." By inference, people-who-stutter were being considered more intellectually impaired, less educable, and less competent--all three harsh judgements of mental functioning--than people who are blind or deaf, or those who have mobility impairments.

Dooley and Gliner (1989) also found communication disabilities to be regarded as somewhat akin to cognitive and emotional disorders and as not being particularly physical in nature. Concerning stuttering, specifically, people with generally negative attitudes toward persons with disabilities equated stuttering not only with dyslexia, but also with the more negatively perceived and potentially serious conditions of epilepsy, Down Syndrome, and schizophrenia.

In particularly revealing research, Ford (1977) compared people with speech impairments to three other groups of people: those without speech impairments, those having mobility impairments, and those who are blind. Similar to studies comparing people-who-stutter with those who do not, Ford's findings showed that people with speech impairments, compared to people without speech impairments, were perceived to be inferior in social adjustment and self-confidence, having traits such as shyness, nervousness, and insecurity. People with speech impairments were also considered lacking in social adjustment and self-confidence in comparison to people who have mobility impairments and people who are blind. However, similar to the already described studies by Schmelkin (1985) and Dooley and Gliner (1989), Ford also found that, when compared with people who are blind, people with speech impairments were regarded as having mental conditions that are more serious. These more serious mental conditions included having mental retardation, an emotional disorder, or a mental impairment.

The finding by Ford (1977) that people with speech impairments were seen not only as less socially adjusted than people who are blind, but also as more seriously mentally impaired may be due to the opposing connections with the mind and brain that have been suggested for each of these disabilities. Blindness is sometimes credited with the granting of or association with extraordinary mental abilities, e.g., "the sixth sense," while evidence has been presented in the discussion here that stuttering is sometimes perceived to be linked with inferior mental abilities and capabilities. Indeed, in assessing the strong negative perceptions concerning both social adjustment and serious mental conditions toward people with speech impairments that Ford uncovered in her research, Ford states that "handicaps associated with the head and brain may be held more negatively than other disorders" (p. 21). Ford, in effect, is suggesting that people with the most severe mental disabilities and, by association, people-who-stutter are more stigmatized than people having other disabilities.

Indeed, it is the head and brain very plausibly, and the extrapolated construct known as the mind most certainly, which are seen to define us as distinctly human. The importance, therefore, of communication and of language, specifically, cannot be underestimated. These are among the highest functions of the brain and products of the mind. Church (quoted in Sacks, 1990) writes:

Language is not just one function among many . . . but an all-pervasive characteristic of the individual such that he becomes a *verbal organism* (all of whose experiences and actions and conceptions are now altered in accordance with a verbalized or symbolic experience). (p. 44)

According to Hughlings-Jackson (quoted in Sacks, 1990), language affords humans the ability to "propositionize" or to connect a string of names of things together, which enables us to think internally about ourselves and the world around us and, in turn, to communicate externally with others. "We speak not only to tell other people what we think, but to tell ourselves what we think. Speech is a part of thought" (pp. 18-19).

That language is so crucial an instrument for the species may explain, in a most profound manner, the stigmatizing perception that people-who-stutter are suffering not only from social maladjustment, but also from extreme mental impairment. People-who-stutter, especially those who stutter severely, may be perceived as slow, or even unable, to think to themselves and to convey those thoughts to others. Thus, to the listener, their very humanness may stand threatened.

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The "Differently Able" as Symbols and Agents of Revolutionary Change in Latin American Fiction

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In two Latin American novels, The Obscene Bird of the Night by Chilean author José Donoso and in Love in the Time of Cholera by Gabriel García Márquez, the "differently able" characters serve as agents of revolutionary change in that they propose an alternative society. Possessing bodies that differ from the norm, they defy the values of order and class structure revered by the feudal Chilean society, and they oppose the rigid class and racial divisions of XIX century Colombian society. These "different" beings serve as key figures in both novels, and their bodies are metaphors and symbols of change. A study of the function played by these characters in both novels enables one to see how the body of the differently able character confronts the discourse and the ordered body of the hierarchical and class conscious society, while at the same time proposes an alternative society.

The metaphor of the body with a disability as one of change appears in the first page of the novel The Obscene Bird of the Night when the author makes an allusion to the "different" body of one of the characters, "Amalia, that little cross-eyed woman who more or less served her" (Donoso, 1988, p. 11). This woman, whose body differs from the norm, is the servant of the lady of the house, Misiá Raquel Ruiz. Amalia not only possesses a different body--a difference which is marked on her face--but she also subverts the class order. The servant is the one who ends up owning the wealth once possessed by the ruling class, and lending money to the lady of the house.

In The Obscene Bird of the Night, those who belong to the Chilean oligarchy, Jerónimo de Acoitía, Inés de Santillana, and don Clemente, Jerónimo's uncle, live and recreate with their discourse a traditional, stable, and ordered world. The aesthetic created by the Chilean oligarchy is Fascist. In her article "Aesthetics and Anesthetics: Walter Benjamin's Artwork Essay Reconsidered," Susan Buck-Morss (1992) points out certain characteristics of the Fascist aesthetic, one of these being the fear of fragmentation and a desire for order. Buck-Morss refers to Jacques Lacan's theory of the mirror-stage. In his Ecrits, Lacan (1977) evokes the image of the child of sixteen to eighteen months who looks at himself in the mirror and tries to integrate his self. However, the image he perceives is an "imago"--a fiction. Like the child, the Fascist ideology aspires to make real an intact ego that can only manifest itself as a fiction.

The members of Chilean society constantly attempt to recreate this fiction of the intact ego so that they are able to create an ordered society composed of "perfect" bodies. They recreate this society, always fearing fragmentation, symbolized in the bodies of

the differently able. In order to insure the propagation of these perfect bodies, the oligarchy praises the union of perfect beings. When describing the marriage of Inés de Santillana and Jerónimo, the union of perfect bodies is celebrated together with the inherited wealth:

Inés de Santillana, heiress, as she was of land and titles, was owner above all of an agile beauty, unsteady as a bird, of an attuned coloring as if cleaned by honey. At her side Jerónimo seemed a giant (Donoso, 1988, p. 177).

The body of Inés is perfect, her race is pure, unlike that of the "criollos," sons of the Spanish colonists, those "adolescents of imperfect skin, wearing tight-fitting cloth who surrounded her to implore the favor of a dance, and she, smiling, chose, accepted, postponed" (Donoso, 1988, p. 177). Jerónimo is the only ideal consort because "no clumsy youngster could compete with a well made and upright man, rich and beautiful dressed still with the prestige of the superior continent from which he came" (p. 178).

Jerónimo, after an initial rebellion, is sucked into his family and assumes a central position in society. Fearing fragmentation and the libido, Jerónimo transforms his body into an armor, creating a barrier that separates him from the rest. This narcissistic identification with himself is analogous to the creation of the fictive ego as described by Lacan (1977) in his writings on the mirror stage. Once this fictive ego is created, Jerónimo feels invulnerable. However, this fiction is vulnerable, and Jerónimo's son, Boy, makes his father see himself as he really is. Once this recognition takes place, Jerónimo dies.

This self recognition takes place at the pond of the Goddess Diana, the huntress. However, in this novel the statue of Diana is that of a differently formed Goddess that defies classical proportions. In Greek mythology Diana is the Goddess of the moon and, as a woman, she represents the "other," who opposes the masculine power. According to Greek mythology, Acteon, symbol of masculine power, is guided by destiny to the lake where Diana lies. Seeing him, the Goddess is enraged and transforms him into a stag. Acteon escapes to the forest where he sees his reflection in the lake and breaks down crying. Like Acteon, Jerónimo breaks down by the lake, victim of his other, the differently able, and the power of women. His classical features become distorted. The aesthetic of the classical, perfect body is defeated. Jerónimo says:

I look down to see what I know I will see, my own classical features, my white hair, my clear features, my blue eyes, my cleft-chin, but someone throws a stone insidiously at the water mirror, fragments my image, decomposes my face, the pain is unbearable, I cry, I howl, I hurt, my factions destroyed (Donoso, 1988, p. 504).

Jerónimo attempts to pull off his face thinking that it is a mask, but fails. Jerónimo's discourse breaks down, and he dies. His son and the differently able characters who surround him assume the responsibility of initiating the funeral. These differently able characters manage to destroy the dominant power and invert the rules that segregate individuals with different bodies or those who belong to a different race or class.

The difference between Donoso's (1988) novel and Love in the Time of Cholera is that García Márquez (1987) celebrates love. The differently able character at the beginning of the novel, Jeremiah de Saint Amour, is a symbol of change whose courage will be emulated by the two main protagonists at the end of the novel. Possessing a different body, Jeremiah defies the racial and sexual mores of society.

The novel Love in the Time of Cholera (Marquez, 1987) opens with a scene in which Dr. Urbino smells the perfume of almonds emitted by the poison cyanide, and then discovers the body of his friend Jeremiah de Saint-Amour. In the first paragraph, the author describes the tragedy and reflects on the power of memory, "The Antillian refugee, Jeremiah de Saint-Amour, a war invalid, photographer of kids and his adversary in chess games, had saved himself from the torments of memory with an aromatic perfume of golden cyanide" (p. 11). But Urbino, the husband of Fermina Daza, not only discovers the body of his friend, but also finds out that Jeremiah had violated one of the taboos of his society by having a long-lasting relationship with a "mulata," a Black woman. When Dr. Urbino discovers this relationship, he says with shock and surprise that he believed that "the incapacity of Jeremiah de Saint-Amour was not only for walking" (p. 25).

The importance of this tragedy is that it invokes the power of memory and serves as a prelude to the novel. Saint Jeremiah's death, like his name, is prophetic. In the scriptures the prophet Jeremiah suffered persecutions due to his threatening prophecies. Jeremiah, close to God, warned his people in vain that something terrible was going to happen. Ignored and considered a coward, Jeremiah is the only character who has sufficient stamina to endure the tragedy. Like this prophet, Jeremiah of Saint Love--as his name indicates--prophesizes the power of love to defy the prejudices of society.

Jeremiah was Dr. Urbino's friend and partner in chess. When Dr. Urbino discovers the body of Saint Jeremiah, he sees on the table the chess board and realizes that the game was never finished. However, this game of live and love will be brought to an end by Dr. Urbino's wife, Fermina Daza, and her long rejected lover in the last chapter of the novel.

In the first chapter, Dr. Urbino reflects on his past and, haunted during the whole day by Saint Jeremiah's death, dies trying to catch a parrot. At Dr. Urbino's funeral, his wife meets her long rejected love, Florentino Ariza, and the chapter ends with Dr.

Urbino's wife thinking of her lover: "Only then she realized that she had slept a lot without dying, crying in dreams, and that while she slept crying she thought more about Florentino Ariza than the dead husband" (Márquez, 1987, p. 74). The novel then goes back into the past and describes the love mishaps of both lovers, Fermina Daza, Dr. Urbino's wife, and Florentino Ariza.

The important theme in the novel Love in the Time of Cholera is the courage of the differently able character who defines the social taboos and mores about sex and race by having a long lasting relationship with a Black woman. Also, his actions are prophetic in that they predict the love between Fermina Daza and Florentino Ariza, who, at seventy odd years, defy the mores of society and celebrate their love in a quarantined boat in the middle of the ocean. Asked how long the boat can continue this route coming and going without touching the shore, Florentino Ariza answers, "All life long" (Márquez, 1987, p. 451).

The sea also plays an important role in the novel The Obscene Bird of the Night (Donoso, 1988). In this novel the sea is the substance that heals and carries the remains of a destructive society back to life. At the end of the novel, an old woman, a servant, with a body that differs from the body of the patriarch, throws the remains of the Chilean oligarchy into the sea, where the water initiates the rite of purification.

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Section II

Family Reactions to Disability

Two of the chapters in these proceedings deal explicitly with family reactions to disability. The first paper, by Tony Sommo, examines the childhood and adolescent socialization of people who are blind. In "Primary and Secondary Responses of the Family to Blindness: Dissocializing Barriers to Development," Sommo challenges the idea promulgated by sociological functionalism that families exist as an integrated social system, a kind of mini-society that functions smoothly through socialization to reproduce social norms. More than half of the interviewees whom Sommo studied experienced family life as conflictual, with the family unsure of guidelines for socializing for adulthood family members who were blind.

In the second part of this section, Marion Cohen shares through poetry her perspective as a partner of a person with a disability. Though families may not function as homeostatic institutions, family members are interdependent. Cohen's experiences remind us of such interdependence and of families' needs for respite, validation of each member's experiences, and the welcome (even if transient and technology-dependent) connection of one human being to another.

Primary and Secondary Responses of the Family to Blindness: Dissocializing Barriers to Development

**Tony Sommo, Ph.D.
Rowan College of New Jersey**

This study examines primary (childhood) and secondary (adolescence and early adulthood) socialization responses of family members to blindness. It is based on focused, nonscheduled interviews with fifty HUD-subsidized legally-blind persons living in an apartment building set aside for persons with disabilities in New York City.

In general, interviewees described family members as passive, negative reactors to blindness, which is perceived as a rare and traumatic event. Unable to draw upon a ready-made set of positive existential scripts (who the child is) and anticipatory scripts (who the child will be), families lacked structural prescriptions for the socialization of the blind child. Limited to devaluing imagery, families also lacked cultural recipes (including the law, technology, and how-to-do-it information), especially from the popularized media.

This study challenges the functionalist notion of the family as an integrated system. In recounting their early experiences, interviewees used I-versus-they, winner-loser terminology. They perceived family life as an arena for the expression of conflict with others over scarce resources including love, money, and power.

Excluding five interviewees who became blind as adults, the data generated a typology, or composite, of six negative affective family reactions (blame, abuse, rejection, denial, overprotection, and embarrassment) experienced by 62% of the sample (28/45) during the formative years of socialization. Twenty-two percent of the sample (10/45) described their early socializing experiences in the family as good to excellent; nine percent (4/45) labelled their family experiences as a mixed bag; and seven percent (3/45) described their childhood as overprotective, but defined the experience in positive terms, stressing safety-minded, caring parents and siblings who looked after them "for their own good." (See Table 1.)

Table 1
Positive and Negative Family Reactions to Blindness

<u>Reaction</u>	<u>Number</u>	<u>Percent</u>
Positive Reactions	10	22
Overprotective but positive	3	7
Both positive and negative reactions	4	9
Negative reactions	<u>28</u>	<u>62</u>
Total	45	100

Working within the constellation of the six negative emotional reactions to blindness, the data generated two salient responses of the family to the adolescent or young adult who is blind. First, unable to redefine the past, the family engaged in the reinforcement or continuance of earlier negative affective reactions (14/28). However, in 78% of these cases (11/14), blind interviewees "broke out" from earlier negative patterns by finding their own apartment, or going to college, and staking out claims of independence. This rebellion against families, locked into the past, led to pseudo-gesellschaft relations, such as pretend civility during the occasional phone conversation, in which family bonds based on infrequent contact were weakened, and the emotional career of previous, significant family encounters was put on the back burner. The remaining 50% of the negative cases (14/28) engaged in "getting a perspective" by confronting earlier negative experiences from a new, positive definition of the situation, leading to acceptance and the forgiveness of past wrongs.

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One Person, One Family

Marion Cohen, Ph.D.
Temple University

The following poems were presented as a reading and poster exhibit. They are about my life and my family's life in the presence of chronic illness and disability. My husband Jeff's multiple sclerosis was diagnosed in 1977; at the time we had two children; we have since had two more. My husband's condition is now quite advanced; e.g., he has movement only above the neck. In recent years I would, in prose, describe our situation, not in terms of "stress," but in terms of "dire straits."

Among the "direst" of our "straits" has been attendants, or lack thereof. The following three poems are about that:

The Attendant Signs Out

The attendant signs out
and we all get that lump.
And Jeff says 'bye four times
and starts staring at the door.
And then he asks one of us for his toothbrush.
And then he asks another of us for his papers.
And then he slumps forward in his chair.
Soon he'll start looking all around
and we'll wonder where his look is gonna land.
(We'll pray not the bathroom.)
It's like we're on a desert island
and the rescuers have already come
and left, somehow, without rescuing us.
"Please," we should beg, "please don't leave us."
But of course, if we did
he still would
each time he would
as all company eventually must
as all company
eventually does.

Lovers' Quarrel

The attendant doesn't take sides.
Pert, expert, not a side does she nibble.
But she is, right now, closer to him than to me.
In fact, she's touching him--well, shaving him.
Anyone looking on sure would say it looks like two against one.
(With the wheelchair it might even look like three against one.)
Oh no she's not taking sides; she never takes sides
but right now she's sure on the same side as he
of the bathroom doorway.

The Cat

The cat
is compassionate.
She does not mind bedpans.
She does not mind respirators.
She does not mind temper tantrums.

The cat
is comforting.
She does not mind
us.

The cat
is there.
"Hey! There's the cat."
"Lookit the cat." "Just lookit that cat."

The cat
is not an attendant.
The cat
is not a savior.
The cat cannot save us
except at times.

When I think about the negative aspects of our situation, the two words that stand out are "anger" and "desperation." What follows are two of my many poems written to express that.

My Disability

If he can have chronic progressive M.S.,
 I can have chronic progressive temper-tantrums.
If he can have incurable M.S.,
 I can have incurable temper-tantrums.

At least I can eat cooked food.
At least I can wear long sleeves.
At least I can go outside in the summer.
At least I can last the night.

At least I have remissions.
Or maybe I don't.
At least I don't need attendants.
Or maybe I do.

The Misfortune Cookie

Help! I'm being held prisoner at 2203 Spruce Street.
Help! I'm being beaten by a jar
raped by a bedpan.
Help! I'm a love slave.
Help! I'm a hate slave.
It's 3:00 A.M. and I'm chained to the bed
and from the typewriter.
I mean it, help!
If you're reading this (and you are), you actually can help.

One person, one family
 cannot do this alone.

Remember my address
(Philadelphia, Pa.
19103)
and help.
Seriously, help.

The next poem is about wrestling with what well-spouses (i.e., the spouses or life-partners of people who have chronic illnesses and/or disabilities) call "invisibility"-- i.e., the world's tendency not to notice us, what we do and how we feel.

Writing as a Disability

If he can have chronic progressive incurable M.S., I can
have chronic progressive incurable books.

Every time he needs another jar, I need another book.
Every time he needs a bedpan I need two new books.
And when he needs scratched
the top-left part of the inside of his right nostril
or something is caught between the two gold teeth bottom-
left-back
or when the home health aide doesn't show

I need excacerbating books.
And when he calls "Mar"
I need a book-signing.
"Dr. Marion Deutsche Cohen," I sign
or just-plain "Marion"
or maybe "Mar" in quotes.

In other words, it's not the books I need but the author.
Or the name of the author.
My chronic, progressive, incurable
excacerbating name.

I close with two poems about nights--one negative, the other positive.

June 1993

So tired am I that I dream in gray. Alleys, mist, the
Davis' driveway minus the pink stone.
So tired am I that even pastels sting my eyes, even white
burns my head, so tired I turn living-color to dead-color.
And so tired, not only must there be one of everything,
there must be half of everything.
Half a word, half a note, half a love, half a God. Half an
L-shaped room, one-quarter an X-shaped room, so tired I
face the corner
and don't dare turn around.

Night Respirator ("for Home Use")

Every night when we turn it on it at first doesn't want to, all four of its lights let out
a wail, a long wail, and it won't be placated, not that fast, we pet it but it starts
up again, and yet again

and then when it gives up its red shriek it tries gagging, grumbling, or it pulls a put-
upon, it pouts, it trudges, it makes quite obvious that particular dry rhythm

and so our dropping off is full of this three-way hard-to-place sound--not metal, not
wood, not paper, not rubber

and not clogged, not squeezed, not rustling, not even undulating.

But it is, in the end, a breathing, the breathing of one of us, or maybe the breathing
of a mother or a grandmother, yes maybe a womb or at least a train ride

and so the sleep it finally allows us is the best ever, the deepest, the most natural.
And so we are buoyed, wafted, sustained, we haven't slept like this since we
were children. Yes, it gives us the sleep we are supposed to have

whether it wants to or not.

Acknowledgments

"The Attendant Signs Out," "Lovers' Quarrel," "The Cat," "My Disability," and "The Misfortune Cookie" are from Cohen, M. (1995). Epsilon Country. New York, NY: Center for Thanatology Research.

"Writing as a Disability" is from Cohen, M. (1994). Extreme Points. New York, NY: Center for Thanatology Research.

The above books are available from the Center for Thanatology Research, 391 Atlantic Avenue, Brooklyn, NY 11217 (718/858-3026).

Of related interest are four other books by Marion Cohen:

Cohen, M.D. (1988). The level of doorknobs: Suggestions for parents with disabilities. Omaha, NE: Centering Corporation. (Available from the Centering Corporation, 1531 No. Saddle Creek Road, Omaha, NE 68104-5064; 402/553-1200.)

Cohen, M.D. (1989). The sitting-down hug. Las Colinas, TX: The Liberal Press. (Available from The Liberal Press, Box 160361, Las Colinas, TX 75016; 214/686-5332.)

Cohen, M.D. (in press). Dear Aunt X: How to ask for help in time of crisis. New York, NY: Center for Thanatology Research. (Available from the Center for Thanatology Research, 391 Atlantic Avenue, Brooklyn, NY 11217; 718/858-3026.)

Cohen, M.D. (1996). Dirty details: The days and nights of a well spouse. Philadelphia, PA: Temple University Press. (Available from Temple University Press, Broad and Oxford Streets, Philadelphia, PA 19122; 215/204-8787.)

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Section III

Cultural Differences in Response to Disability

One criticism of disability-related studies is that they too often reflect only white, Western experiences of and assumptions about disability. In this section, five authors address the importance of developing research that addresses multicultural experiences of disability.

For example, it is important that researchers devise and use scales, interview guides, etc., that are appropriate for the populations they are studying. One example of this is the revising of the Modified Issues in Disability Scale (the MIDS), described in Elaine Makas' "Respecting Cultural Differences in Disability Research: Developing Appropriate Measures of Attitudes toward People with Disabilities." From the beginning, Makas has designed the MIDS with the understanding that "the only people who are entitled to set the standards against which attitudes toward them are judged are the people who are the targets of these attitudes" (p. 57). In this chapter Makas describes how she has redesigned the MIDS to produce an African-American/Caribbean Black version, and how she is working on another version that will reflect the attitudes of American Indians and Alaska Natives.

In "Not Just a White Person's Disease': The Experience of African-Americans with Multiple Sclerosis," Christine A. Loveland draws on 100 interviews with people who have MS (24% African-Americans). In particular, she describes how a common misconception that MS is "just a white person's disease" could affect diagnosis and response to the diagnosis. Different conceptions of "cause," and interactions between ethnicity and class also influenced experiences of MS. An adequate understanding of cross-cultural differences would benefit those who have MS, as well as family members and health care providers.

The importance of trying to understand relationships between ethnicity and class is underscored in Marsha Lichtenstein's chapter, "The Relationship of Interest in Independent Living to Ethnicity, Demographic Characteristics, and Disability-Related Variables." From a survey of nursing home residents aged 55 or younger, Lichtenstein found that age was the strongest predictor of whether residents would rather live in the community than in a nursing home. Differences based on ethnicity were insignificant. However, she recommends that further research designed to examine social class/ethnicity interrelationships should be undertaken.

Diane Weiner's research on Luiseño underscores the importance of understanding disability and illness in a social context. In this paper Weiner reports on one aspect of a wider study of Luiseño Indian chronic illness behaviors, specifically reactions to

Type II non-insulin dependent diabetes mellitus. Without an understanding of Luiseño cultural history and worldview, responses to diabetes too often may be perceived by health providers as noncompliance. Rather, as Weiner notes, chronic illness behaviors should be understood as "assertions of the perceived validity of both Luiseño and biomedical health beliefs and practices. Each is pursued in accordance with social situations and constructs" (p. 78).

Joanne Y. Yamada addresses stereotypes of Asian Americans as they relate to images of and experiences of people with disabilities. Her chapter, "The Disabled Asian American Identity," provides five case histories of people who had had polio (four women and one man). Yamada describes how stereotypes based on ethnicity and disability interact to encourage the treatment of others as "types." Like Hertz, in Section I, Yamada asks crucial questions about what it means to treat others as fully human and to be accepted by others as fully human.

Respecting Cultural Differences in Disability Research: Developing Appropriate Measures of Attitudes toward People with Disabilities

Elaine Makas, Ph.D.

Lewiston-Auburn College of the University of Southern Maine

As many of you know, I developed a measure of attitudes toward people with disabilities in 1985, an assessment tool known as the Modified Issues in Disability Scale (the MIDS) (Makas, 1985, 1991). Two years ago, I updated the scale and named this version the Revised MIDS (the MIDS-R) (Makas, 1993, 1994a). At approximately the same time, I produced a third attitudinal measure, the African-American/Caribbean Black Version of the MIDS (the MIDS-AA/CB) to be used in areas with large concentrations of people with African and/or Caribbean heritage (Makas, 1994b, 1994c). I am now in the process of developing, under the auspices of the American Indian Rehabilitation Research and Training Center at Northern Arizona University, yet another version, the American Indian/Alaska Native MIDS (the MIDS-AI/AN) to be used in areas where these cultures predominate.

Despite considerable differences among these four attitudinal measures and my own very strong convictions that the appropriate assessment tool must be carefully selected for each subject population, I tend to refer to all four of these variations simply as "the MIDS." The reason for my sometimes and somewhat careless terminology is that I, myself, see "the MIDS" as a concept, rather than a particular cluster of attitudinal items, a cluster that changes over time, and one that changes depending on the culture to which it belongs.

The concept--MIDS--is simple. I sincerely believe that the only people who are entitled to set the standards against which attitudes toward them are judged are the people who are the targets of these attitudes. As a result, the experts that I recruited to help in the development of each version of the scale were individuals with disabilities from the particular demographic group for whom the measure was being constructed. For example, the people asked to set the standards (or the "judges," as I call them) for the original MIDS (n=92) and for the (revised) MIDS-R (n=44) are people with disabilities who approximated the racial/ethnic population of the U.S. in 1984 and in 1992, respectively. The fact that the standards set by these two groups of judges were quite different, despite the groups' similarity in terms of ethnic representation, age, sex, types of disability, etc., suggests that time, itself, plays a role in the validity of attitudinal measures (Makas, 1994a).

The importance of cultural background is evidenced by the differences between the standards set by the African-American/Caribbean Black judges (n=42) for the MIDS-

AA/CB in 1991 and 1992 and those set by the "general population" judges who participated in the development of the MIDS-R (Makas, 1994c) in 1992 and 1993. Initial responses from my currently-expanding group of American Indian/Alaska Native judges who are assisting in the selection of items for the MIDS-AI/AN seem to be re-emphasizing the need for attentiveness to cultural values.

I want to reiterate that the judges involved in the development of both the original MIDS and the Revised MIDS included individuals from racial/ethnic minority groups; however, African-Americans/Caribbean Blacks, Mexican-Americans/Hispanics, Asian-Americans/Pacific Islanders, and American Indians/Alaska Natives participated as judges only to the extent that they represented the ethnic composition of the general population of the U.S. at that time. In other words, they remained "minorities" among the judges, making it very likely, therefore, that any culturally-specific experiences and values expressed by them were overwhelmed by those of the "majority culture." In a sense this is fair, since "minority" views often are overwhelmed by the cultures which we refer to collectively as the "majority culture"--but this is fair only when we are dealing with the measurement of attitudes within the general population.

On the other hand, when we are measuring attitudes within a community in which a so-called "minority culture" is, in fact, the majority culture, then, we need a scale based on standards set by people with disabilities representing this particular "minority" culture. That is the reason for the American Indian/Alaska Native Version of the MIDS which I am currently developing, and that is what led to the African-American/Caribbean Black Version of the MIDS. In both instances, a scale was needed for the assessment of attitudes within settings in which the percentage of people from these respective ethnic groups was very high.

For the MIDS-AA/CB, I asked African-Americans and Caribbean Blacks with disabilities to be my judges, my standard setters. And, when making comparisons between responses to the MIDS-AA/CB and responses to the (general population) MIDS-R, I asked African-Americans and Caribbean Blacks to help me to interpret the similarities and differences. I needed their help in interpretation as much as I needed their help in setting the standards. The reason is that I am not African-American or Caribbean Black, and I would have run the very real risk of distorting the points of view evidenced by these groups by analyzing their values and experiences on the basis of my own "majority culture" standards. It is not enough to simply review the literature--most of which has been written by Whites anyway. I needed African-American/Caribbean Black "interpreters" to tell me what they and the other judges meant by their responses. Had I not done so, it is likely that I would have diminished or devalued the significance of their responses, simply because some of their cultural values and experiences differed from my own.

I will give a concrete example. There are very few statements in my pool of potential items which have a factually correct answer. However, there were two of these items--

one dealing with blindness, and one dealing with diabetes--on which the "general population" judges and the African-American/Caribbean Black judges differed greatly. I found that the majority of judges in both groups indicated that the "right" answer was correct. However, the African-American and Caribbean Black judges were more accurate than the "general population" judges on the question related to blindness. I will add that the responses of a group of African-American students to this item were also more accurate than those of their non-African-American/Caribbean Black peers to the same item (Makas, 1994c). This made sense to me, since blindness is more prevalent among non-Whites than among Whites. One would expect African-Americans and Caribbean Blacks to know more than those in "general population" groups about blindness.

However, when I looked at the responses of the two groups of judges to a question on diabetes, I found those of the "general population" judges to be more accurate than those of the African-American/Caribbean Black judges. This difference was even more obvious when I compared the responses given by the two groups of students--to the extent that the African-American/Caribbean Black students seemed to know very little about diabetes (Makas, 1994c). This made absolutely no sense to me, since diabetes is even more disproportionately prevalent than blindness among African-Americans and Caribbean Blacks. I racked my brain for quite a while before realizing that I was racking my "majority culture" brain, searching for an explanation for responses given by people who were not part of the "majority culture" to which I, supposedly, belong.

Once I did find a proper source for an interpretation (i.e., someone who had been raised in that particular culture), I was given a very logical explanation. An African-American colleague told me that he was constantly amazed at how much "White folks" talked about hidden medical problems. He said that people were always telling him about their physical ailments, their latest surgeries, their hidden disabilities, and even their psychological problems, all of which represented extremely rude behavior according to the moral standards with which he had been raised. He said that he had been taught that it was very impolite to discuss one's physiological or mental difficulties or to inquire about anyone else's medical/psychological difficulties. People raised as he had been raised, therefore, would have information on disabilities that are visible, such as blindness or wheelchair use, since much of this information can be acquired without discussion, but they would have very little knowledge about hidden disabilities, such as diabetes.

With this new explanation, I re-examined the data which I had gathered, and found that the African-American/Caribbean Black judges and students were less likely than their "general population" counterparts to choose the "don't know/no opinion" response to the item related to blindness, but they were more likely to choose the "don't know/no opinion" response to the item related to diabetes--response tendencies

which are completely consistent with the explanation which my African-American colleague/friend had offered (Makas, 1994c).

So, does this mean that African-Americans and Caribbean Blacks have "bad attitudes" toward diabetes and other hidden disabilities, simply because their culture teaches that it is rude to discuss them? Of course not! What it does mean is that people from these cultural groups may respond differently than "normative" standards to questions designed to assess attitudes within the "majority culture."

Which brings me back, at long last, to my current project, the development of a culturally-appropriate measure of attitudes toward American Indians and Alaska Natives who have disabilities. Since we want an evaluation tool that is valid for use in settings such as the Indian Health Service, we need to ask American Indians and Alaska Natives to participate in all stages of the test construction process. I am currently collecting data from more than 50 American Indians and Alaska Natives with disabilities on the standards by which attitudes toward them are to be judged. This method will allow us to develop one of our project's primary evaluation measures--the American Indian/Alaska Native Version of the Modified Issues in Disabilities Scale. Once the judges have selected the items for the MIDS-AI/AN, I will compare the responses given to these items by American Indian/Alaska Native judges and students with the responses given by "general population" judges and students. And, when I make these comparisons, I shall do so with considerable assistance in interpretation from American Indians and Alaska Natives who have disabilities.

If I had to guess at this point, I would say that the responses and interpretations I will get from the American Indian/Alaska Native groups will be similar in some ways to those which were given to me by the African-American and Caribbean Black participants. This is not to say that these are not uniquely different cultural groups (or, for that matter, that important differences do not exist within cultures). But, if I have learned anything from talking with individuals from "minority cultures," it is that so-called "minorities" do not hold such "minority" opinions after all. Since we, as researchers, always seem to be comparing other ethnic groups, one at a time, to a vastly overwhelming Anglo majority, we may miss seeing that the biggest gap may be the difference between our so-called "majority culture" and a combination of "minority cultures." For example, have you noticed the very consistent finding that "respect for elders" is a "minority" value, but only in comparison with the "majority culture"?

When I began this project, I was gently warned not to be upset if American Indians and Alaska Natives turned down my request for assistance. I was told that they might do so because I, myself, am not an American Indian or Alaska Native. This has not happened, but I think that is because I have told the potential judges at the outset not only that I am not a member of their ethnic group(s), but that I know I am not,

and that is precisely the reason why I need their assistance. One of my nicest experiences of many while doing this project was when one American Indian man interrupted me (a very non-Indian thing to do) after those few introductory words--and said, "Elaine, I trust you. I'll do anything you want me to do."

I wish that I had some concrete results to offer you at this point. I do not, since I do not yet have responses from all of the American Indian/Alaska Native judges, and, therefore, I have no interpretations from American Indians/Alaska Natives either. And, being true to the MIDS (as a concept), I cannot even offer you any guesses as to what my results will be. I am not an American Indian or an Alaska Native, so that is not my decision to make.

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"Not Just a White Person's Disease": The Experience of African-Americans with Multiple Sclerosis

**Christine A. Loveland, Ph.D.
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This paper is based on research conducted in 1992 and 1993 which was funded by the National Multiple Sclerosis Society (NMSS). The author and three undergraduate students interviewed 100 people with MS who lived in Maryland, Pennsylvania, and Virginia; the interviews were conducted either in their homes or at one of the three NMSS-sponsored retreats held in Maryland in 1992. Voluntary participation was solicited through notices in NMSS newsletters and local newspapers, as well as through word-of-mouth. A particular goal of this study was to include African-Americans who have MS.

Interviews were based on a three-page questionnaire which structured responses, but did not rigidly limit them. The interviews ranged in length from 30 minutes to more than two hours, depending on the depth of the responses and, in some cases, on the degree of disability of the participant. Each person was asked at the end of the interview to add personal comments about living with MS. All interviews were tape-recorded and later transcribed.

The grounded theory method was helpful in analysis of the interviews; a number of themes and patterns emerged as the material was examined and coded. (See Glaser & Strauss, 1967; Seidman, 1991; and Strauss & Corbin, 1990.) Both Word Perfect 5.2 and the computer program ETHNOGRAPH (Seidel, Kjolseth, & Seymour, 1988) were helpful in organizing and coding the interviews. (See Walker, 1993, for a comparison of three software packages designed for the analysis of qualitative data.)

Demographic characteristics of the sample

This was a qualitative study which, in many ways, should also be considered an exploratory study, especially given the lack of information on people with MS who are members of minority groups. No attempt was made to randomize the sample, nor does it accurately represent the estimated total population of 250,000 Americans who have multiple sclerosis, 60% of whom are women, and the majority of whom are of Northern European heritage (National Multiple Sclerosis Society, 1992). In our sample, 74% were women, and 26% were men; 76% were white, while 24% were African-American. Among the total U.S. population of people with MS, most spent the first fifteen years of life in the northern regions of this country, and most were diagnosed between the ages of 20 and 40 years (National Multiple Sclerosis Society, 1992). In the present study, people ranged in age from 17 to 80 years of age, with the

earliest age of diagnosis at 15 years, and the latest, 63 years. The average age of diagnosis in our sample was 37 years. Our ratio of white participants to African-American participants was very close to that of the Towson, MD, NMSS office's 1992 caseload, in which one in four clients was African-American.

A processual approach was effective in highlighting the differences in the experiences of men and women, and of whites and African-Americans. Responses to initial symptoms, communication by health care professionals, reactions to the diagnosis, rationalization and adjustment to a chronic condition, and the nature of caregiving by relatives were affected by race and gender.

Diagnosis

There is an extensive literature which confirms that age, gender, race, and social class can influence interactions between physicians and patients. Research has also shown that a patient's cultural background is extremely important in his/her interpretation of symptoms, decision to seek medical advice, and acceptance or rejection of that advice (e.g., Ayanian & Epstein, 1991; Brooks, Smith, & Anderson, 1991; Chavez, Hubbell, McMullin, Martinez & Mishra, 1995; Fischer, 1991; Kenton, 1991; LeVeist, 1992; Marshall & Bennett, 1990; McLaughlin & Zeeburg, 1993; Smart & Smart, 1991). None of the 100 people in the present study had seen an African-American physician; several had consulted female physicians, a fact which they saw as unusual enough to warrant comment. The population of physicians, therefore, was relatively homogeneous, even though the population of patients was not.

Because the initial symptoms of MS can be so bizarre and fleeting, many people do not go to the doctor until they have a second or more severe exacerbation. Some of the people we interviewed, however, waited for many years to either consult a physician or receive a diagnosis from a physician. African-Americans provided the most egregious examples of this.

One African-American woman did not consult a physician until she could no longer walk; she was not diagnosed until age 51. Another African-American woman did not receive a diagnosis of MS until 26 years after her first hospitalization for optic neuritis, even though she had gone to a neurology clinic repeatedly during that time. A third only found out about her MS because her family doctor had died, and his successor mentioned it to her, assuming that she already knew about it. There were at least six other interviews with African-Americans in which similar experiences were reported. Some physicians have difficulty accepting a diagnosis of MS in an African-American patient; and, since many African-Americans do not know anyone with MS, they think of it as a "white person's disease." Family members are usually equally unfamiliar with the disease and may reject the diagnosis.

When they did consult a doctor, about 30% of the African-American women in our sample were told that they had a psychological or emotional problem. This was usually described by the doctor as stress-related, a problem with "nerves," or as indicative of a "nervous breakdown." About 11% of the white women had similar experiences. None of the men in our study had this experience; all were assumed to have a physical, quantifiable condition.

Response to the Diagnosis

Since people are often told at the time of diagnosis that there is no known cause or cure for MS, they are left groping for an explanation or reason for this seemingly random occurrence. There is no answer to the familiar question, "Why me?" However, most people need some kind of answer before they can begin to adjust to the diagnosis and an uncertain future.

The most widely accepted biomedical explanation identifies MS as an autoimmune disease of unknown, but possibly viral, origin. The most widely accepted explanation among the people we interviewed was that stress had caused their MS. Among those in our sample who were female and/or African-American, all believed that stress caused their MS. The people in our sample who cited the biomedical explanation--possibly a virus, most likely an autoimmune disorder--were all white men.

The majority of people did not believe the most widely accepted biomedical explanation for the occurrence of MS, suggesting that they and their physicians are viewing MS with very different explanatory models. This has enormous implications for a patient's understanding and her/his involvement in long-term treatment for a chronic condition.

Rationalization and Adjustment: He Feels Angry; She Feels Guilty

Six distinct patterns of adjustment were identified during the interviews. The first is a long-term continuing state of denial that sometimes lasts for years after diagnosis. The second is resignation, characterized by anger, depression, frustration, and, sometimes, thoughts of suicide or actual suicide attempts. A third pattern is characterized by a shift in the person's reference group, from able-bodied people to people with more problems than the person with MS has. A fourth pattern is found among people who believe that MS has caused positive changes in their lives, often in their value systems. Another response stresses control or dominance over MS, a feeling that the person has won the fight with the disease. The last pattern is one of final acceptance, of an integration of MS into the person's identity.

There was no clear correlation between race and pattern of adjustment, but gender was very important. Men most often mentioned their frustration over the limitations imposed by MS, often in reference to their jobs or former jobs. Women most often

mentioned guilt over their inability to do as much for others, at home or at work. Some African-American women who were married mentioned another source of guilt, noting that it is hard enough for an African-American male in our culture without the added burden of a wife with MS.

Family Composition and Caregiving

Many of the African-American families were female-headed, and they were based on consanguineal rather than conjugal relationships. Only 33% of the African-Americans were living with a domestic partner or spouse when we interviewed them, while 61% of the white participants were. This meant that 80% of the African-Americans relied on a female relative (usually a mother or daughter) rather than on a spouse or a partner for care, while 40% of the white participants relied on a spouse for caregiving, and only 25% relied on a female relative.

Recognition of these basic differences in family composition is vital for informed planning for hospital discharge, formation of support groups, and long-term adjustment. For example, a support group for spouses would not have been useful for most of the African-American women in our study.

Because many African-Americans are not familiar with MS, or do not know anyone with MS, they often perceive it as a "white person's disease." Some physicians seem to share this belief and, as a result, may be less likely to order appropriate tests that could lead to early diagnosis. Once a diagnosis is given, it may be more difficult for the patient and her/his family to accept; it is not easy to integrate a "white disease" into an African-American identity. African-American women face particularly steep hurdles because of stereotypes about both women and African-Americans. MS is not just a white person's disease, and recognition of this fact would help the many thousands of people of color who have multiple sclerosis.

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The Relationship of Interest in Independent Living to Ethnicity, Demographic Characteristics, and Disability-Related Variables

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Literature Review

Two major tenets of the independent living movement are self-direction and full participation in the community (Cole, 1983). By mobilizing appropriate personnel and assistive technology, consumers with severe disabilities can establish and maintain personal relationships and engage in social and cultural activities while residing in the community (Cole, 1983; Crewe & Zola, 1983; Zola, 1983a, 1983b).

Recent studies have found that persons with severe mobility impairments prefer housing which is integrated within the community (Boschen, 1988; Fanning, Judge, Weihe, & Emener, 1991). However, the community participation levels of persons involved in independent living programs did not increase after one year, although their quality of life had improved (Asher, Asher, & Hobbs, 1988; Tate, Maynard, & Forcheimer, 1992).

Finding affordable and reliable attendant care is an overriding concern for people with severe disabilities (Cockerill & Durham, 1992). Although the independent living philosophy encourages individuals who have disabilities to manage their own attendants, many participants in independent living programs prefer to share the responsibility of hiring and training attendants with the agencies (Asher et al., 1988).

The independent living movement attracts few minorities, despite their higher rates of physical and emotional disabilities. Both Hispanics and Native Americans experience cultural and language barriers to receiving adequate health care (Braswell & Wong, 1994; Campbell, 1989; Clark & Kelley, 1992; Smart & Smart, 1992). They underreport disability, and they ignore signs of poor health (Angel, 1984; Hodge, 1989; Marshall, Johnson, Martin, & Saravanabhavan, 1992). Reliance on others is a normative part of life in minority communities; strong family and social interdependency is characteristic (Angel, 1984; Clark & Kelley, 1992; Marshall et al., 1992). Values such as these can reduce the appeal of the independent living movement.

This paper examines the degree of interest among respondents with severe physical disabilities in independent living and in receiving training to facilitate independent living.

Methodology

The goal of the research project was to survey the population of persons 55 years of age and younger who have physical disabilities and who reside in nursing homes in a Southwestern state. There were 193 residents in the nursing homes in November 1992, and, of these, 166 were capable of responding to the survey either independently or with assistance. Of the 160 surveys sent out, 62 were returned, 11 of which were unusable. The final response rate was 32%.

The relationships among race, age, education, and disability-related variables were examined using cross tabulation, correlational analysis, and multiple regression.

Living arrangement preference was collapsed into two categories, desire to remain in the nursing home vs. desire to live outside. It was found that 39.2% of the respondents preferred the nursing home; 60.8% preferred living outside the nursing home, either with their families, in their own apartments, or in a group situation.

Two scales measured interest in skills training for social and community participation and for decision-making and self-direction. The inclusion scale addressed interest in exploring the community, meeting with persons with similar disabilities now living in the community, getting vocational training, and developing interpersonal skills ($\alpha=.8806$). The self-direction scale included training in assertiveness, decision-making, and educational skills ($\alpha=.8508$).

Two scales were created for level of care needed. Bodily Maintenance and Mobility included activities of daily living (ADLs) such as needing help getting in and out of bed, eating, and dressing. Participation and Relationships included items such as shopping, doing errands, dealing with government agencies, and managing attendants.

Demographics and Diagnoses

The respondents had a mean age of 43.4 years; 54% of them were female; and 48% were Anglo, 34% were Hispanic, 14% were Native American, and 4% did not specify race. The majority of respondents completed high school (46.7%); 13.3% dropped out before eighth grade, and an equal percentage completed college or had some post-college education. Neurological disorders were the predominant diagnoses, being reported by 74.5% of the respondents.

Onset of disability ranged from birth to 53, with an average age of 29.8. More than half of the respondents first entered a nursing home after 1989. The age at which respondents were institutionalized anywhere ranged from 14 to 53, with a mean age of 38. The average length of time spent in a nursing home was 4.9 years.

Results

Bivariate Relationships

Seventy-one percent of Anglos, 57.1% of Native Americans, and 43.8% of Hispanics preferred living in the community. However, these differences were not statistically significant. None of the discrete training items differentiated among the three ethnic groups. Consequently, there were no significant relationships between ethnicity and the two skills training scales.

Correlational analysis yielded statistically significant relationships between age and educational attainment, and residential preferences. Younger respondents and those with more education were more likely to want to live in the community ($r=-.33$, $p=.024$, and $r=.30$, $p=.04$, respectively). Age was negatively correlated with both the inclusion scale ($r=-.43$, $p=.002$) and the self-direction scale ($r=-.44$, $p=.001$).

The only disability-related variable which was correlated with skills training was Bodily Maintenance and Mobility. Respondents with lower scores expressed more interest in skills training for inclusion ($r=-.29$, $p=.04$).

Multivariate Analyses

Age, education, Bodily Maintenance and Mobility, and living preference were regressed in two separate analyses on the inclusion scale and the self-direction scale. Only age was permitted to enter into either of the stepwise regression procedures. Age explained 20% of the variance in interest in both inclusion and self-direction skills training.

Conclusions

Initially, the respondents who needed less assistance with ADLs expressed stronger interest in community living. Disability-related factors, ultimately, were not significant contributors to explaining any of the variance.

Age accounted for 20% of the variance in interest in skills training and was significantly correlated with living preference. The movement for independent living began on college campuses and is primarily a movement comprised of younger people who have disabilities. Nursing homes do not provide stimulation and support for young individuals with disabilities. Age was also highly correlated with age at onset ($r=.56$, $p=.000$). The younger respondents acquired their disabilities at earlier ages and have probably become more accomplished at dealing with them than individuals with more recent disabilities. Their levels of comfort with self may be higher. Deprivation and confidence combine in the younger respondents, resulting in greater willingness to leave the nursing home and to expand their skills for independent living.

The ethnic differences were insignificant, an unexpected finding. It is possible that class, not ethnicity, has a stronger influence on independence and self-sufficiency. However, the income data collected in the study were unusable; nearly one-half of the respondents did not answer the questions on income source and amount. Future research should examine how ethnicity and class interact to shape attitudes toward independent living. Reliance on others, weaker attraction to individualism, and greater acceptance of "fate" may be more a function of class than of ethnic group membership.

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Luiseno Indian Chronic Illness Behaviors

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Luiseno individuals of San Diego County, California, perceive Type II non-insulin dependent diabetes mellitus to be a physiological, emotional, and spiritual condition linked to aspects of ethnic identity. Medical practitioners and many Luiseno individuals tend to believe chronic ailments, such as Type II diabetes mellitus, may develop among the latter due to genetic predilection and/or current dietary habits. Health care workers emphasize that Type II diabetes occurs among individuals, thereby necessitating personal biomedical therapies. In contrast, Luiseno people with and without diabetes stress the collective historical, cultural, and social components of illness transmission and treatment.

Methodology

Data were collected between June 1990 and October 1992 for an anthropological field study on Luiseno Indian chronic illness health practices. Research participants included Luiseno between the ages of 18 and 91 years from three reservations situated in rural northeastern San Diego County.

Luiseno Ethnohistory

The Luiseno are the indigenous tenants of northern San Diego and southern Riverside Counties, California. Historically, the diet of the Luiseno included semi-cultivated acorns, greens, and grains, as well as seeds, bulbs, roots, fruits, game, fish, and marine products. Political, social, and economic interactions with Spanish, Mexican, and U.S. civil and religious authorities since the late 1700's have all shaped Luiseno access to aboriginal resources.

Luiseno religious and social ideologies continue to permeate contemporary health beliefs and behaviors. The Luiseno creation and related tales prescribe rites and lessons for appropriate behaviors, well-being, and longevity. Each being in the universe exists in a productive, hierarchically-arranged, and mutually-supportive relationship with all others. A primary means of enacting this belief is to share food or drink with anyone encountered, unless the individual appears to be overtly hostile. To refuse such sustenance, according to one 60 year old woman, "means you don't really like it or want it." Such an act is insulting. Collective well-being may be endangered. Individual well-being is considered to exist when body, mind, and spirit are in harmony.

Historically, illness among the Luiseño was reportedly caused by accidents, sorcery, and/or transgression of social rules (see Bean, 1992; DuBois, 1908). The goal of most preventive and curative therapies was to address the social, physiological, and emotional imbalance of a person and members of his/her social network.

Currently, according to many Luiseño, diabetes is, as one individual states, "something you got to look forward to when you're older." As of October 1991, self-reports of diabetes among Luiseño research participants reflected a prevalence rate of 24.77% (27/109); the local Indian Health Service contract facility estimated 10.77% (46/127) of the service population who participated in my study had diabetes. This numerical disparity may reflect treatment choices.

The overwhelming majority of Luiseño with diabetes with whom I had contact utilized biomedical providers associated with an Indian Health Service contract facility. Many persons also sought the care of practitioners affiliated with health maintenance organizations, Veterans Administration hospitals, urgent care units, and private practices. Often people also obtained assistance from lay people, "Indian doctors," priests, ministers, masseurs, and/or herbalists.

Diabetes Causation Theories

According to the biomedical model, Type II, or non-insulin dependent diabetes mellitus (NIDDM), is a condition of insulin resistance that results in poor glucose utilization, hyperglycemia, hyperinsulinemia, and/or hyperlipemia. Many biomedical researchers stress American Indians have a genetic predilection for this type of diabetes. The "thrifty gene theory" espoused by Neel (1962), argues that myriad indigenous populations regularly underwent feast and famine cycles. A so-called thrifty gene would have a selective advantage, increasing people's ability to store fats to be metabolized later during times of food shortages. This gene becomes detrimental with a more consistent food supply high in fats and carbohydrates, associated with decreased physical activity and upper body obesity (see Neel, 1962, 1982; Weiss, Ulbrecht, Cavanagh, & Buchanan, 1989). Recent studies demonstrate that acorns aid in controlling blood sugar. These plants enable carbohydrates to be digested and converted into sugars slowly, thereby allowing relatively low glucose levels into the bloodstream (Cowen, 1990).

The majority of Luiseño whom I interviewed considered diabetes to be an incurable condition whereby the production of a necessary body element is underproduced or a harmful element is overproduced. It may be, as one diabetic woman notes, a situation in which "the pancreas doesn't secrete something . . . gene related."

According to most Luiseño, diabetes may develop among members of this ethnic group due to consumption patterns and/or inheritance. Dietary changes within the last century have reportedly had an impact on their health. Food "additives,

preservatives, starches, sugars, and grease" were all listed by Luiseño as contributing to ailments. Limited access to water and irrigable land, especially during the past four decades, have discouraged the collection and processing of fresh foods. Wage labor has expanded income resources, but, according to many Luiseño, dissuades them from gardening, collecting, or hunting. Contemporary diets, those felt, as one man states, to have "a surplus of sugar, processed flour, and/or animal fat, overloads your body," influencing susceptibility to diabetes. However, diabetes was also reportedly inherited.

Passage of diabetes from one generation to the next is considered by certain individuals to occur by genealogical means. The biological consequences of diabetes was frequently mentioned with reference to genetics. Yet, this term appeared to have been quite confusing to almost everyone I interviewed. Individuals tended to feel that diabetes is inherited and "runs more or less through families."

Diabetes is also perceived to have a social basis for inheritance. People who shared this stance noted the relationship between blood ties and the inevitability of having diabetes. The belief commonly espoused that "all [Luiseño are] related somehow" suggests that "if one person has [diabetes], you're gonna get it."

The transfer of diabetes also has cultural components. Interest in and tastes for foods were thought by Luiseño to be acquired. Knowledge of diet and food preparation was also perceived to be learned.

Treatment Processes

Biomedical providers interviewed stressed that individuals delay seeking preventive care and subsequent treatments because symptoms associated with this disease are unfamiliar to Luiseño. The majority of Luiseño agreed that diabetes may be asymptomatic at onset. Unless conditions interrupted desired daily activities, care was generally deemed unnecessary. After diagnosis, clients and providers tended to note similar symptoms associated with blood sugar fluctuations categorized to necessitate care. Progressive complications designated as strokes, renal failure, circulatory problems, insomnia, and vision problems are sure signs, according to Luiseño, that biomedical care is needed.

All of the Luiseño with diabetes whom I encountered had engaged in or continued to engage in biomedical treatment programs. Transportation limitations, the fear of pain associated with needles, and the perceived obligation to perform certain social roles were frequently cited by Luiseño as arguments for therapeutic delay.

Also, a number of Luiseño with diabetes reported not feeling sick; they claimed to feel well or to feel differently than in a pre-diagnosis state. Thus, they "fixed" particular problems when deemed necessary. Men and women of varying ages

learned what worked under particular conditions through trial and error. Individuals asserted that biomedicine may not offer alleviation of symptoms or that symptoms may be treatable but incurable. Biomedicine as one individual stated, "just prolongs your life," and restrictions were socially, culturally, and emotionally impossible to maintain. After a perceived threat to life (e.g., stroke, diabetic coma) or to a body part (e.g., diabetic ulcer, retinal problems) biomedical treatments were viewed as helpful. The onset of unbearable pain and/or criticism from respected relatives and other Luiseño also encouraged persons with diabetes to seek aid. Attempts to utilize biomedicine, thus, were made. The use of other resources such as prayer, counseling, therapeutic plants, and/or self designed exercise regimens also may have occurred.

Conclusion

For the Luiseño, concepts concerning the cause and treatment of diabetes are tied to collective historical experiences. The objective of biomedicine is to relieve symptoms and to "control" the individual's blood sugar levels, yet the objective of many Luiseño is to regain the health of the individual and the family. Terminologies associated with diabetes may be shared by health providers and their clients; the ideas expressed are often distinct. According to the Luiseño, the physiological representation of diabetes is linked to biological, social, and cultural notions of inheritance.

Resistance to particular biomedical etiological theories and treatment regimens must not be considered denials of accepting health resources per se, but rather assertions of the perceived validity of both Luiseño and biomedical health beliefs and practices. Each is pursued in accordance with specific social situations and constructs.

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The Disabled Asian American Identity

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Introduction

Media have portrayed people with disabilities as "courageous cripples," "survivors of polio," "suffering from M.S.," or "victims" of one condition or another. Labels and stereotypic groupings deny individuality and are used as easy explanations for differences. As indicated by today's sound-byte media, there is a tendency for society to use brief descriptions. A society that promotes the "quick and easy" has no time to go beyond the convenience of the abbreviated packaging. How then should we speak of persons with differences--be they physical, emotional, mental, or ethnic?

Objective

The purpose of this paper is to discuss the concept of stereotype, to examine stereotypes that have been created to describe Asian Americans, and to consider these images in reference to five Asian Americans with disabilities. Four of them live in Honolulu and participated in a Pacific Basin Rehabilitation Research and Training Center's study on people who had polio. The other person lives in California and, although she did not participate in the Honolulu study, she, too, is exhibiting the late effects of polio.

Stereotypes

Historically, social stereotypes have been viewed as a type of "aberrant thinking involving beliefs that were in large part incorrect, illogical, and/or unfavorable. Today, theorists are stating that stereotypes are simply generalizations about groups of people and not necessarily bad" (Williams & Best, 1986, p. 244). However, all too often explanations of social events are consistent with preexisting stereotypes (Sanbonmatsu, Akimoto, & Gibson, 1994). For example, Fong and So (cited in Solmo, 1983) studied the Seattle Post-Intelligencer and The Seattle Times for articles on Asian/Pacific Americans and concluded that articles attribute the characteristic of one person or a few individuals to an ethnic group. Conversely, an ascribed stereotype is used to describe the individual. A Japanese man's intelligence, for example, is not credited to him alone, but rather to the Japanese culture. Fong and So reported that articles on Asian/Pacific Americans follow predictable patterns. Stereotypes about Chinese Americans are perpetuated by articles that relate to cooking, martial arts, family tradition, holidays, and superstitions. Articles about Japanese Americans focus on education, high tech, work ethic, and saving "face," while articles on Indo-Chinese

Americans emphasize their lack of education, training, and income, their need for aid, and their corruption and drug abuse. For Filipino Americans, articles focus on street gang involvement and illegal gambling.

With these ethnic stereotypes as a backdrop, five brief life "stories" of Asian Americans with disabilities will be shared, and a few questions will be raised.

The Life Stories

Individual #1. Sucheng Chan (1994) contracted polio in pre-Communist China when she was four. Her family emigrated to Hong Kong, then to Malaysia. During her childhood, her father was blamed for her physical condition. In Southeast Asia, it is believed that punishment for the past "sins" of the parents are passed to children in this life. The "face" of her father was constantly mirrored through the neighborhood children's taunting cries of "Baikah! Baikah!" ("cripple" in the Hokkein dialect). During a piano recital when Sucheng was twelve, she fell on stage before she reached the piano. A woman from the audience shouted, "Ayah! A baikah shouldn't be allowed to perform in public!" Irrespective of this comment, Sucheng was able to get herself up and complete her Beethoven piece.

Sucheng relates that, because she was a star student and had won most of her school's prizes, her community's negative attitudes did not affect her. When Sucheng was asked to write about being an Asian American woman with a physical disability, she said, "I considered it an insult. After all, my accomplishments are many, yet I was not asked to write about them. Is being handicapped the most salient feature about me?" (Chan, 1994, p. 434). Sucheng is a history professor and the director of Asian American Studies at the University of California, Santa Barbara. She held a Guggenheim Fellowship in 1988-1989. Her book, This Bittersweet Soil: The Chinese in California Agriculture, 1860-1910, won the 1988 Asian American Studies Book Award, the 1987 American Historical Association Pacific Branch Book Award, and the 1986 Theodore Saloutos Award in Agricultural History.

Individual #2. Sharon (personal communication, November 27, 1989) contracted polio when she was 11 months old. Like Sucheng, Sharon was born in pre-Communist China and emigrated with her family to Taiwan. She came to Honolulu, where she has completed her Master's degree in Education Communication and Technology, and where she has also earned her teaching credentials. Despite her degrees, Sharon has never been able to establish her career.

Regarding this, Sharon said, "I was depressed because with my condition, finding a job here is awfully difficult. If I can't be an able-bodied person, I will end up with no job."

Sharon shared her experience about applying for a Federal position, but being denied the job, despite passing all three tests, because her brothers work for the Taiwan government. After demanding information through the Freedom of Information Act, she learned that she was considered a security risk because of her brothers' political affiliation.

Currently, Sharon is recovering from surgery resulting from secondary disabilities; she has not found employment.

Individual #3. Rose (personal communication, November 1990) contracted polio when she was seven years old. Rose, a third generation Japanese American, finished high school but has never worked. Since childhood, she has been forced to eat alone in the kitchen and to do most of the house work. Rose said that she has no friends.

In 1984 she was involved in a car crash. Since that time, she has become involved with a post-polio support group. This is her only social contact. Rose classifies herself as a homemaker, but now, because of the late effects of polio, her chores have become more laborious. For example, it now takes her one and one-half hours to change linens for one bed.

Individual #4. Dianne (personal communication, February 14, 1990), now in her sixties, is second generation Japanese-American. Dianne does not recall when she contracted poliomyelitis, but she remembers going to Honolulu to have surgery on both legs when she was in the sixth grade.

When asked about her childhood experiences in relation to having a disability, Dianne said, "Didn't seem like it was a big thing." She continued, "I know [that] kids are really mean, but when you grow up on the plantation [everyone] knew each other, so there were no expectations." Dianne continued, "The only thing I had a difficult time was when I was buying my shoes." When she was asked whether this bothered her, Dianne responded, "I guess maybe if I had lived in a city but [I was] living in the country. No. You [didn't] have to dress up and you [didn't] have to wear shoes."

Individual #5. Leigh (personal communication, February 13, 1990), a fourth generation Chinese American, contracted polio when he was nine months old. He has no memory of living without a full-leg brace. Leigh finished his law degree and has been a council member for the City and County of Honolulu since the 1980's. Currently, he is considering an end to his political career and has remodeled his home to accommodate the use of a wheelchair.

Although self-conscious of his "awkward" look as an adolescent and hesitant about participating fully in social activities because he did not want to "hold the others up," Leigh gives credit to his mother, who told him "never to settle for second best." As

a youth, he learned to surf, but he was dependent on others to get the board from the car to the water. Leigh, reflecting on this, said, "I think it had that influence of affecting my life by ingraining in me the necessity of speaking well to others so that they would be glad to help."

Regarding his physical disability, Leigh says, "I'm able to overcome a lot of inhibitions. . . . You come to accept what you cannot change and to change what can be changed. And pain comes into this discussion. If you got pain that you can't change, then one tries to accept it."

Conclusion

Do the persons I have described fit stereotypic images of Asian Americans? If not, how do we go beyond the established stereotypes to understand and know the individual? What is required to promote the acceptance of and respect for physical, mental, and/or ethnic differences?

Stereotypes are products of labels and categories. Labels and categories cannot be eliminated. However, more research is required to go beyond the catch-all categories; to understand that the generalities need to be investigated in order that individuals who seem "different" can function in their environments. Furthermore, time and commitment are needed to acknowledge that there are differences and that they all need to be respected.

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Section IV

Acknowledging Challenges to Self Determination

The chapters in Section IV deal with some of the profoundly difficult personal and political challenges that often face those seeking self-determination and independence. The first two papers specifically address questions of decision-making regarding the assignment of "do not resuscitate" orders to children with disabilities.

In "Life and Death Issues: The Placement of 'Do Not Resuscitate' Orders on Children with Disabilities," Elaine Makas describes how one community struggled when often-abstract questions of individual rights and quality of life became an impassioned debate about one 12-year-old member of that community. Corey Brown, who had cerebral palsy and scoliosis and was nonverbal, was the focus of that debate: Should her mother and physician be allowed to place a DNR order on her, and should DNRs be placed on other non-terminally ill children? What does "terminally ill" mean, and who can define quality of life? Makas describes her own activism in trying to get the DNR order revoked, as well as the variety of reactions she received both from people with disabilities and from people without disabilities. Kristi L. Kirschner specifically addresses physicians' actual and potential roles in placing DNR orders on children with disabilities. She asks crucial questions concerning the training of physicians in disability-related issues, and the substantial power physicians have as role models and decision makers.

A potential for exploitation and the undermining of self-determination exists when vulnerable people rely on others for care, especially daily care. In "Abuse and Neglect of People with Disabilities by Personal Care Providers: An Exploratory Survey," Julianne S. Oktay, Catherine A. Tompkins, and Caroline Downing report the results of a telephone survey of persons with disabilities who received help with personal care activities. Forty percent of the respondents reported that they had been abused in some way (and, as the authors note, because people are apt to underreport abuse, 40% may be an under-representative figure). This preliminary study indicates a need for further research that will clarify the circumstances under which abuse is more likely to occur in order to develop adequate training for prevention and advocacy.

**Life and Death Issues:
The Placement of "Do Not Resuscitate" Orders
on Children with Disabilities**

**Elaine Makas, Ph.D.
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On October 25, 1993, Mrs. Linda LaFrance, the mother of 12-year old Corey Brown, and Dr. Richard Marsh, Corey's pediatrician, formally requested that the Lewiston (Maine) School Committee (LSC) make an exception to its usual emergency care policy and place a "Do Not Resuscitate" (DNR) order in Corey's file. In other words, they requested that, if Corey were to stop breathing for any reason, or if her heart were to stop beating, nothing should be done to prevent her death. Although the School Committee rejected this initial DNR request, they accepted a revision offered by Dr. Marsh, the placement of a "No Cardiopulmonary Resuscitation" (no CPR) order in Corey's file (Shanahan, 1993c). Dr. Richard McFaul, a pediatric cardiologist, informed the LSC at its November 8 meeting that a "no CPR" order is virtually the same as a DNR order ("Board OKs," 1993).

On November 8, 1993, the School Committee voted not to accept future DNR or "no CPR" orders for any child, but they specifically exempted orders agreed to on or before October 25 (Shanahan, 1993f).

At the School Committee's December 13 meeting, faced with the threat of an ADA complaint (based on the denial of Corey's right to equitable services within the schools, including emergency medical care), the LSC reversed its earlier decision, thus protecting Corey under the November 8 policy (Shanahan, 1993g).

I live in Lewiston, and, if I had a child, my child would attend the Farwell School, the school that Corey Brown attended. I went to all the LSC meetings at which Corey's case was discussed. I spoke at each one. And I fought very, very hard to protect Corey and the other Lewiston children with disabilities that Dr. Marsh said were "waiting in the wings" for a decision on Corey (LSC meeting, 10/25/93; Shanahan, 1993e). With the exception of Corey, I knew or, at least, had met all of the people involved--the teachers, the members of the LSC, the Superintendent of Schools, Corey's mother, her pediatrician, her educational aide, and her physical therapist. I also personally knew most of the people with disabilities who chose to get involved--and many of those who chose not to.

Cases such as Corey's will have profound attitudinal and behavioral consequences. The resolution of these cases (and, just as importantly, the media's interpretations of their resolution) will influence reactions to similar requests elsewhere, and cases such as Corey's will affect public attitudes toward mainstreaming in general. Over and over again, I was asked, "What are those children doing in school anyway?" However, I will leave a discussion of these attitudinal consequences to others and focus instead on the pre-existing attitudes--of physicians, of family members, of teachers, of the general public, and of people with disabilities--which influenced the debate on Corey Brown.

Attitudes of Physicians

The literature suggests that physicians tend to have negative attitudes toward people with disabilities, but that medical training is changing, and this change may result in more positive attitudes (DeLoach & Greer, 1981; Gerhart, Koziol-McLain, Lowenstein, & Whiteneck, 1994; Gething, 1992; Sloper & Turner, 1991). I sincerely hope so because physicians do have life and death power over their patients. The combination of a physician's strong ego and his/her medical training, which has traditionally taught that the only true measure of a physician's success is the cure (Robinson, 1988), can literally be deadly to people with disabilities. Corey will never be cured, and, for a physician who measures personal success by his or her cure rate, Corey and others like her are constant reminders of "failure."

The training of nurses, physical therapists, and occupational therapists is different; they are taught to judge success by their patients' improved quality of life, increased physical comfort, and enhanced abilities (Etherington, 1990; Robinson, 1988). Why not teach physicians to judge success by the same standards?

Dr. Marsh admitted that he had no specialized training in disability but that, as Corey's physician, he knew her best (LSC meeting, 10/25/93). He said that there was no need for a second medical opinion, and that the teachers and staff at the Farwell School should not be making medical decisions by trying to resuscitate Corey in an emergency, when he, as her physician, had already decided, years ago, that everyone should "just let her go" (LSC meeting, 10/25/93; Van Biema, 1993).

Attitudes of Family Members

Research suggests that people who have close relatives with disabilities tend to have positive attitudes toward persons with disabilities (e.g., Begab, 1970; Makas, 1989; Schwab, 1989). I believe that intimate and long-term contact allows them to focus on

the individual they love rather than on one characteristic of that person, such as a disability.

I truly believe that Corey's mother is more mindful of her daughter than of her disability--although others, including some who know Mrs. LaFrance far better than I do, disagree strongly. What I see in this particular case, though, is an intelligent, but poorly educated, woman--one who grew up in poverty and who continues to live in poverty--one who has acknowledged publically that she herself has been physically abused (Leykis, 1993; Shanahan, 1993d).

How would you expect her to react when she is told repeatedly by a self-confident, well-educated, and affluent man that her child is suffering greatly and that any attempts to resuscitate Corey would cause her child further pain? Dr. Marsh defended Mrs. LaFrance as being a loving mother. He said that he had been trying to convince her for more than two years to place a DNR on Corey, and that Mrs. LaFrance had only recently agreed to do so (LSC meeting, 10/25/93; Larrabee, 1993).

Attitudes of Teachers

Although research on teachers' attitudes has produced very mixed results (e.g., Brodwin & Gardner, 1978; Rizzo, 1985; Schmelkin, 1981), the reaction of the Lewiston teachers to the DNR request was extremely clear. The approximately 200 members of the Lewiston Education Association voted nearly unanimously to fight the request, and several key participants vowed publically that, no matter what the LSC decided, they, personally, would do everything in their power to resuscitate any child in an emergency, including Corey (Shanahan, 1993a).

These teachers are the true unsung heroines/heroes of this battle. The ones with whom I spoke did not see themselves as disability rights advocates. Most admitted that they had received very little training about disability, either before or since mainstreaming began. Their reasoning was much more basic than that. As one teacher said, "Why on earth wouldn't I resuscitate Corey? She is one of our children."

Attitudes of the General Public

Needless to say, one crucial factor in the Corey Brown case was the attitudinal predisposition within the community. In some ways, Lewiston is unique--40,000 residents and somewhat off the beaten track--but, in other ways, it is very typical, and I honestly believe that the attitudes encountered in Lewiston are representative of those that would be encountered elsewhere in similar situations.

That said, I will note that the initial reaction by all but the teachers and me was surprisingly small. Most people seemed to accept the idea that, if the pediatrician and the parents agree, then it is perfectly okay to "let" a child with severe disabilities die.

Several people expressed some concern that the other children--the "normal" ones--might be distressed by the sight of Corey dying in their classroom. One of Dr. Marsh's strongest LSC supporters suggested that seeing frantic resuscitation efforts might be even more disturbing to the other children. He offered a simple solution--get Corey out of the classroom as quickly as possible (LSC meeting, 10/25/93).

My primary concerns were not logistical. I pointed out that people were discussing Corey's case as a right to die issue, when, in fact, it was a quality of life issue. I noted that Corey was not--and is not--terminally ill, and that Corey had never been asked her opinion on the issue. (Corey has cerebral palsy and scoliosis, and she is non-verbal.)

Dr. Marsh stated that he did not expect Corey to live beyond the age of 30 (Shanahan, 1993b; LSC meeting, 10/25/93). When I suggested that the likelihood of death sometime after the year 2011 might not qualify as "imminent death" under Maine law, Dr. Marsh argued that, although Corey was not "technically" terminally ill, she was suffering a great deal, and that a DNR would be in her "best interests" (LSC meeting 10/25/93; Shanahan, 1993e).

Mrs. LaFrance claimed that Corey simply could not express her wishes because she is "profoundly retarded." When Mrs. LaFrance was asked to explain this diagnosis, she said that Corey is "obviously" profoundly retarded, since she is non-verbal, and that assistive communication technology is "obviously" useless, since Corey is profoundly retarded. Although Dr. Marsh carefully avoided using specific terminology related to mental retardation, he did support Mrs. LaFrance's circular logic, and his assumed expertise on the issue effectively shut down further questions from the School Committee (LSC meeting 10/25/93).

Clearly, the LSC and the general public were predisposed to accept the interchangeability of being nonverbal and having mental retardation--as well as the perceived equation between severe disability and terminal illness. These two confoundings allowed the debate to continue as a "right to die" matter despite the absence of both any right and any imminent death.

Adding fuel to the fire was the most devastating attitudinal predisposition of all--that people with severe disabilities would obviously prefer death to "a life of suffering." I was both publically and privately accused of cruelty to Corey for speaking out against the DNR request. As one LSC member pointed out to me and to others, anyone who had ever met Corey (as he had done on one occasion) and seen what a "sweet, beautiful, loving child she is" would certainly want her suffering to end (LSC meeting, 11/8/93).

Attitudes of People with Disabilities

The research suggests that individuals who have disabilities, compared to nondisabled persons, should have more positive attitudes toward people with disabilities (Beresford, 1993; Sweidel, 1991, 1993). On the plus side, the debate on Corey's situation elicited a tremendous outpouring of letters, FAXes, and phone calls from advocacy groups across the country expressing their concern and, often, their outrage at the LSC's initial decision.

This reaction, however, came primarily from advocacy groups outside of Maine. One of the largest and best-known groups in Maine told me outright on several occasions that they did not want to get involved. Another smaller group said that they "don't do advocacy." One individual who is a dedicated activist on other disability issues simply said that Mrs. LaFrance should have the final say. I received some very accusatory correspondence and several extremely hostile phone calls from individuals claiming to have disabilities who said that I had no business trying to deny them their "right to die."

Certainly, people with disabilities can and do have differing points of view, including minority opinions such as these. One disturbing possibility, however, is that some people with disabilities may lack empathy with others whose life situations are so different from their own (Makas, 1994). Individuals who are adults, who are verbal, and who have fewer and less debilitating disabilities may find it difficult to identify with Corey Brown and to value her quality of life.

It is interesting to note that, of the six individuals with significant disabilities who attended the School Committee meetings with me, only one had not had severe, multiple disabilities since birth--and that woman had been a teacher prior to her disability. Among them were a woman who had been labelled both nonverbal and profoundly retarded as a child--and two women whose pediatricians had tried to convince their parents to place DNRs on them as children.

A friend of mine who has cerebral palsy told me that it is comfortable, even invigorating, to fight for the placement of a ramp in a public place, but that Corey's situation strikes too close to home. She said that it is absolutely terrifying to have to confront the fact that so many people believe that you would be better off dead.

Some disability rights advocates questioned my heavy involvement in Corey's case, since I do not have significant, visible disabilities. I agree that it would have been far better for others to take the lead, and many people know how hard I tried for that to happen. But the truth of the matter is that it just was not going to happen, and my concern for Corey Brown, for Dr. Marsh's other child patients "waiting in the wings,"

and for any child for whom the decision on Corey might set a dangerous precedent--far outweighed my commitment to that principle.

We must all confront this issue, and we must work together.

Postscript

Soon after the events related above, Corey was removed from school for "home schooling." Corey died on December 7, 1995, at St. Mary's Regional Medical Center in Lewiston after a three-day stay for treatment of pneumonia. A front page article entitled "Struggle ends for student" (Weir, 1995) reported that, according to a hospital spokesperson, the DNR order which had been placed on Corey by her physician had been "honored" (p. 1A). Corey's obituary noted that she had died "after a long illness" ("Obituaries," 1995, p. 2A), which suggests to me the continued confounding of disability and terminal illness. At the time of this publication, I do not know whether the DNR orders which Dr. Marsh claimed at the time of the LSC controversy were in place in all non-school settings on his other child patients "waiting in the wings" are currently in effect.

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DNR Issues in Children with Disabilities: The Physician's Role

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Physicians are in a pivotal role to shape a family's outlook toward a child with a congenital or acquired disability. Families will often turn to physicians as primary sources of information about disability--what will my child's life be like? What is the physician's medical prognosis? What is their functional prognosis? If the physician has a negative attitude and views the disability as a tragedy, the family (and consequently the child) are more likely to adopt this view themselves. On the other hand, a well-informed physician with a broad perspective and a positive attitude about life with a disability can be extremely important in facilitating a positive adjustment.

What do we know about physicians' and health care providers' attitudes toward disability? Most health care providers have grown up in a society that has devalued disability. Many of our attitudes and perspectives are deeply ingrained during our childhood. They are shaped by the images of the poster child, the pathos of the telethons, and the very language we acquire--"crippled," "invalid," "wheelchair bound." We also know that physicians receive little formal training in disability-specific issues. Their knowledge base is often grossly inadequate, and their opportunities for heightening awareness about disability and for reducing prejudice are often limited.

There have been a number of studies looking at the attitudes of health care providers toward severe disability and comparing these assessments to the quality of life responses of people living with these disabilities (Bach & Barnett, 1994; Bach & Tilton, 1994; Gerhart, Koziol-McLain, Lowenstein, & Whiteneck, 1994). These studies confirm that, overall, health care providers consistently underestimate quality of life as seen by persons with disabilities. While there is some preliminary evidence to believe that the situation is improving, quality of life assessments are fraught with significant potential for misuse (Paris, 1993).

Surrogate decision-making in do-not-resuscitate (DNR) decisions necessarily involves assessment of medical prognosis and potential quality of life by the surrogate decision-maker and the health care provider. A DNR decision for a child is necessarily a proxy decision, often made by parents or guardians in concert with the child's physician. Recent attention has focused on the surprising use of DNR decisions in children with non-terminal, disabling conditions. Given the significant potential for negative bias and misinformation in such circumstances, the child with a disability may be particularly vulnerable. In a society whose "default" position has

been in favor of preserving life, the moral foundations of these decisions require critical analysis.

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Abuse and Neglect of People with Disabilities by Personal Care Providers: An Exploratory Survey

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In recent years, awareness of the importance of personal care services has increased dramatically. Personal care refers to assistance in performing activities of daily living (ADLs), such as feeding, dressing, walking, and toileting. Two trends are serving to call attention to the importance of personal care services. One is the increase in the size of the population of people with disabilities. This is caused by a number of trends, the most dramatic of which is the rapid increase in the elderly population. Others include increased survival rates in chronic disabilities/illnesses, such as stroke, MS, and cancer. Improved techniques in emergency services have led to more people surviving accidents and heart attacks. All of these trends contribute to the number of people who are living with disabilities and who are in need of assistance with personal care. A report to the National Institute on Disability and Rehabilitation Research estimates that there are 780,000 adults, age 18-64, who need assistance with ADLs (LaPlante, 1993). In addition, approximately six million elderly people need assistance with daily living activities.

Traditionally, assistance to elderly persons and to people with disabilities is provided by female family members (mothers, wives, and daughters), but as more and more women are in the work force, they are less available to perform these functions. Increasingly, personal care assistance is being performed by a rapidly expanding home care industry. Informal arrangements, such as help from neighbors, landlords, students, and friends, are also common.

When the informal system (family, friends, or neighbors) is unable to meet the needs, help must be sought by the formal system. While the majority of those with activity limitations have health insurance (LaPlante, 1993), most health insurance does not cover assistance with daily living. Private insurance and Medicare cover home health services only when a "skilled" nursing need is present--usually for a short period of time after an injury or illness. Medicaid provides personal care services as an option for states, as well as through its waiver programs, but these programs are small, and they serve only a small minority of the population in need (Oktay & Palley, 1991). Because there is little or no national supervision or standards for personal care services, there is concern about the quality of care provided and, more alarmingly, about the possibility of maltreatment of the individual by personal care service providers (Hawes & Kane, 1991).

Increasing awareness of abuse and neglect of vulnerable populations focused first on children, then on women, and, more recently, on elderly persons. While maltreatment (abuse and neglect) by personal care providers has not been studied in relation to people with disabilities, there are a number of reasons to expect that it does exist. First, caring for individuals who have disabilities is hard work, and personal care tasks are often unpleasant. The work is highly repetitive, and there are few inherent rewards. Second, the pay is very low, and there are few opportunities for advancement (Donovan, Kurzman, & Rotman, 1993). While home health agencies require training and provide supervision, there is tremendous variation in these requirements across states and across programs (Oktay & Palley, 1991), and informal arrangements do not usually involve any outside supervision. To this combination of hard work, low pay, and little training or supervision is added the fact that the work takes place in the home, where it cannot be easily observed by others. Since many people with disabilities who have personal care assistants are so completely dependent on them, it is unlikely that maltreatment will get reported to authorities. Even if it is reported, it often comes down to the word of the individual who has the disability against that of the personal care provider. Without concrete evidence, such charges are difficult to prove. The agencies responsible for investigating such abuse--Adult Protective Services in local Departments of Social Services--are often understaffed, and they have to take on only the most horrendous cases. Even when maltreatment is pervasive, many people will choose not to report it out of fear that they will lose their independence if they lose their aide. Persons who have disabilities and professionals are both concerned that problems of maltreatment will increase as more and more people become dependent on formal personal care services (Hawes & Kane, 1991).

Method

An anonymous telephone survey was designed to measure maltreatment among people with disabilities who receive assistance with personal care. The survey was administered by Masters of Social Work (M.S.W.) students in three waves, from 1991 to 1993. The first wave was a survey of members of an advocacy organization (n=48). The second wave, completed in 1992, involved members of a local Spinal Cord Injury Network (n=28). The third wave, completed in 1993, was focused on elderly users of personal care services who were clients of three agencies--a local health department, Visiting Nurses Association, and Senior Care agency (n=82). In all, 158 interviews were completed. All respondents agreed to participate in the study, and all were capable of responding to a telephone interview. This eliminated those who were too ill, those with cognitive or physical disabilities that interfered with communication, and those who did not speak English. It is impossible to calculate an accurate response rate for this survey, and the results cannot be generalized to any particular population. It is important to note that most of the younger respondents came from consumer organizations, and most of the older respondents came from provider organizations. This is reflected in the study results.

Measurement of maltreatment is very difficult, as there is no universal definition of what is meant by "abuse" or "neglect." Also, there is reason to believe that reported rates are not valid, because people routinely deny that they are being abused out of fear of the abuser, embarrassment, or concern that they will lose the assistant and will have to enter a nursing home. This study developed an instrument to measure maltreatment using the Conflict Tactics Scale (Straus, 1979) as a model. The respondents were asked whether their primary personal care assistant, or any other personal care assistant, had engaged in specific behaviors. The behaviors were designed to measure verbal abuse, neglect, poor care, physical abuse, theft, extortion, and sexual abuse. The respondents were also asked for demographic information and for information describing the caregiving situation. If respondents indicated that they had experienced maltreatment, they were asked to give an example, and this was recorded verbatim. All reported maltreatment was analyzed as maltreatment. No attempt was made to verify whether the incident had occurred. However, the correspondence between the incidents cited as examples and the definitions suggests that the respondents understood the questions. Also, given the inclination to underreport maltreatment, the estimate of maltreatment obtained is probably a minimum.

Results

The age of respondents ranged from 20 to 91 years, with a mean age of 61 years. Approximately half of the respondents were male, and half were female. Their monthly income averaged in the \$500-\$750 range, with Social Security being the single largest source of income. Over half of the respondents lived with family, and about a third lived alone. Most respondents reported needing assistance with bathing, dressing, and mobility; and approximately half also needed assistance with continence (56%) and feeding (44%).

Theft was found to be the most common form of maltreatment, experienced by almost one-quarter of the respondents; it was especially common in attendants other than the primary attendant. The most common problem reported among primary personal care assistants was verbal abuse (10%), followed by physical abuse (5%). Neglect and poor care were reported for 3-4% of primary attendants and for 12-15% of "other" personal care attendants. Sexual abuse was the least likely to be reported. Overall, about 20% of the respondents reported at least one type of maltreatment by a primary personal care provider, and 40% reported maltreatment from another personal care provider.

Predictors of maltreatment were examined by looking at characteristics of the respondent, characteristics of the primary attendant, and characteristics of the caregiving situation. This analysis was exploratory; it was not based on a set of hypotheses and, therefore, must be interpreted with caution. In terms of characteristics of the respondent, age was the variable most powerfully correlated with maltreatment. The younger respondents (less than 65 years old) were far more likely

to report maltreatment. Thirty-two percent of those under 65 reported maltreatment by primary attendants, compared to 22% for those 65 and over. Forty percent of those under 65 reported maltreatment by other attendants, compared to 33% of those 65 and over ($t=3.70$, $p<.001$). Two characteristics of the attendants were correlated with maltreatment: gender and whether the attendant was a family member. Forty-three percent of those who had male attendants reported maltreatment, compared to 17% of those whose attendants were women ($t=3.76$, $p<.001$). Also, those whose primary attendant was a family member reported less maltreatment ($t=2.37$, $p<.05$). In terms of the caregiving situation, those who utilized the highest numbers of hours of personal care, and those whose personal care attendant had worked for them for the shortest length of time also reported more maltreatment ($t=3.07$, $p<.01$, and $t=2.49$, $p=.01$ respectively). Taken together, these five variables explained 29% of the variance in maltreatment ($F=8.55$, $p<.001$).

Conclusion

This exploratory study shows high rates of reported maltreatment of people with disabilities by personal care assistants; 40% have experienced some form of maltreatment. Further research with larger, more representative samples is needed. Findings that younger respondents who have disabilities, and those with male attendants are more likely to report maltreatment need further study. If supported by additional research, preventive services can be targeted to those at highest risk for maltreatment.

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Section V

A Progress Report on the ADA

In 1990 President Bush signed the Americans with Disabilities Act (the ADA). Enacting civil rights legislation does not guarantee how well or how thoroughly it will be implemented, nor the extent to which discrimination will be reduced. The papers in this section are three examinations of the ADA's actual or perceived effects on communities and individuals.

Joan Finn and David Pfeiffer surveyed local governments for the study reported in "The Americans with Disabilities Act: An Evaluation of Compliance by Local Governments in the U.S." Among those that responded, implementation of the ADA was positively affected by size of community and state, and whether or not there was an ADA Coordinator: the larger the state and local community, and the more likely the presence of an ADA Coordinator, the greater the possibility that the ADA was being implemented. Finn and Pfeiffer also provide examples of confusion that still remain about what resources exist for communities trying to comply, what the ADA requires, etc. Those responsible for implementing the ADA need appropriate information and education.

While Finn and Pfeiffer's work looks at implementation in many communities, G. Thomas Behler, Jr., focuses on one case in his chapter, "An Inside Look at a Small Mid-Western Community's Attempts to Comply with the Americans With Disabilities Act: Some Preliminary Personal Observations and Qualitative Research Findings." Closely examining the community for compliance with ADA Titles I-IV, Behler and his students found some examples of compliance and also several areas in which the community had not achieved full compliance with the ADA. Ironically, many of the problems that Behler and his students found are ones that could be fixed relatively easily (e.g., guide rails, appropriate signage, sidewalk maintenance). Others require more planning and resources.

Finally, Bob Worthington writes about "How Workers Who Have Disabilities Perceive the Provisions of the 1990 Americans with Disabilities Act." Worthington's study is useful both for the results and for providing a model for future research. As Worthington points out, trying to pursue a large, nationwide survey of workers with disabilities entails significant resources and raises ethical questions. Smaller-scale studies that allow researchers to build on previous work can be done. In the pilot study reported here, Worthington found that employees "felt that managers were aware of the ADA and that there was compliance with employment provisions of the Act" (p. 20). The return rate for this survey was small, but future research studies

could be designed to ensure a higher return rate, and to expand our knowledge of how workers with disabilities are affected by implementation of the ADA.

All of the papers in this section remind us that the ADA is law and that governments, organizations, etc., are legally mandated to comply. We know from historical experience, however, that enactment does not guarantee implementation and enforcement. We also know that attempts to make discrimination illegal does not mean that prejudice will be reduced. The authors in Section V celebrate the ADA and the extent to which communities and businesses have complied. As Finn and Pfeiffer point out, however, "There can never be enough done in terms of barrier removal and of opening society to all persons, including those who have disabilities" (p. 112).

The Americans with Disabilities Act: An Evaluation of Compliance by Local Governments in the U.S.

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The Americans with Disabilities Act (ADA) extends protection against discrimination on the basis of disability from the public to the private sector. It covers all state and local governments, whether or not they receive federal funds; requires a communications relay system in each state; and builds upon the coverage mandated by the 1988 Fair Housing Amendments Act, the Air Carriers Access Act, the Individuals with Disabilities Education Act, and other federal statutes. The ADA has been described as the most significant civil rights statute since the 1964 Civil Rights Act.

Title II of the ADA prohibits public entities from discriminating against people with disabilities. The term "public entity" includes all state and local governments in the United States, including special districts, other instrumentalities, commuter authorities, and AMTRAK. In addition to the fifty state governments, there are 38,978 local governments in the United States. However, most of the population lives in approximately 600 government locales, and about one-half reside in a dozen metropolitan areas.

All public entities with 50 or more employees must designate an ADA coordinator, and they must establish an internal grievance procedure to resolve complaints. These public entities (regardless of size) must conduct self-evaluations to identify policies and practices (including those related to their physical plants) which violate Title II. Those not in compliance are required to undertake necessary modifications and to detail these changes in a transition plan, which must be filed with the U.S. Department of Justice.

All of the above were to have been carried out by the end of 1992, except for major physical changes, which had a January 1995 deadline. However, only the City of Boston had filed its transition plan with the Department of Justice by that date. Other public entities were beginning to comply.

In January 1994, we sent out 2500 questionnaires to local governments, using 1000 address labels from the National League of Cities, 1000 from the National Association of Towns and Townships, and 500 from the International City Management Association. As of May 3, 1994, 828 questionnaires (33%) had been returned.

Local governments were asked if they currently had a 504 compliance officer and/or an ADA coordinator. Seventy percent answered in the affirmative. When asked if they had a committee or commission on disability, 45% answered "yes." Twenty percent of the local governments which did not have a committee or commission indicated that they had plans for establishing ones.

A self-evaluation plan, which must involve persons with disabilities, is required of all local governments. This plan had been completed by 77% of the sample; persons with disabilities were involved in the process in 68% of the local governments. However, only 51% of the local governments had completed a required transition plan. One local official said that they had not completed their self-evaluation plan because they had not yet received it.

We asked if specific local government buildings or facilities had been surveyed for accessibility. Recognizing that some of the facilities did not exist in certain jurisdictions, or were under the control of another government entity, we gave respondents the option of answering "not applicable." Following are the percentages of facilities that had been surveyed (with the "not applicable" responses excluded): town hall, 93%; police station, 95%; library, 93%; senior center, 94%; schools, 88%; community center, 94%; parks, 93%; voting sites, 91%; court house, 92%.

We also inquired whether there were Telecommunication Devices (TTY, TDD, or Text Telephones) which were strategically located in specific local government buildings and facilities. The results (again with "not applicable" responses excluded) were as follows: city hall, 41%; police station, 62%; library, 36%; senior center, 16%; schools, 13%; community center, 17%; voting sites, 8%; court house, 30%.

We then asked a question which we considered would separate the most concerned and knowledgeable local governments from the others, whether the local government provided sign language interpreters for public meetings upon request. An astounding 64.2% of the respondents answered "yes."

In order to determine how active the local governments were, we posed a series of questions to determine whether their personnel departments had taken steps to comply with the ADA. Following are the questions asked, and the percentages of positive responses received: Had they (a) changed applications to eliminate questions about disability? 64%; (b) provided alternative formats for persons with visual or print disabilities? 35%; (c) provided alternative locations for interviews in the case of an inaccessible site? 49%; (d) assisted a supervisor in providing a reasonable accommodation, such as job restructuring or schedule change? 38%.

We found that 12.8% of the local governments had faced at least one ADA, Title II, complaint. The number of complaints per locality ranged from zero to sixty with most being less than ten (mean = 0.51; standard deviation = 3.16; median = 0.00; mode

= 0.00). Excluding localities with no complaints resulted in the following statistics: mean = 4.15; standard deviation = 8.17; median = 1.00; mode = 1.00.

Percentages of respondents who received complaints in the areas noted on the questionnaire were as follows: employment, 6%; education, 0.5%; public meetings access, 2%; services or program access, 3%; provision of programmatic access upon request, 0.6%; other areas (primarily access), 5%. Most of the local governments had taken steps to solve problems associated with the complaints, (11% of the 13% who had received complaints), but six had not (0.8%).

Generally, the respondents indicated that they had taken a number of steps, even if there had been no formal complaints: met with complaining party to discuss solutions, 11%; brought concerns to and requested assistance from the municipal, county, or state offices on disabilities, 5%; provided reasonable accommodation for an employee, 7%; relocated future public meetings, programs, or services to accessible locations, 7%; currently provided and would continue to provide programmatic access, 7%; currently provided and would continue to provide ADA and awareness training to key staff, 9%; made modification to a building, 12%; took other steps, mainly by making various physical modifications, 5%.

We explored whether the local governments had utilized the resources available to them: 66.7% had used the technical assistance manual developed by the Equal Employment Opportunity Commission (EEOC); 60.1% had used the Title II Technical Assistance Manual developed by the Department of Justice (DOJ); 19.3% had contacted their Regional Disability and Business Technical Assistance Center (DBTAC) (one respondent stated that he/she did not believe such an entity existed); and only 12.2% had contacted the Job Accommodation Network (JAN) to develop programs or to resolve current or potential problems. While the EEOC and the DOJ appear to be informing local governments that help is available, the regional DBTACs and the President's Committee on the Employment of People with Disabilities (which runs JAN) need more funding to make their services better known.

We then turned our attention to what might encourage the implementation of the ADA. To test our hypothesis, that having an ADA Coordinator made things happen, we constructed three cross tabulation tables using the gamma statistic, which measures the strength of an association, and a significance level of 0.05. In all three cases, there was a statistically significant relationship ($p < 0.00001$) between having an ADA Coordinator and completing the self-evaluation, involving persons with disabilities in the self-evaluation process, and completing the transition plan. These relationships were moderate to strong, with gammas of 0.81, 0.81, and 0.88, respectively.

Using the activities which local governments said they had done, we calculated an implementation index score (mean = 11.13; standard deviation = 6.52; median = 12.00;

mode = 15.00). By using ordinary least squares regression through the origin and pairwise deletion of missing values ($r^2=0.66$, standard error=7.58, $F=110.57$, $p=.0001$), we developed the following model for the implementation index score:

$$Y = 0.49STPOP + 0.28COORD + 0.22POP + 0.08NUMBER$$

In other words, the larger the population of the state (STPOP) and of the local jurisdiction (POP) were, the higher the implementation index score (Y). The existence of an ADA Coordinator (COORD) explained most of the remaining variance in the index, with the number of complaints (NUMBER) having a statistically significant, but slight, positive influence. In large states and in large local governments with ADA Coordinators, the ADA is being implemented.

What does this all mean? There is considerable activity on the local level, and the ADA is being implemented by a number of local government officials, often with pressure from local groups of persons with disabilities. Is the implementation of the ADA sufficient? There can never be enough done in terms of barrier removal and of opening society to all persons, including those who have disabilities. When compared with the Civil Rights Movement, the Women's Movement, and the Gay Rights Movement, the Disability Rights Movement has come a long way. The ADA is being implemented and must continue to be implemented at the local government level.

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An Inside Look at a Small Mid-Western Community's Attempts to Comply with the Americans with Disabilities Act: Some Preliminary Personal Observations and Qualitative Research Findings

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The purpose of this paper is to present some preliminary observations and research findings regarding the efforts of Big Rapids, Michigan (a small mid-western university town with a population of 12,631) to comply with the major provisions of the Americans with Disabilities Act. The paper will begin with a brief overview of the most important provisions of the ADA and the apparent implications of those provisions for small-sized communities such as Big Rapids. Once this basic summary overview has been provided, attention will be turned to the various successes, failures, and ongoing struggles that have been experienced by Big Rapids in relation to these basic ADA provisions.

The observations and research findings to be presented here include the findings of a required class project at Ferris State University during the Fall 1993 semester. Several self-selected groups, consisting of six to eight nondisabled undergraduate students, simulated blindness, deafness, wheelchair use, and crutch use as a means of identifying accessibility-related problems in city and country facilities/services and on both commercial area and residential area sidewalks and streets. Included also are my own personal reflections as a totally blind sociologist and community resident.

General Overview of Major ADA Titles

Title I: Employment Provisions

The ADA prohibits discrimination against qualified persons with disabilities because of their disabilities. The prohibition applies to job application procedures; the hiring, advancement, or discharge of employees; employee compensation; job training; and other terms, conditions, and privileges of employment. Employers must make reasonable accommodations for qualified applicants or employees with disabilities unless an undue hardship would result. Employers with 25 or more employees were accountable under this provision of the law as of July 26, 1992, and employers with 15 or more employees were required to be in compliance as of July 26, 1994. This title and its various provisions apply to both public and private employers.

Title II: Public Service Provisions

The ADA prohibits state and local governments from excluding persons with disabilities from participation in services, programs, or activities. The title applies to all state and local government agencies or programs as well as to any instrumentalities or departments of state and local governments. One key aspect of Title II pertains to public transportation. Specifically, the ADA requires every public entity which operates a "fixed route" transportation system to purchase only new busses or rail vehicles which are readily accessible to, and usable by, individuals with disabilities. The ADA also requires public operators of "fixed route" transportation systems to provide para-transit that offers a comparable level of service to that which is available to people without disabilities. These transportation requirements have already taken effect, for the most part.

Title III: Public Accommodation Provisions

The ADA requires both privately- and publicly-owned establishments that are used by the general public to be accessible to people with disabilities who are customers, visitors, employees, or clients. The following are examples of the kinds of establishments that are covered by the ADA in this regard: hotels or motels; restaurants, bars, or other establishments serving food or drink; theaters, concert halls, or stadiums; auditoriums, lecture halls, or convention centers; stores and shops; gasoline service stations; law offices; accounting offices; insurance offices; the professional offices of health care providers; hospitals; museums; libraries; public transportation terminals; parks or zoos; nurseries, schools, and other educational facilities; child day-care and senior citizens' centers; social service centers; and gyms, health clubs, and other recreational facilities. Exceptions include religious establishments, certain small private clubs, and certain structures of fewer than three stories or 3,000 square feet per floor. These Title III provisions, generally, have already taken effect.

Title IV: Telecommunications Provisions

The telecommunications provisions are designed to ensure that hearing- and speech-impaired individuals have access to telephone services that are functionally equivalent to those provided to individuals without speech or hearing impairments. These services include TTY voice-relay systems which enable people with speech or hearing impairments to make interstate phone calls to non-TTY users. Title IV applies to all telecommunications carriers who provide intrastate or interstate communications services. Users of these telecommunications services or systems cannot be charged higher rates for the use of the new services or systems. The provisions of Title IV, generally, have already taken effect.

Preliminary Assessment of the Degree of Compliance to Basic ADA Provisions

City and County Services and Facilities

A group of eight students visited City Hall, the County Administration building, the local post office, and the public library. The areas of greatest ADA-related concern included the following:

Title II: Government public service

1. Mobility-impairment--Obvious accessibility problems when it comes to entering and using facilities, especially City Hall and the local post office.
2. Visual-impairment--Accessibility problems, and possibly dangerous situations (e.g., at the post office); a lack of Braille signage in many locations; and extreme lack of reading material in accessible formats at the community public library.
3. Hearing-impairment--Lack of adequate visual signage in places; the unavailability of an individual, particularly in City Hall, who knows sign language; pronounced lack of lighted fire alarms in many instances.

Title IV: Telecommunications--I know of no TTYs or other helpful telecommunications equipment for people with hearing or speech impairments.

Title I: Employment--I have no knowledge of people with disabilities working in any of the aforementioned city/county facilities. On the more positive side, though, the city of Big Rapids has developed a rather comprehensive handbook and a grievance procedure for dealing with various employment-related concerns of people with disabilities.

City/County Parks and Recreational Facilities

Six students surveyed accessibility at Big Rapids' two primary recreational areas, Hemlock Park and Mitchell Creek Park. In addition, the group visited a number of other local parks and recreational facilities, both public and private. The assessment revealed the following ADA-related concerns:

Title III: Public accommodation provisions

1. Mobility-impairment---Basic accessibility problems, including a lack of available and conveniently-located handicapped parking spots, especially at Hemlock Park.

2. Visual-impairment---Various safety-related concerns, including lack of warnings about proximity to bodies of water; lack of adequate side railings on athletic-field bleachers; lack of guide rails on stairways leading to restrooms; and a lack of appropriate, helpful Braille signage.
3. Hearing-impairment---No pronounced difficulties.

Title IV: Telecommunications--I know of no TTYs or other assistive telecommunications devices for people with hearing or speech impairments.

Title I: Employment--I know of no employees with disabilities at any of the aforementioned facilities.

City Streets and Sidewalks

A group of six students surveyed the accessibility of sidewalks and streets in both commercial and residential areas throughout Big Rapids. The following ADA-related concerns were noted:

Title II: Government public services; and Title III: Public accommodation provisions

1. Mobility- and visual-impairment--The problems here are obvious, since people with mobility or visual impairments must use sidewalks for safe and efficient travel from one destination to the next. The problems basically amount to inaccessible, discontinuous, unusable, or poorly-maintained sidewalks due to various circumstances or situations. Many of these circumstances or situations are actually quite controllable either by city residents or officials. Although some progress has occurred here, it is quite clear that much remains to be done.
2. Concerns unique to people with visual impairments---No Braille signage for identification of streets and directions of travel; no audible signals at busy street intersections to assist those with visual impairments in assessing changing lights and traffic flows.

Public Transportation

Even though Big Rapids does not have a continuously-running fixed-route public transportation system, it does have an "on demand" dial-a-ride bus system which operates throughout the community Monday through Saturday from early morning through early evening. Children, senior citizens, and people with disabilities can ride for half the usual one dollar fare.

The following ADA-related observations are based on my own personal experiences as a Big Rapids City resident who uses this public transportation system regularly for commuting to and from work as well as for other assorted everyday purposes:

Title II: Government public services: It clearly seems that, given its nature and size, Big Rapids is in compliance with the ADA on this matter. This is particularly true when the specific public transportation provisions are considered.

There are, nevertheless, a few basic areas of concern that should be noted, especially for those with mobility or visual impairments. First, there is a possible need for a more comprehensive "fixed route" transportation system that could serve the community on a regular basis both on weekdays and on weekends. Such a system should have lift-equipped busses, should be staffed by drivers who are licensed Passenger Assistance Technicians, and should be affordable. Although a system of this nature was tried in Big Rapids during the late 1980's, ridership was quite low, and success was not realized. The reasons for these failures need to be examined thoroughly. In addition, more needs to be done to link people with disabilities who lack their own sources of transportation to opportunities and events beyond the boundaries of Big Rapids proper.

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How Workers Who Have Disabilities Perceive the Provisions of the 1990 Americans with Disabilities Act

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Introduction

On July 26, 1990, President Bush signed into law the Americans with Disabilities Act (ADA), the most sweeping employment legislation since the 1964 Civil Rights Act. The ADA has the potential to beneficially influence the work lives of America's 36 million citizens who have disabilities. Implementations of the employment provisions of the ADA were July 26, 1992, for businesses with 25 or more employees; and July 26, 1994, for businesses with 15 or more workers. This paper presents limited data on how workers who have disabilities perceive the employment provisions of the ADA. More importantly, it documents the problems associated with a major project designed to locate and survey workers who have disabilities.

Background

When the ADA became law, about twenty-one million Americans with disabilities were physically able to work, but only six million were employed. A concern of ADA advocates was that, while 79% of nondisabled Americans work or seek work, only 32% of Americans with disabilities work or seek work (Barlow, 1991). The ADA was created to provide people with disabilities an equal opportunity to seek and gain employment.

Several surveys conducted before the ADA suggested that hiring people who have disabilities would increase health insurance costs beyond the means of most small businesses. Other studies projected that workers' compensation costs would skyrocket. Architects and contractors estimated workplace reconstruction to accommodate workers who have disabilities could run into billions of dollars, while personnel administrators believed the entire process of recruiting, selecting, and hiring employees would have to be examined and restructured (e.g., Ballenger, Franklin, & Robinson, 1992; LaFraniere, 1992; Otis, 1991; and Saddler, 1991, 1992). These projected high costs of Title I compliance led many attorneys to feel that a lack of compliance could be expected to generate numerous law suits. The Equal Employment Opportunity Commission (the EEOC) predicted about 12,000 to 15,000 new complaints, a 20% to 25% caseload increase. The Employment Policy Foundation projected 12,000 ADA discrimination suits (LaFraniere, 1992).

Other studies, though, refuted these high costs, suggesting compliance would be neither difficult nor costly (e.g., Kornblau & Ellexson, 1991; Lublin, 1992; and Ward, 1991). This author, in 1992, completed national studies of two industries (media and aviation) assessing problems businesses encountered complying with the ADA. The majority of businesses reported compliance did not require an inordinate amount of time or effort, nor was it expensive (Worthington, 1994).

This research also found that most businesses felt they were in compliance with Title I of the ADA, and compliance was neither a financial burden nor arduous. The question that remained unanswered was how workers with disabilities perceived their employers' ADA compliance. Were they as satisfied as management reported? Did they feel their employers were making every effort possible to accommodate employees with disabilities?

While it is still too early to know the full legal repercussions of the ADA, the Justice Department reported receiving over 1,500 complaints in 1992 (Dunne, 1993); and the EEOC received about 100 discrimination claims a week in the first five months of the ADA. EEOC claims were up to 1,000 per month in the first half of 1993, and, by September, they had risen to almost 1,700 a month ("Lawyers Disable Disability," 1993; "Disability Cases Rise," 1993; and "Disability Docket," 1993).

In the fall of 1993 this author and a colleague conducted a national pilot study of workers with disabilities who were located in 21 cities. The purpose was two-fold: to determine if problems would be encountered conducting a major national survey of workers with disabilities, and to ascertain how successful workers believed the ADA was in their place of employment (Worthington & Eatough, 1994).

A questionnaire was designed for employees with disabilities working in public and private organizations. This survey was mailed to all attendees of the Sixth Annual Meeting of the Society for Disability Studies who had a U.S. address. Enclosed was a cover letter requesting assistance in this study. This yielded a sample of 115 individuals in 25 states and the District of Columbia. Each survey packet included three surveys with a request for the recipient to return as many surveys as possible.

While this method of gathering research data from a group purporting to have an interest in the topic had potential for a decent pilot sample, the actual return was very poor, only 24%. This study suggested that employees tended to agree with management that businesses were in compliance with Title I of the ADA. Employees felt that managers were aware of the ADA and that there was compliance with employment provisions of the Act. Most businesses were at least addressing the concerns of their employees who had disabilities to some extent even before the legislation took place.

Problems Conducting the Satisfaction Survey

Creating a survey for America's workers with disabilities brings researchers face-to-face with two immediate problems. First, how does one identify and locate workers who have disabilities; and, second, how does one design a questionnaire that can be applicable and usable by people with different types of disabilities?

Four years ago the EEOC attempted to conduct a similar study of employees with disabilities in private industry (C. Kirchner, personal communication, August 23, 1993). One agency which had been asked to assist declined because the printed survey form was inaccessible to workers with certain disabilities (e.g., those with visual impairments, mental retardation, or limited fine motor coordination skills, just to name a few). Anonymity was not possible if respondents with disabilities required assistance to complete the survey.

Recommendations to overcome these problems present another dilemma: the cost of creating and successfully distributing sufficient alternative forms of a survey to make accommodations for most types of disabilities. Another problem is the task of locating employees with disabilities.

This author presumed that, in most cases, keeping a list of employees with disabilities could be a violation of Title I of the ADA (Worthington & Worthington, 1993). Therefore, there would be no record of which workers had disabilities and which ones did not (except for confidential medical records).

Nationwide random sampling of organizations with employees with disabilities appears to be an impossible task. To test this assumption, in the Spring of 1994, a simple four-question survey with a cover letter was sent to 33 managers or owners of small businesses across the nation which ranged in size from under 15 employees to over 100 (the smallest business had 4 employees while the largest over 2,700). Surveys were returned by 27 respondents, yielding an 82% return rate.

The results of the survey clearly suggest that the majority of the businesses sampled (78%) do not keep lists of names of employees with disabilities. Of the six who indicated that a list was kept, two said it was required for compliance with Worker's Compensation regulations. It is interesting to note that the majority of respondents (70%) did acknowledge that many managers know which employees have disabilities. A cross-checking based on company size of the companies which did or did not keep lists, or which did or did not have managers who knew about employees with disabilities reveals that there is no relationship between the number of employees and formal or informal knowledge of which workers have disabilities. This limited survey suggests that lists of employees with disabilities are not maintained by business organizations, but most managers know which employees have disabilities.

Conclusions

The results of the several research projects presented in this paper suggest: (1) limited sample size studies regarding individuals with disabilities can be effectively conducted; (2) massive nationwide surveys of individuals with disabilities may be impossible to conduct because of problems locating a large, truly random sample and the expense of developing and administering surveys acceptable to people with a wide range of disabilities; and (3) most managers are aware of the ADA, are in compliance with Title I, and were attempting to address some employee concerns even before the ADA.

Most research projects in this vein will likely continue to be small sample size projects in which the findings will increase in potency and validity through sheer volume. This is assuming, of course, that the findings are replications of previous results. Divergent findings will only add confusion to the question of how workers who have disabilities perceive the success of Title I of the ADA in their workplaces.

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Section VI

Increasing Access to Services

Even while the ADA formally acknowledges the civil rights of people with disabilities in the United States, actions being considered and taken at federal and state levels pose serious challenges to consumers attempting to increase or even retain access to services. As programs, including independent living centers, face financial cuts and redefined policy directions (e.g., managed care), we must continue to seek fair, effective access to a variety of services including, but not limited to, Personal Assistance Services (PAS) and assistive technologies. The papers in this section address such concerns.

In "The Cost of a National System of Personal Assistance Services (PAS)," Lance C. Egley describes a study conducted by the World Institute on Disability (WID) in which WID identified six models of PAS and estimated costs for each model. The study concluded that offering consumers a choice of services provided either by agencies or by individuals would optimize cost benefits and best encourage support for independent living.

One way in which some states have provided PAS services has been through the use of Medicaid Waivers. Ray Glazier describes such a program in Pennsylvania in his chapter, "Feasibility Study for a Personal Assistance Services Home- and Community-Based Medicaid Waiver Program: Some Dilemmas Encountered Conducting Applied Social Research." In examining the feasibility of establishing such a program, Glazier concludes that proposed waivers would be economically feasible. However, Glazier also notes a number of ways in which such a program raises policy, bureaucratic, and ethical challenges.

Many of the same dilemmas facing agencies and individuals who want to establish access to PAS also face those who want to broaden access to and effective use of assistive technology. Bonnie L. O'Day outlines many of these issues in her paper, "Assistive Technology: Problems and Policy Alternatives." Like Glazier, O'Day points out the ways in which the construction of current policies too often allows individuals to "fall through the cracks." Even if consumers do receive assistive technology, there is often no support for training and maintenance. Consumers may also be told what they need, rather than participating in decision making. O'Day corroborates what other authors in this section emphasize: access to cost effective and personally meaningful services will require significant policy modifications and the real (not just stated) inclusion of consumers.

Optimal access to services involves the coordination of consumers and organizations. In "Family Involvement and Technology Use at Home by Children and Youth with Disabilities: Promoting Home-School Collaboration," Adele Schwartz summarizes results of a survey designed to evaluate home use of technology by young people with disabilities. Families who responded to the survey indicated strong interest in assistive technologies. Unfortunately, collaboration between home and schools too often is unorganized and limited. Schwartz outlines a number of ways in which the mandate of the Individuals with Disabilities Education Act can be realized.

In this section's last chapter, Paula Sotnik describes a successful collaborative effort, "Utilizing Community Resources to Provide Assistive Technology Training to Diverse Cultural and Linguistic Minority Individuals with Disabilities and their Families." As we noted in Section III of this book, too often research on and policies directed towards people with disabilities have not taken cultural differences into account. Sotnik outlines a program that sought to give Portuguese-speaking, Latino, and Cambodian communities accessible information about assistive technologies. A key element of this program was the inclusion of community members from the beginning to provide advice and oversight. We end the section with this paper in order to remind readers that, with careful planning, inclusion, and mechanisms for feedback, collaboration can produce positive results, in this case the provision of meaningful and useful information about assistive technologies to "underserved" communities.

The Cost of a National System of Personal Assistance Services (PAS)

**Lance C. Egley, Ph.D.
World Institute on Disability**

Cost has been a major barrier to implementing a national system of Personal Assistance Services (PAS). As was true under the Pepper Commission (U.S. Bipartisan Commission, 1988), it is again a barrier in recent Health Care Reform proposals (ASPE, 1994). Senator Moynihan's Finance Committee marked up the Health Security Act without the Long Term Care provisions of which PAS constitutes roughly 20%. (The other 80% is nursing home or home medical services.)

To address the cost issue, the World Institute on Disability (WID) in Oakland, CA, designed a study to estimate the cost of and the support for independent living provided by a national system of PAS under various service delivery models. WID staff believed that service delivery mode was a crucial cost factor which had not been considered in previous estimates.

Models

WID identified six models and determined their cost and their support for independent living from the 1989 WID survey of all publicly-funded programs providing PAS primarily to people with physical disabilities in the 50 U.S. states and the District of Columbia. (For methodological details, see Litvak & Kennedy, 1991; Litvak, Zukas, & Heumann, 1987.)

In the Individual (or independent) Providers model (IP), an individual attendant provides services to a specific person with a disability. In the Agency Providers model (AP), organizations arrange the connections between attendants and people with disabilities. Both IP and AP can require medical supervision or not. Together these features combine into four models. A fifth model, High Management programs, requires extremely high levels of supervision, paying up to \$50 per hour to supervisors who account for 20% of direct service staff time. In a sixth model, states legislate reimbursement rates, paying agency and individual providers at equal rates.

Principle Findings about the Models

1. Individual Providers offer more support for independent living than Agency Providers.
2. The cost for Individual Providers per hour of service is one-half the cost for Agency Providers. Although IP wages and benefits are lower than those of

direct service workers from Agency Providers, when IP wages and benefits are raised to equal those of agency workers, IP hourly costs are still only three-quarters of those for APs. The difference is in administrative costs.

3. When given a choice between IP and AP services, 70%-80% of the people under age 65 in Pennsylvania and Illinois who were surveyed indicated that they would choose IP, enough people to realize most of the cost savings.

Support for Independent Living

The use of Individual Providers and having no requirement for medical supervision add separately, but equally, to support for independent living. States with legislated rates have support for independent living which is about equal to the lowest of the first four models, the Medically Supervised Agency Provider. A sixth model, High Management programs, provides even less support for independent living.

Cost Per Hour of Service

Programs in states with legislated rates were nearly as inexpensive as IP programs. Medical supervision costs only slightly more, adding about 10% to the cost of AP or IP programs. High Management programs' cost per hour was twice the cost per hour of AP programs, and four times that of IP programs. In other words, for every dollar spent to deliver services through Home Care Agency Providers with frequent supervision by RNs and/or case managers, it would cost

- * 50 cents to use agency providers requiring minimal supervision
- * 38 cents to use IPs whose wages and benefits equal those of other workers
- * 25 cents to use IPs working at today's average wage

Cost Estimates

To make cost estimates from the average costs per hour of various models requires multiplying hourly costs by the total number of hours of expected use nationwide. The number of hours can be estimated as the product of the number of people with disabilities using paid assistance and the average hours of service used. This information was calculated from the 1987 National Medical Expenditure Survey (NMES) data (Edwards & Berlin, 1989), which has been validated by two other national surveys. These data are used in administration estimates.

Hours of Service Finding

The total hours of paid services used by people with three or more Activity of Daily Living (ADL) limitations, the eligibility criterion for services in the Health Security Act, is one-half the number of hours used by people with any ADL or Instrumental Activities of Daily Living (IADL) limitation. Since the cost of using IP programs is only one-half the cost of using AP programs, the savings realized from choosing an appropriate model could be enough to expand services to all people with ADL or IADL limitations.

Increased Use with More Government Funding

Many people do not consider a cost estimate complete unless it considers the possibility that, when government funding increases, the amount of paid services used may also increase above current use. Since more than 80% of people with disabilities receive some voluntary assistance, policy makers worry that the effect of increased usage might be very large. To determine how much this expansion would be, WID examined the proportion of all people with disabilities who receive paid PAS from publicly-funded programs in each state. A national program designed like any particular state program would be expected to have participation from a similar proportion of people with disabilities. Specific participation rates for the different models could not be found because many states mix various models and because other factors, such as how well established the programs are, and the state's rural or urban character, affect these rates. Research has found that no state serves more than 38% of its residents who have disabilities. An estimate based on this participation rate was nearly double the estimate based on the current rate of use. When adjusted for increased hours of use, the estimate was just over twice the amount. Other research, using National Long Term Care Experiment data (Liu, McBride, & Coughlin, 1990), suggested doubling the number of hours of usage as a result of increased funding. These data were assumed to be correct by the Pepper Commission (U.S. Bipartisan Commission, 1988) and are intended for use in official estimates of the costs of the Health Security Act (HSA), although the HSA formula used was somewhat higher than WID's or the Pepper Commission's (ASPE, 1994).

Cost Findings

Anticipating double the current usage, services can be provided to people with *any ADL or IADL limitation* under the different service models for the following annual costs:

Individual Provider without Medical Supervision	\$ 12.8 billion
State Legislated Rates for Reimbursement	12.9 billion
Agency Provider without Medical Supervision	22.2 billion
(for Medical Supervision add 10% to the above)	
High Management Provider	54.3 billion
Consumer Choice of AP and IP	14.0 billion

Since the above estimates cover a wider population than the Health Security Act, we should remember that, using the consumer choice model, the cost of serving only people with 3 or more ADL limitations would be \$7 billion. Extending WID's 1989 data to the present, publicly-funded federal and state programs are *already spending some \$5 billion.*

Policy Recommendation

WID recommends a national program of PAS for people with disabilities under a consumer choice model. The United States can afford it.

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Feasibility Study for a Personal Assistance Services Home- and Community-Based Medicaid Waiver Program: Some Dilemmas Encountered Conducting Applied Social Research

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Introduction

In the context of this research, the concept of "personal assistance services" (PAS) was limited to in-home, non-medical services provided to a person with a severe physical disability by an attendant, performing ADL/IADL functions the consumer would ordinarily do for himself/herself absent the disability (exclusive of reader and interpreter services, for example).

PAS services are provided by Medicaid with federal/state cost-sharing to citizens with disabilities in more than half the states under Home- and Community-Based Services (2176) Waivers, through which the federal Health Care Financing Administration (HCFA) allows states to waive certain standard restrictions: statewideness; universality; amount, scope, or duration of services; and/or financial eligibility requirements. Some states (like New York, the nation's largest such program, and Massachusetts, one of the most accessible) have PAS as an optional benefit under their state Medicaid plan.

In order to obtain (and maintain) HCFA approval of a Medicaid waiver, the state must prove cost-neutrality and give HCFA assurances that recipients' health and welfare will be safeguarded, that there will be a written plan of care for each recipient, that there will be provider standards, that declined consumers will receive a fair appeals hearing, and that there will be an independent evaluation and audit of the program.

Background

Pennsylvania's Attendant Care Program (ACP), designed and pilot-tested beginning in 1984 and established by the Legislature of the Commonwealth by Act 150 in 1986, has been a landmark program used as a model by other states. However, the constraints of state funding supplemented only by Social Security Administration Block Grant funds have resulted in a substantial waiting list for in-home attendant care or personal assistance services and limitations on the numbers of hours of service that can be provided to ACP consumers. This situation, given greater urgency by consumer litigation seeking more PAS, led policy makers in the Department of Public Welfare (DPW) to consider the possibility of a Medicaid waiver that would have the

effect of permitting expansion of PAS service provision in the Commonwealth. The state's intent became to "clone" the successful ACP, insofar as Medicaid regulations allowed this.

Abt Associates Inc., an independent, employee-owned social research organization, was selected to conduct for the Pennsylvania DPW a Feasibility Study for a Personal Assistance Services Home- and Community-Based (2176) Medicaid Waiver Program. The major declared HCFA criterion for a 2176 waiver program is that it must be at least as cost-effective as maintaining the same persons in nursing homes or other institutional settings. To prove this, the state must be able to demonstrate that the total average annual per person Medicaid expenditures under the waiver (PAS costs, doctor bills, pharmacy bills, and other outpatient medical bills, all added together) will not exceed the average annual per person Medicaid expenditures if the waiver were not in place (nursing home costs plus other medical bills); this is referred to as "cost neutrality." However, documenting the potential for cost savings that common sense seemed to indicate would result from a waiver PAS program was far from simple.

Research Methodology

The study reported here employed both qualitative research (a literature review, a series of constituency focus groups, a set of state case studies, and meetings with HCFA) and quantitative research (compilation and analysis of data on characteristics of ACP consumers and waiting listees, a direct mail survey of a sample of same, analysis of historical ACP service volume and cost data, statistical projections of PAS needs in Pennsylvania, and cost-neutrality analyses). The subjects of this research were Pennsylvanians possessing a combination of three Medicaid Waiver PAS Program eligibilities: Medicaid eligibility (financial and medical need), nursing home eligibility (as assessed for our sample by an experienced Pennsylvania registered nurse's review of survey responses), and Act 150 program eligibility (ages 18 through 59, having a physical disability, being "mentally alert," i.e., having the ability to participate in the direction of the attendant).

Findings

The results demonstrated that, even if administrative costs (and, therefore, total per capita costs) are significantly higher under a waiver program, a *substantially greater* number of consumers could be served if a waiver program were made available along with the ACP, compared to an alternative in which only the Attendant Care Program exists. If all Medicaid-eligibles transfer into the Waiver PAS Program, the waiting list can be reduced to zero, even in the "worst case" Oregon administrative expense estimate. The Commonwealth decided, therefore, to proceed with a 2176 waiver application to HCFA that was ultimately successful.

Remaining Dilemmas

Areas of continuing policy concern include:

1. There is a basic conflict in that Medicaid is a medical assistance program, and PAS is a non-medical, independent living concept. However, historically, a major way to get funding for it has been via Medicaid; private health care insurance almost never pays for PAS.
2. Until 1994, the HCFA application form for 2176 waivers had a check-off for "personal care services," the definition of which was based on a home health agency/visiting nurse model. Pennsylvania's existing program is proudly non-medical in orientation, and consumers wanted a parallel Medicaid Waiver program to include provisions for consumer control. In April 1994 HCFA released a new waiver application form with a check-off for consumer-directed "attendant care services" that was used for the Pennsylvania application authored by Abt Associates Inc.
3. In Pennsylvania, as in most other states, PAS service delivery is fragmented along bureaucratic departmental lines; the waiver application to "clone" the Attendant Care Program, defined as being for "mentally alert," non-aged adults with physical disabilities, will be the fourth Medicaid waiver attendant care program in the Commonwealth and will create the fifth separate state PAS program. The patchwork system of PAS provision through five different state-funded programs lets those not considered "mentally alert" fall through the cracks; there is no provision for PAS to persons with traumatic brain injury (TBI) or chronic mental illness (CMI), and PAS is so defined as to exclude reader and mobility services for people who are blind and interpreter services for those who are deaf.
4. Although the "Pennsylvania Model" assumes a level of consumer direction of services on a day-to-day basis, its provision for a continuum of consumer control/agency provider control is amenable to the inclusion of those persons with TBI or CMI, perhaps with an increased emphasis on case management.
5. In order to provide the PA Model, with 24-hour a day, 7 days a week service availability, a number of the ACP's current network of 16 agency providers, who would form the natural nucleus for the Medicaid waiver provider network, must subcontract for certain service elements. (Providers who are agencies of local governments must, in fact, subcontract out all in-home service provision in order to avoid paying civil service wages and benefits to attendants.) Yet, HCFA forbids subcontracting, which it terms "factoring," but it does permit the practice by Organized Health Care Delivery Systems, as which most PAS providers could be construed.

6. The Medicaid Waiver PAS Program (like the ACP) must provide for transitioning of individuals into the Department of Aging PAS program on the 60th birthday, as well as for "seamless" (or invisible to the recipient) transition from the Medicaid waiver to the ACP for those who lose Medicaid eligibility, e.g., by going to work. But PAS consumers do not fall neatly into departmental spheres of responsibility, and consumer/attendant relationships are often intense and, sometimes, mutual dependencies.
7. There is an inherent danger in creating a parallel program for Medicaid-eligible persons that a class-based delivery system will result, in which services are perceived to be of lesser quality or availing less consumer control and more medical involvement.
8. Given state budget neutrality, new PAS consumers will only be served to the extent that Medicaid-eligible ACP consumers move from the state-funded ACP into the Medicaid Waiver PAS Program. There is need for an incentive for consumers to make this shift.
9. HCFA's insistence on a "first come, first served" waiting list, ironically, does not allow prioritization of persons most at risk for institutionalization, even though that is the purpose.

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Assistive Technology: Problems and Policy Alternatives

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The technology exists to allow people with severe disabilities to work, live independently, and participate fully in community life. Yet, the majority of people with disabilities find the technology and devices they need to support their independence and productivity out of reach. Contributing factors include lack of personal finances, complexity of third party payment sources, rigid federal and state regulations, and lack of health care coverage. The purpose of this paper is to make recommendations to increase the availability of technology under health care reform proposals.

The Technology-Related Assistance for Individuals With Disabilities Act of 1988, often referred to as the "Tech Act," defines an assistive technology (AT) device as "any item, piece of equipment or product system, whether acquired commercially off the shelf, modified or customized, that is used to increase, maintain or improve the functional capabilities of individuals with disabilities" (P.L. 100-407, Section 3.1). In other words, AT refers to any device or product that allows a disabled individual to accomplish tasks of daily living, participate in the work force, and partake in community activities. AT includes durable medical equipment (DME), simple devices, such as one-handed can openers and hearing aids, as well as more costly and complex items, such as environmental control systems and reading machines. Modifications to the home, such as lever faucets are also included.

AT is cost effective (Symington, Lywood, Lawson, & MacLean, 1986) and beneficial to individuals and their families; and it increases the capacity of both children and adults with disabilities to function independently in the home, at work or school, and in the community (McGrath, Goodman, Cunningham, MacDonald, Nichols, & Unruh, 1985). In a comprehensive study on the financing of AT, individuals and families who had received AT devices and services reported that

About 75% of the children who received AT were able to remain in a regular classroom, and about 45% were able to reduce school-related services.

About 62% of working age persons were able to reduce dependency on the family, and 58% were able to reduce dependence on paid assistance.

About 80% of older persons were able to reduce their dependence on others, and about half were able to avoid entering a nursing home.

About 92% of employed persons reported that AT helped them to work faster or better, 83% indicated that they earned more money, and 67% reported that AT had helped them to obtain employment (National Council on Disability, 1993).

Problems

To receive assistance in purchasing AT, the individual with a disability must generally meet eligibility requirements for one of many programs that are often quite complex; then, they must determine, based upon intricate rules and guidelines, whether the desired equipment is covered by the program. The system is difficult to negotiate, and many needy individuals fall through the cracks. While the cost of some equipment, such as adapted computer technology, is beginning to decrease, financing is still the most significant problem faced by individuals who need AT. More than 2.5 million Americans say they need AT that they do not have, with about 70% citing cost as the primary reason (LaPlante, Hendershot, & Moss, 1992). The low income of people with disabilities exacerbates this problem. Another issue is equipment denials by third party payers (Donovan, Carter, & Wilkerson, 1987). Still another is quality assurance: confidence that the equipment is of good quality, will be of benefit to the individual who gets it, and that the person who prescribed it was qualified to do so (Reeb, 1987).

At the root of these problems is a multifarious system in the United States for acquisition of AT. Congressional mandates, federal and state funding formulas, administrative rules and procedures, private insurance policies, and non-profit agencies all provide funding for AT. Most of these agencies use complicated and cumbersome eligibility requirements. Lack of funds to purchase AT, no centralized information and evaluation system, fraud and abuse by some medical suppliers, and inconsistent policies within and between programs face consumers who need AT (National Council on Disability, 1993; Phillips, 1989; Ward, 1990).

In recognition of these problems, Congress passed the Tech Act, which provides state grants of one-half million to one million dollars to increase the financing and availability of AT. While the goals of the Act are laudable, funding limits the program's impact. Most states maximize resources by focusing on information and referral, advocacy for individuals seeking equipment, and policy reforms to improve programs that already fund AT. The projects have attained important policy modifications in some states, but not wholesale policy reform.

An interesting contrast to this complex federal funding and policy framework can be found in programs operated by the Veterans Administration (the VA). As the most extensive single health care system in the country, the VA is one of the largest buyers of assistive devices, and it has one of the most systematic structures to evaluate and pay for them. Similar to other federal programs, services are targeted to those who

are perceived to be most in need through an extremely complex eligibility system. But, unlike other programs, the VA system covers a broad range of equipment, including hearing aids, eyeglasses, speech and sensory aids, adapted computers, van modifications, and home access equipment. The equipment can be used for any purpose, including employment, education, or independent living.

The VA also differs from other programs in that it has invested heavily in personnel to assist recipients in making decisions about the equipment they need, and it makes this equipment available through local VA centers and hospitals. Consumers receive evaluation, training, repair, and other services from the same provider, minimizing the hurdles to successful use of AT. The VA also invests substantial resources in research and demonstration activities, developing new and innovative technology for everyday use (Reeb & Stripling, 1989).

Analysis

Most health care reform proposals allow coverage of extended periods of hospitalization, organ transplants, or expensive, life sustaining intervention. Under many of these same proposals, individuals with disabilities will not be able to obtain simple AT devices that may allow them to remain in their homes, even though this option is more cost effective. People with heart conditions, kidney failure, or cancer can obtain high cost operations and other medical care to facilitate recovery. Yet, people with other types of disabilities who need technology to make the adaptation to a "hostile" and inaccessible environment cannot obtain the assistance they need. If the disability can be "fixed" with surgery or technology inside the body, financial assistance and services are readily available. Assistance is often not available if the person requires technology outside the body to "fix" the interaction between the body and the environment. AT, as well as support services, such as prescription, evaluation, training, and repair should be included in health care reform.

Another problem is the use of the term "durable medical equipment" (DME) and the definition of "medically necessary" contained in most health care reform proposals. These medically-based terms do not reflect the reality of what people with disabilities need in order to be independent. Yet, using the all-inclusive definition of AT contained in the Tech Act would make it extremely difficult to establish limitations on what equipment should be covered. The concept of medically necessary could be broadened to include provisions for equipment needed for an individual to live independently in his/her home and to reduce reliance on medical services or other supports. Criteria could then be established that limit the equipment to what is necessary for the health and safety of the individual.

Cost is a major barrier to including coverage of AT in health care reform proposals. In the current economic climate, Congress and the Administration are reluctant to expand coverage. The immediate short term costs of this proposal should be

considered, along with any potential savings in hospital or institutional care. Costs could be contained by emphasizing requirements for assurance that the equipment will facilitate increased independence, rather than by placing blanket restrictions on the types of equipment that can be purchased.

Another major issue is the lack of consumer involvement in selecting, procuring, and evaluating the equipment. For a person who has a disability, being an active consumer rather than a passive recipient insures that the individual will have a stake in procuring equipment that is truly necessary, and that she or he will utilize the equipment to its fullest capacity (Reeb, 1986). Consumers who benefit from increased opportunities to acquire AT should also bear some responsibility to insure its effective utilization. Too often, consumers are given AT with no assurance that the equipment will actually be used. Consumers should document that they have evaluated alternative solutions and made the optimal choice, they should delineate a training plan, and they should make income-based co-payments to assure the payer that the equipment will be used effectively.

Finally, the VA system for procurement and distribution of AT should be examined more closely for potential broader application. If mechanisms can be developed to control costs, this strategy may offer the greatest potential for the equitable provision of AT to individuals with disabilities. The VA assures that the equipment is provided as part of a service plan, including in-home services, medical care, and follow up. Payment of equipment is handled through a central source, minimizing red tape and multiple bureaucracies. Prescription is provided by experts in the particular field of disability in conjunction with the consumer, assuring the best fit between the equipment and the patient, and curtailing unnecessary expenditure. Training and distribution are handled locally through centralized clinics, assuring maximum benefit from the equipment and a high level of local access.

AT is crucial to the independence, dignity, and productivity of millions of Americans with disabilities. Not only can AT transform the lives of its users; it can decrease the medical, hospital, and institutional costs of disability. The policy modifications outlined in this article will bring us closer to realizing the potential of AT.

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Family Involvement and Technology Use at Home by Children and Youth with Disabilities: Promoting Home-School Collaboration

**Adele Schwartz, Ed.D.
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The passage of the Individuals with Disabilities Education Act (I.D.E.A.) gives schools greater responsibility to identify students' technology needs, to secure the appropriate hardware and software, and to provide assistive services to enhance technology use. The development of computers and related assistive and augmentative devices offers unprecedented opportunities for independence and learning to children and youth with disabilities. The home may become an effective place in which to provide extended instructional and independence-enabling experiences. Consequently, there will be a need to implement home-school collaboration relative to technology use.

Too little is known about the nature and extent of current technology use at home and the school factors which influence that use. This study was designed to provide baseline data in this area. The findings indicate a need for schools to develop highly individualized models of home-school collaboration which attend to the wide range of family needs, strengths, interests, and abilities for involvement. Family and school roles in the collaboration are addressed, as are services needed to enhance home technology use by school-aged children and youth with disabilities.

Background and Rationale for the Study

In the early 1980's, the infusion of computers and assistive technologies into the home and school lives of America's children and youth was touted as the beginning of a revolutionary era in education, one that would empower both parents and children by turning the home into an educational hub (Papert, 1980; Toffler, 1980; Turkle, 1984). In 1991 it was estimated that there were more than 30 million computers used at home (Keizer, 1991), and that one in every four households had a computer ("More Homes," 1991). In the classroom, technology access is limited by time and availability; at home, children and youth can accomplish more because time and access may be more readily available (Wright & Church, 1986). Educational software can enhance inclusion by matching needs and interests with effective interventions, by providing sequenced content and appropriate feedback, and by consistently and accurately monitoring performance in an unbiased and non-judgmental manner (Goldenberg, Russell, & Carter, 1984; Semmel, Cosden, Semmel, & Kelemen, 1984). Assistive technologies, such as augmentative communication, environmental control, and alternative input and output devices, can enable children and youth with disabilities

either to participate in activities otherwise impossible without that technology or to perform educational operations more fully and independently (Male, 1988).

Since the mid-1970's, there has been a substantial body of research confirming that family involvement in the education of children with disabilities is a powerful, positive factor in the child's development and learning (Lillie, 1975; Shearer & Shearer, 1976; Yoshida, Fenton, Kaufman & Maxwell, 1978). The need for parent involvement has become widely accepted both in policy and in practice. Further research has demonstrated that the home-school connection is also important in regard to technology use (Epstein, 1985) and that the educational use of home computers, for example, would increase considerably if parent/school relationships involving their use were improved (Giacquinta & Lane, 1989).

Unfortunately, it appears that schools have made inadequate, if any, attempts to coordinate home-school collaboration, and they have not developed systematic models for supporting families in technology use at home (O.T.A., 1988; Brooks & Kopp, 1989). They do not comprehensively inform parents of the benefits and the need for technology use, nor do they create a need or opportunity for school to home follow-up, reinforcement, integration, or collaboration (Edyburn & Lartz, 1987; Giacquinta & Lane, 1989; Levin, 1988; Margalit, 1990). There is general agreement that there is a need for effective technology collaboration between school personnel and families (Moss, 1988; Perelman, 1988; Taylor, 1987; Tetenbaum & Mulkeen, 1986).

Educational legislation strongly supports the increased use of technology by children and youth with disabilities. Public Law 100-407, The Technology Assistance Act of 1988, issued mandates which set state education departments into motion, establishing networks of support; independent service centers, such as those of the Alliance for Technology Access, further encouraged these efforts. Yet universal access has been woefully inadequate. The Individuals with Disabilities Education Act of 1990 strengthened the technology mandate in specific ways. Schools are required to: identify each student's technology needs, including training, and indicate this on the I.E.P.; assume responsibility for securing this technology; and assure the provision of training services, maintenance, and repair. In most schools, this is not happening.

The Study: Subjects, Questions, and Design

A study was conducted to learn about the use of technology at home by children and youth with disabilities. A national survey was distributed to families who had used eleven of the 46 Alliance for Technology Access (ATA) resource centers. Random samples were selected by their computerized databases; of the over 400 surveys mailed, 234 families (or 59% of those polled) returned eligible surveys which were then analyzed. There were 154 boys and 80 girls in the student response sample; 18% were below age 5, 56% were 6 to 12 years old, and 26% were between the ages of 13 and 21. Approximately three quarters of the students had moderate to significant

disabilities. According to parent responses, 83% attended public schools; 39% participated in some kind of mainstreaming, while 26% were in self-contained special education classes.

Findings and Implications for Home-School Collaboration

Despite the availability of computers, printers, and educational and recreational software, the majority of the students used them at home for no more than two hours per week. The assistive and augmentative technology available was utilized to a much greater extent (approximately ten hours per week) at home, but even these figures were disappointing. In addition to data on the nature and extent of use, the data on inclusion of technology in the IEP, instruction in technology in school, and collaboration with families regarding its use were woefully inadequate, and certainly not in compliance with the mandates of the I.D.E.A.

Families responding to this survey were asked two questions about ten specific kinds of services reported as most frequently requested in the limited but seminal literature on the subject. The ten services were the following:

- . Information about purchase of hardware
- . Information about purchase of software
- . Loan of hardware to try out at home before purchase
- . Loan of software to try out at home before purchase
- . Demonstrations on how to assist their children at home
- . Technology literacy training for the family "helper"
- . Connections with other families in similar situations
- . Information about design of the home technology environment
- . Information about financial entitlements and sources
- . The availability of on-going expert consultation

Since ATA centers were the source of the mailing lists, it was not surprising to find that most families secured the highest percentage of all ten services from these centers. More than half received information on purchase and/or loan of hardware and software in addition to demonstrations on their use at home. Forty-four percent used the centers for on-going consultation, and thirty-two percent received literacy training for themselves and connections to other families in similar situations. In the ten service categories, 20-55% of the subjects receiving services indicated that they could still use more. Since they could give more than one response in each category, it was interesting to note how many used several or all of the available sources of assistance. Most disturbing and disappointing were the very low percentages of each service provided by the students' schools. The percentages in each of the ten categories ranged from 4% (for advice on home design) to a mere 20% who reported being able to get some information about buying hardware. The study, conducted

three years after the passage of the I.D.E.A., points to a glaring lack of schools' compliance with this mandate of the law.

In evaluating the usefulness of each of the ten services in extending and enhancing home use, parents were strongly supportive of the need for almost all of the ten services. The percentages of upper-end scale responses ("4" and "3" combined) were as follows:

- 83% for demonstrations on how to help at home
- 81% for loan of software, and for information about its purchase
- 78% for the availability of on-going expert consultation
- 76% for literacy training for family members
- 71% for the loan of hardware, and for information about its purchase
- 69% for financial aid assistance and information
- 62% for introductions to other families in similar situations
- 59% for help with the design of a home technology environment

The "0" and "1" combined responses (i.e., "not at all useful") never exceeded 20%, indicating a consistently high assessment of the value of these services.

Developing Home-School Collaboration

Research indicates that school leadership is a primary factor in the expanded use of technology at home (Giacquinta & Lane, 1989). There is little doubt that parents and school personnel need to develop collaborative models for technology use, as they have for other academic involvement areas. There are pivotal roles for all to play.

Administrators must: arrange for comprehensive training of all school personnel; develop sensitive ways to assess individual family technology interest, availability, and capability; and address parents' apprehensions, concerns, and time constraints. They need to make expert information readily available to families, and they must provide parents with the kinds of services described previously as "most useful." Further, administrators need to work with staff to develop model programs of involvement which empower families to make their own decisions regarding the amount of assistance they realistically can provide at home.

School staff need to: provide cohesive continuity of instruction, using both school and home technology; keep parents informed about the curriculum and the student's progress; and apply existing, effective models of family involvement to technology in education. They need to get creative with software sharing, sales, and lending libraries of donated or outgrown hardware and software, and they must encourage local businesses to help. To the extent that computer and assistive technology can expand independence and competence, school personnel and families need to

cooperate more closely to provide students who have disabilities with the opportunities to succeed that technology.

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**Utilizing Community Resources
to Provide Assistive Technology Training
to Diverse Cultural and Linguistic Minority Individuals
with Disabilities and their Families**

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The following describes a two-year training and public awareness project, the Technology Training Project (TTP), which was designed to provide information to "underserved populations" about assistive technology. "Underserved populations" are described, relative to this project, as groups which, because of their cultural and/or linguistic diversity, may not have access to assistive technology information that is available to the English-speaking population.

TTP reached out to the Latino, Cambodian, and Portuguese-speaking communities, particularly to families of individuals with disabilities who were not receiving specialized services from a disability-specific provider. The project also served people, such as those with AIDS, who may not traditionally have been associated with disability-related groups.

TTP recognized that it is customary in these communities for families to value the interdependence of their members and to "take care of their own." In order to provide information and training to these families, several non-typical outreach strategies were employed, and many adjustments to standard training practices were tested and implemented. The following are effective service delivery strategies developed during the project.

Demographics

Initial steps focused on developing a demographic, cultural profile of the project's service region. The profile included information on population pockets in specific geographic locations. In addition to a population overview, the profile included other important factors such as past experiential and immigration patterns, religious and other traditional beliefs, sociopolitical issues, levels of adaptation to Anglo-American culture, and potential barriers to receiving services.

Project Implementation

Recruitment of the Project Advisory Committee (PAC)

Initial PAC members were recruited from the network of contacts established through Seaside's other multicultural outreach project and from among members and leaders of the Latino, Portuguese-speaking, and Cambodian communities known to project staff. In addition, PAC members were recruited during the course of the project among those who had received project training. This brought total minority representation on the PAC to 65%. The PAC included people with disabilities and their families, members of parent/family organizations, disability advocates, advocates for refugees and immigrants, service providers from multicultural communities, representatives from ethnic support groups, assistive technology specialists, trainers, educators, health care providers, and funding agents.

The PAC was involved in every stage of development of the training curriculum, from review of materials and translations to observation of pilot presentations. PAC members participated in the Train the Trainers program in order to continue providing disability-related and assistive technology information to their clients after the project ended.

Recruitment and Training of Staff

It was decided initially that the training specialists hired by the project would be native Portuguese, Spanish, and Khmer speakers who were *active* and *involved* members of their respective communities. "*Non-traditional*" staff recruitment methods were employed, including the placement of advertisements in disability and minority newspapers; word-of-mouth and networking by members of the Project Advisory Committee; and job postings mailed to multiservice/multicultural agencies such as ethnic support organizations, disability advocacy agencies, independent living centers, and employment and job training agencies and programs that serve multicultural communities.

The project found, however, that *there are shortages of disability professionals* in the Latino, Cambodian, and Portuguese-speaking communities. Therefore, the decision was made to hire staff with strong *community connections* who would be trained in disability issues and assistive technology. (Since an important goal of the project was the "training-of-trainers" from local communities to present the project's assistive technology training, staff's community connections proved, over time, to be an excellent pool from which to recruit trainees to replicate and perpetuate the project.)

Curriculum Development

Project staff developed an assistive technology training curriculum that respects Latino, Cambodian, and Portuguese-Brazilian-Azorean cultural attitudes and belief systems regarding disabilities, the use of assistive technology, service provision, and training/presentation style.

Case studies were used to present information on assistive technology devices and funding options. This format allowed the trainer to present assistive technology information within a framework of *specific advice and practical solutions*. The approach encouraged the greatest amount of trainee follow-through, and it proved to be a more successful training approach--and more culturally appropriate--than a theoretical discussion of technology solutions or a presentation that relied heavily on legislative mandates and service system responses. The training *focused on the entire family*, not just the individual member who had a disability, and the case studies reflected such cultural beliefs and traditions as family interdependence and respect for the roles of parents and elders.

A pre-training assessment was conducted to ascertain trainee expectations and interests, language needs, and accommodation needs. Accessibility guidelines were provided to the sponsoring agency to help ensure that the site would be appropriate. The training was *delivered in the group's native language*, and all materials were made available in English, Spanish, Khmer, and Portuguese as well as large print and audio cassette formats (and Braille, upon request).

While the curriculum adheres to a traditional format, including pre- and post-tests and evaluations, these were often administered in alternative formats depending on the needs of the trainees. For instance, tests and evaluations were frequently conducted verbally. This increased access for those with limited reading or writing skills, and it also helped alleviate the anxiety that some trainees felt at being "tested."

Handouts on funding options and statewide assistive technology resources were developed and translated. Written and audio cassette versions were available. The resources handout contained information on over 50 assistive technology service providers, information and referral programs, and advocacy organizations. It included lists of services offered, areas of expertise, ages served, disabilities served, geographic areas served, eligibility criteria, languages spoken by staff, fees, and payment methods.

All materials were reviewed by the PAC, and the training was piloted in all three languages plus English. PAC members attended all pilot presentations. Modifications were made to replace "jargon" and to simplify/clarify the language for purposes of translation. The project also developed a variety of presentation styles, from formal to decidedly informal. For example, the Cambodian trainer utilized what

she termed "*chat and gossip*," a necessary first step in developing a personal rapport with trainees prior to getting down to the business of training.

In the second project year, a self-contained Train-the-Trainers curriculum was developed that included the basic training described above plus a presenter's guide, training activities, written scripts for the case studies, overhead masters, and a section on outreach strategies.

Outreach and Delivery of Training

The project recognized that the training would be most readily accepted if it were delivered with the approval and cooperation of respected community "gatekeepers." After eliciting support from such leaders, trainers began scheduling, advertising, and delivering both informational presentations on the project and trainings in assistive technology. Presentations and trainings were scheduled through the agencies' and the trainers' prior community contacts rather than through disability-specific service provider agencies. Community contacts included multiservice agencies, churches, temples, English as a second language (ESL) programs, ethnic support groups, mutual assistance associations, and health care clinics. Trainings were regularly advertised on Spanish, Portuguese, and Cambodian language TV and radio programs, and in minority and disability newspapers. In addition, project staff regularly appeared on local TV and radio programs to discuss assistive technology and the project.

Trainings were offered both to people with disabilities and to people who were not members of traditional disability groups. Trainees included members of senior citizen groups, parent support groups, women's support groups and health cooperatives, children and youth groups, church groups, prison inmates organizations, and labor union locals. Trainings were often scheduled in conjunction with religious services and ceremonies, ESL classes, or regular monthly meetings of community organizations.

The project found that members of the target cultural groups often resist specialized services for people with disabilities, especially as these services are too often provided: (1) outside of the home and the community, and (2) by staff who speak English only and who are unfamiliar with the groups' cultural beliefs, practices, and traditions. Therefore, an informal presentation that is open to people both with and without disabilities acknowledges the importance of family and community, and it reaches people who might otherwise stay away and remain outside the information loop.

Over 1,100 people received assistive technology training during the two-year project. The greatest number of trainees were Latinos, and, while the majority of the rest of the trainees were from the other two target populations (Cambodians and Portuguese-

speaking persons), the project also trained Vietnamese, Laotian, Chinese, and African-American individuals.

In the second year of the project, day-long training-for-trainers sessions were conducted in locations across the state. Invitees to these sessions included staff of the host agencies and all individuals who had participated in the initial (basic) training. Each of the Train-the-Trainers sessions included a culturally-diverse group of trainees. A total of 48 people received training as trainers from the project and will serve as assistive technology trainers and resources in their own communities.

Technical Assistance

The project developed several options for the provision of technical assistance including follow-up/consulting in the home, accompanying families/individuals to vendors and provider agencies to help interpret, and assisting individuals/families to receive the funding to which they are entitled. Technical assistance was also available to participants in the Train-the-Trainers program, some of whom went on to provide formal, project-developed assistive technology training, and some of whom chose to serve less formally as assistive technology resources for their clients and fellow agency staff.

Trainees at each session were asked to contribute their suggestions and recommendations for outreach to their communities. These suggestions were compiled and added to the curriculum in the Multicultural Outreach section of the manual.

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Section VII

Designing Relevant Research

Designing relevant research is crucial if we want to correct past mistakes (e.g., the exclusion of people with disabilities in research planning, gender bias and other biases, etc.). Kate Seelman, Director of the National Institute on Disability and Rehabilitation Research (NIDRR) presents OSERS goals and NIDRR research directions in her chapter, "Variations on a Theme." Seelman's chapter offers a challenge to all of us, to "creatively design research in recognition of the impacts on our constituency of the extraordinary mainstream trends in populations, the economy, science and technology, skill requirements, health, and social unrest" (p. 162).

Papers in Section VI addressed unmet needs and described programs designed to increase access to services. Marcus J. Fuhrer examines why we need to broaden our concerns and refocus research agenda in his chapter, "Reforming Health Care for People with Disabilities: Improving Access is Not Enough." Fuhrer raises a crucial question when he recommends that we need to look at effectiveness as well as access to health care. Fuhrer warns that the data currently used to evaluate effectiveness form a "shaky information base" (p. 169). Fuhrer presents the National Center for Medical Rehabilitation Research (NCMRR) as a possible model: "Joining in common cause with other funding sources as well as with service providers, sponsors, and people with disabilities, we are intent on shoring up the scientific information base upon which future health care for persons with disabilities will stand" (p. 171). David Gray further defines the goals of the NCMRR in "Mission of and Funding Opportunities at National Center for Medical Rehabilitation Research." Gray's paper provides a good introduction for those who want to pursue funding opportunities through NCMRR and, more generally, through NIH.

Kate Seelman, in the chapter described above, wrote: "I am impressed when you develop these ideas into challenging and even brilliant and controversial research designs with well thought out methodology which proactively integrates consumers, where possible. I am even more impressed when you communicate these findings to various constituencies, including consumers, researchers and providers, and other people" (p. 162). Sheila Newman and Carolyn Vash provide a specific example of information dissemination in their chapter, "Making Research Results Useful." Newman and Vash describe a variety of ways by which NIDRR has made research results available. These include Rehabilitation Research and Training Centers, the Rehab BRIEFs, Regional Rehabilitation Continuing Education Projects, Regional Information Exchanges, the Consensus Validation Project, and the Rehabilitation Engineering Research Center on Technology Transfer and Evaluation. The authors

note that "the trend is moving toward integrated dissemination and utilization instead of tacking them on at the end of projects" (p. 184).

One problem facing researchers and policy planners who are interested in disability research is the difficulty in determining disability prevalence. Mark McAdam, Lance Egley, and Barbara Altman address this problem in their paper, "Accuracy and Consistency of Estimates of the Population of People with Disabilities in the United States." The authors provide a clear summary of the similarities and differences among already-completed surveys. Their analyses can be used to help make sense of past research, and also to help plan future research designs.

In "Review of Research on Psychosocial Reactions to Neuromuscular Disorders," Hanoch Livneh and Richard F. Antonak review research related to cerebral palsy, spina bifida, muscular dystrophy, neurofibromatosis, multiple sclerosis, amyotrophic lateral sclerosis, myasthenia gravis, and Parkinson's disease. Like McAdam, Egley, and Altman, Livneh and Antonak found a number of methodological and conceptual problems with past research. They offer recommendations that could strengthen research designs, not only in the study of neuromuscular disorders, but in disability research generally.

In the last chapter in this section, "Managing the Interface between Treatment Technology and Children with Disabilities," Keith Slifer, Ramasamy Manikam, Marilyn Cataldo, Arlene Gerson, Gary Pace, and Cindy Tucker explore how the results of past research in behavioral therapy can be used to facilitate treatment experiences for children with disabilities. As the authors note, "medical procedures can be frightening and behaviorally demanding, especially for children with developmental disabilities" (p. 197). Rather than denying children access to technology, or using more coercive means of social control (e.g., anesthesia), behavioral therapy techniques can help make treatment settings less stressful for children, family members, and health providers. The authors reiterate Seelman's call for collaborative research based on, applied to, and for the benefit of people with disabilities.

Variations on a Theme

**Katherine D. Seelman, Ph.D., Director
National Institute on Disability and Rehabilitation Research**

It is a true pleasure for me to address you as friends and members of the society that I care so much about. As Director of NIDRR, I am dedicated to accomplishing objectives that have been formed through my association with many of you, and I feel deeply honored that fortune has cast me in a position to actually make some of them happen. But I must admit that, after a half year on the job, I find the labyrinth of the Federal Government to be exceedingly challenging.

Background

I will take this opportunity to present the OSERS mission statement which serves as a value framework for our work--the work of NIDRR, RSA, and OSEP: to promote full integration and participation in society of individuals with disabilities through equal access to, and excellence in education, rehabilitation, and disability research. Clearly, the leadership of OSERS has identified rehabilitation and disability research as a vehicle to impact society and to bring about full integration and participation of individuals with disabilities, especially those of culturally diverse backgrounds. Disability researchers are an important part of the OSERS team. The OSERS mission statement suggests both challenge and responsibility, a point to which I will return later.

Based on the OSERS mission, and as part of our strategic planning process, OSERS has drafted five goals. They are:

- 1. Improving outcomes for individuals with disabilities through systemic reform;**
- 2. Ensuring access to and the accessibility of technology;**
- 3. Supporting the development of a new, diverse generation of leaders with disabilities;**
- 4. Understanding and adjusting to an expanding universe of disabilities; and**
- 5. Transforming OSERS into a high performance organization.**

The OSERS mission and goals are a challenge to attend to relationships with individuals with disabilities and with each other--especially relationships which reflect the diversity of abilities and culture here in the U.S. and in the global economy. This Administration has placed great emphasis on working with our customers, on teamwork, and on coordination within and across government agencies and sectors of society.

Collaboration, coordination, and teamwork are visible strategies of this Administration. Under Secretary Riley's outstanding leadership, President Clinton has signed Goals 2000 and the School to Work Opportunities Act. OSERS is committed to the success of this legislation. It is vital that you are involved in education and systems reform in your subject areas and in your states. Share your knowledge and expertise with the larger community. The Clinton Administration is also providing leadership in many other areas, including health reform, the national information infrastructure, and in reinventing government. OSERS/NIDRR is also committed to these initiatives.

NIDRR

As a young adult, I heard a compelling call to service from another young President. Many of you will join me in remembering the feeling when President Kennedy said, "Ask not what your country can do for you but what you can do for your country." In that spirit, I challenge all of us--individuals with disabilities, families, researchers, providers, and other citizens--to be proactively responsible for our common work and to be committed to equity, excellence, and diversity. Our strategies include an unrelenting commitment to communication--sometimes viewed as persuasion!

Let us be relevant. Let us creatively design research in recognition of the impacts on our constituency of the extraordinary mainstream trends in populations, the economy, science and technology, skill requirements, health, and social unrest. As researchers, it is our special responsibility to recognize the implications of these trends for our constituencies. NIDRR is a research institute which works its wonders in the world, not in the laboratory. NIDRR staff and grantees have long shown respect for knowledge based on experience as well as on science. While I am not surprised if you ask for money, I am delighted when you provide ideas and insights that address the impact of global and national trends on our knowledge base. I am impressed when you develop these ideas into challenging and even brilliant and controversial research designs with well thought out methodology which proactively integrates consumers, where possible. I am even more impressed when you communicate these findings to various constituencies, including consumers, researchers, providers, and other people. Perhaps, there is no greater compliment to any of us than evidence that our research is relevant and that individuals with disabilities have benefited through increased access to and inclusion in society and through systems change. I urge you, using modern means of FAX and Internet, to communicate your successes.

Let me review with you some of the guiding themes for NIDRR:

- Equity in the distribution of NIDRR's resources to address the challenge of "the expanding universe of disability" (e.g., HIV/AIDS, violence, crack cocaine, FAS, environmental illness, stress, attention deficit disorders, etc.).
- Excellence and rigor in research, demonstration, best practices and training designs, methodologies, definition of terms, and evaluation.
- Cultural competency so that diverse cultures are represented in all aspects of NIDRR's work.
- Foresight in future/present and mainstream/disability interfaces so that global and national trends in economics, population, science and technology, and public policy are reflected in disability research and training.
- Communication, dissemination, and utilization of research results so that consumers, providers, and researchers have the results in an accessible, useful form and find them relevant.
- Collaboration, coordination, and teamwork among the government, private sector, and the disability community in a shared vision of empowerment, community integration, equal opportunity, and independent living.
- Participation by consumers/families with NIDRR's grant recipients, through innovative research methodologies, inclusion strategies in demonstrations, best practices and training, and the establishment of consumer advisory boards at the centers; within NIDRR in planning, peer reviews, site reviews, and round table discussions.
- Communication proactively with consumers/families recognizing a joint responsibility by consumers/families, researchers, and providers to initiate communication with each other and NIDRR about needs and ideas.
- Communication between NIDRR and grant recipients using modern means such as Internet and Fax to share quickly examples of newspaper coverage, consumer newsletter coverage, peer reviewed articles and other indications of NIDRR supported work which is recognized and utilized within the mainstream, disability, research, and provider sectors.

- Outcome measures which show systems change, especially related to the goals of the ADA.

NIDRR will continue to meet the challenge of a fast changing world, of a constituency that wants nothing less than to actively engage in competition and change, and an Administration that wants all of us to participate and contribute to meeting these challenges. NIDRR's planning and priorities will reflect the need to be responsible stewards in a time of diminishing budget and personnel. NIDRR's strong commitment to various program areas continues, including medical and vocational rehabilitation, the behavioral sciences, technology, dissemination and utilization, and, of course, the ADA.

Many of us have been involved through dialogue, research, and action over a lifetime in many of the challenges and underlying values which I bring to you today. Equity, diversity, excellence, and participation are not new to you. NIDRR will continue to have individuals with disabilities at the center of our processes and projects. As researchers, we are painfully aware that research has been used to undermine the very humanity of individuals with disabilities. NIDRR is unique, a research institute in which individuals with disabilities are collaborators in the fulfillment of our mission.

In closing, I want to acknowledge the healthy tension between research and advocacy. Many of you are both researchers and advocates. In my doctoral dissertation about social movements, I analyzed the development and pathways of values that eventually converged into issues which moved from the social/advocacy arena to the public policy arena. Many people here today know that the disability community has challenged the values that underpin contemporary knowledge about disability. With success come new challenges in research and advocacy. Speaking of research, we have recently been thinking about the kinds of research that are inherent in the broad mandate of NIDRR. We have become particularly concerned with the differences between quantitative and qualitative research. While the process and tools of qualitative research differ from those of quantitative research, we are convinced that qualitative research can be no less scientific, and we are moving toward changing some of our criteria to reflect this.

I regard the membership of Society for Disability Studies as friends and colleagues, and I regard SDS as means to bridge advocacy and research so that social transformations we seek become a reality. I look forward to our continuing communication and dialogue. Please visit NIDRR when you are in town and tell us about your work and your ideas.

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Reforming Health Care for People with Disabilities: Improving Access is Not Enough

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The past two decades or so, beginning with passage of the Rehabilitation Act of 1973 and culminating with passage of the ADA, have been marked by a dramatic enlargement of the opportunities for persons with disabilities to participate more fully in American life. These advances have been wrested from American society by advocates for people with disabilities who have pressed their cases in court rooms, legislatures, and offices of the bureaucracy across this country. The action agenda of the disabilities rights movement has been extended more recently to include vigorous advocacy for health care reform legislation that assures that people with disabilities will have access to the services they need to maintain their health, independence, and productivity.

The thrust of my remarks is to look beyond the current legislative struggle, even assuming the wildly improbable outcome of complete victory for people with disabilities, to examine the likely effectiveness of that health care. I believe that the effectiveness of many rehabilitation and health care practices of importance to people with disabilities will remain gravely suspect because of the questionable information upon which they are based. I want to explain the grounds for those concerns, and to discuss what is being done--and what remains to be done--to address those concerns.

The debate on reforming health care legislation that has been joined by people with disabilities is focused upon the financing of health services, the organization of those services, and their categorical nature. Almost completely ignored are issues regarding the *effectiveness* of those services, e.g., whether they actually reverse, control, or otherwise resolve the health problems that motivate people's encounters with the health care system in the first place. Winning access to health care practices of questionable effectiveness will certainly not be much of a victory. Spokespersons for persons with disabilities seem to assume that effective health care practices exist for people with disabilities, so that the issue is simply one of making the related services available to everyone who needs them. Quite to the contrary, I submit that the scientific knowledge needed to address innumerable health problems of people with disabilities does not exist, and, as such, that lack of knowledge places absolute limits on the effectiveness of the health and rehabilitation services that are provided.

What do I mean by "effectiveness?" Judging the effectiveness of a health care practice involves a comparison of available evidence about the effects of that practice against some kind of standard. That evidence may come in a variety of forms. It may derive from scientifically sound studies about the effects of a particular practice in terms of the probability of patients benefiting from it, the extent of that benefit, the characteristics of people who benefit more or less from it, and any unintended effects that occur. However, scientific evidence is by no means the only kind of evidence that may be drawn upon in arguing for a practice's effectiveness. Other kinds include the individual practitioner's own clinical experience, authority that is represented, for example, by the recommendations of mentors or textbooks, anecdotal information from fellow practitioners, or the testimony of individual patients.

The evolution of health care in this country and in most of the world as well has been such that these different evidentiary bases for judging the effectiveness of practices do not have equal status. The preferred basis is that which is consistent with the canons of scientific evidence. Scientifically buttressed health care practices are expected to emerge in connection with an orderly development process in which their efficacy is established under rigorously controlled circumstances as an integral part of that process. Contemporary scientific standards of evidence go further by requiring that the effects of those practices also be established when they are embedded in the hustle and bustle of ordinary service provision. Adducing that kind of evidence is the burden of treatment effectiveness research.

Quite the opposite state of affairs characterizes most important health care and rehabilitation practices relevant to people with disabilities. Even in instances where some formal research has been conducted, the available evidence is frequently so poor that it is impossible to gauge the effects of a given practice, whether considered in isolation or in comparison with alternative practices. Lacking satisfactory evidence for the probable effects of a treatment choice, practitioners are required to formulate a complex judgment that integrates what is known about the pathophysiology of a given problem and about the mechanism of action of the intervention being considered. Credible information of that kind is often unavailable as well for many health problems experienced by people with various primary disabling conditions.

Numerous, indeed, are the approaches to managing health problems of people with disabilities that have never been investigated adequately from the standpoint of their effects--intended or unintended. Save for a handful of studies conducted in Northern Europe, randomized clinical trials have not been conducted to examine the effectiveness of programmatic rehabilitation services for persons with newly incurred disabling conditions such as traumatic brain injury, spinal cord injury, stroke, or multiple amputations. Problematic, too, is the large number of medications that are prescribed to people who have experienced injury of the brain or spinal cord, the possible interactions of those medications, and the resulting negative side effects. Related concerns are effects later in life of medication regimens that were begun

shortly after the onset of a physically disabling condition and that are continued indefinitely thereafter. The questions go on and on. What are the long-term effects of oral contraceptives or other hormonal treatments on women with disabilities who are sedentary and who may have related circulatory problems? How can the various forms of chronic pain which are reported by such a shockingly high percentage of persons with various disabling conditions be effectively managed? And then there are the large number of aging-related health problems being reported by persons with disabilities that are associated, for example, with polio and spinal cord injury.

In other instances, we become aware of the inadequate knowledge base underlying health practices for persons with disabilities because the inadequacy of those practices simply jumps out at us. Consider, for example, many of the preventive regimens to which persons with disabilities are exhorted to adhere, for example, to prevent pressure ulcers, urinary tract infections, obesity, or wear and tear on shoulders associated with transferring to and from wheelchairs. The intrusiveness of those regimens in one's daily life and in the life of family members, and the intolerance of those procedures to the slightest deviations virtually ensure their being dismissed along the way.

Many of the treatment principles underlying specific health care practices for persons with disabilities have never been systematically tested from a scientific standpoint. An example is the hallowed principle of an interdisciplinary team approach to providing rehabilitation services. Such "term care" entails quite high overhead in terms of the time needed for communication among team members, and that translates directly into higher care costs. The cost-effectiveness of the interdisciplinary team approach to care is, therefore, an urgent candidate for research. In a similar respect, we continue to organize hospital bed-based rehabilitation programs in a manner that emphasizes the "packaging" of the greatest number of specific services, in the shortest time, as early as possible following onset of a disabling condition. Largely untested are approaches in which services are distributed over more lengthy time periods, with some services taking place in the hospital and others in people's homes in accordance with their readiness to benefit from those services.

Now I would like to turn to the question of why so much health care for people with disabilities rests on such a shaky information base. It is important to understand the reasons for this state of affairs so that we can envision the appropriate correctives. The reasons are several fold:

1. The imperative to serve people in need. Providers simply have not had the luxury of withholding services until their soundness was established by direct study.
2. Lack of a well-established research tradition for several of the human service professions that provide this care. These professions are relative

latecomers on the health care scene, so they have been in fairly early stages of development. As such, an emphasis on research has been secondary to staking out practice foci and boundaries, establishing credentialing requirements, and planning appropriate training curricula.

3. An unbalanced research agenda. The bulk of research to date has been targeted on early (acute) rehabilitation issues rather than on issues pertinent to the life-long maintenance of people's health and functional capabilities. As a result, very little is known in a systematic manner about the risk factors, including those that are controllable by the individual, for secondary problems with potentialities of compromising health and personal independence.
4. Too little demand by persons with disabilities for the needed research. The disability community has not demonstrably insisted on more and better research relevant to solving health problems. That quiescence contrasts sharply with the thunderous demands that have been heard, for example, from advocates for women, people with AIDs, African-Americans, and people of Hispanic origin for a larger share of the national health research investment. That inattention is unfortunate, because the maintenance of health and the maintenance of personal independence are intimately connected. Few life changes have greater potential for eroding the already narrowed functional reserve of persons with disabilities than occurrence of health problems such as new muscular weakness, urinary tract infections, or chronic pain. All pose threats of disrupting life routines, narrowing personal options, and undercutting personal strategies for minimizing dependence on others.

Happily, I believe there are some signs of movement in the needed directions. Some of them are as follows:

1. Both service providers and sponsors are emphasizing the development of documented treatment guidelines as a basis for assuring care quality. The formulation of such guidelines inevitably provokes questions of how we know that practice A is preferable to practice B. Such dialog often leads to questions of whether available research provides an answer and, if not, what kinds of investigations are required.
2. The professions responsible for providing health services for persons with disabilities have been taking decisive steps to strengthen the scientific foundation of their practices.
3. The mix of ongoing research effort is moving toward a better balance between an early rehabilitation focus and a focus on the health problems

of people with disabilities over the entire life course. Certainly, we see that in the research planning of the National Center for Medical Rehabilitation Research. The Center's very mission is to engage the enormous capabilities of the biomedical research community in addressing rehabilitative and health care issues of foremost concern to people with disabilities. We place particularly high priority on treatment effectiveness research to sort out which practices work and which do not. Joining in common cause with other funding sources as well as with service providers, sponsors, and people with disabilities, we are intent on shoring up the scientific information base upon which future health care for persons with disabilities will stand.

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Mission of and Funding Opportunities at National Center for Medical Rehabilitation Research

**David B. Gray, Ph.D.
National Center for Medical Rehabilitation Research**

The National Center for Medical Rehabilitation Research (NCMRR) within the National Institutes of Health (NIH) was established in 1990 through passage of legislation (P.L. 101-613). The mission of the NCMRR is to enhance the health, productivity, independence, and quality of life of persons with physical disabilities resulting from injuries, diseases, or disorders of the neurological, musculoskeletal, cardiovascular, or pulmonary systems, or any other physiological system. This mission is to be accomplished through the support of research and research training on restoration, replacement, or enhancement of functioning required by people to be effective in daily life. The goal of the Center is to bring the health-related problems of people with disabilities to the attention of America's best scientists in order to capitalize upon the myriad advances occurring in the behavioral, biological, and engineering sciences.

The authorizing legislation required the NIH to establish a National Advisory Board on Medical Rehabilitation Research (NABMRR) for the purpose of advising the Director, NIH, the Director, NICHD, and the Director, NCMRR, on matters and policies relating to the Center's medical rehabilitation research and training programs. The Board reviews and assesses Federal research priorities, activities, and findings regarding medical rehabilitation research and advises on the provisions of the statute-required comprehensive plan for the conduct and support of medical rehabilitation research. The legislation requires that at least six members of the NABMRR be persons with disabilities or those representing people with disabilities. The remaining 12 Board members represent the rehabilitative sciences associated with health care problems of people with disabilities.

In its first eighteen months, the NABMRR produced a report to Congress titled Research Plan for Medical Rehabilitation Research (available from the National Center for Medical Rehabilitation Research, National Institute of Child Health and Human Development, National Institutes of Health, Executive Office Building, Room 2A03, 6100 Executive Boulevard, MSC 7510, Bethesda, MD 20892-7510). The Report describes a framework for research to be supported by the NCMRR and by other agencies that fund medical rehabilitation research. The focus of this research is on the person with a disability and how that person's functional limitations affect and are affected by multiple, interacting biological, personal, and societal forces. It provides for within-group comparisons in addition to traditional studies comparing people with disabilities to "normal" populations. It also focuses upon how the person

with a disability interrelates with his or her family, work, and local community. Major issues in medical rehabilitation research are reviewed including early and late onset of disability, traumatic injury, chronic and reoccurring disorders, effects of aging, and changes in functioning.

The research initiatives and opportunities described in the Research Plan for Medical Rehabilitation Research reflect Advisory Board judgment about cross-cutting areas where increased funding for research is needed. The research initiatives and opportunities recommended by the Board are presented in seven general categories.

- research on improving functional mobility
- studies of behavioral adaptation to functional loss
- examinations of the whole body system response to physical impairment and function change
- facilitation or replacement of function through the development or modification of technical devices
- measurement, assessment, and epidemiology aspects of reduced function in people with disabilities
- treatment evaluation studies of new or currently-used clinical therapies used to improve, restore, or replace function
- training research scientists in the field of rehabilitation

To implement the recommendations made by the NABMRR, the Center has supported conferences and workshops on a variety of topics related to the health of people with disabilities. Some of the conferences supported with Center funds from 1992-1994 include:

- March 1992 Medical diagnosis of musculoskeletal disorders: Directions for future research
- July 1992 Prosthetic/orthotic research for the Twenty-first Century
- September 1992 Frontiers in rehabilitation medicine: Osteogenesis imperfecta
- February 1993 Training scientists in medical rehabilitation research

- March 1993 Chronic pain management: Developing a treatment system for people with disabilities
- April 1993 Pulmonary rehabilitation
- May 1993 Mechanisms for function after chronic injury of the nervous system
- February 1994 Prevention of secondary conditions in two primary disabilities: Spina bifida and cerebral palsy
- May 1994 Impact of disabilities on women's health
- June 1994 Society for Disability Studies
- August 1994 An agenda for medical rehabilitation outcomes research

These meetings often form the basis for designating portions of the Center's budget for funding grant applications related to the research ideas formulated and expressed during the meetings. Requests for applications (RFAs) is the terminology used by the NIH to designate to the research community that funds are allocated for supporting grants for specific areas of research. Announcements of RFAs are found in the NIH Guide to Grants and Contracts (available from the National Institutes of Health, Institutional Affairs Office, Building 31, Room 5B3, Bethesda, MD 20892).

Requests for applications issued from Fiscal Year 1991 through 1993 are listed below:

	<u>Title of Request for Applications</u>	<u># of Awards</u>
3/91	Pre-and Post-doctoral Research Institutional Training ¹	16
2/92	Improvement in Reproductive Function in Persons with Physical Disabilities ²	6

¹National Research Service Award Institutional Training Grants in Medical Rehabilitation Research, RFA: HD-91-11. NIH Guide to Grants and Contracts, Vol. 20 (No 13), March 29, 1991.

²Reproductive Function in People with Physical Disabilities, RFA: HD-92-09. NIH Guide to Grants and Contracts, Vol. 21 (No. 7), February 21, 1992.

2/92	Orthotic and Prosthetics Research ³	10
5/92	Managing Bowel and Bladder Functioning ⁴	6
1/93	Assistive Devices and Skin Integrity ⁵	6
2/93	Biomaterials to Restore Function in People with Physical Disabilities ⁶	6

The NCMRR receives an annual budget for funding research programs germane to medical rehabilitation. In Fiscal Year (FY) 1991 the amount was \$600,000; in FY 1992 it was \$7.2 million; in FY 1993 it was \$10 million; in FY 1994 it was \$14 million; and in FY 1995 it will be \$15 million. Distribution of funds by NCMRR in Fiscal Year 1994 by granting mechanism was 63% (\$9 million) of the Center's budget for regular research grants (R01); 14% (\$2 million) for research training and career development programs; 14% (\$2 million) for small business innovation research (SBIR) grant programs (R43 and R44); and 7% (\$1 million) of the Center's funds for transfer to other agencies to support medical rehabilitation-related research projects.

The NIH Grant Application, Review, and Management Process

Most NIH awards are made to universities, using over 12 types of research program granting methods referred to as funding mechanisms. Descriptions of each of these funding mechanisms are available from the NCMRR. The most frequently-used mechanism for funding research at the NIH is called the regular or investigator-initiated research award (R01). This mechanism is used to support research on a single topic over a one- to five-year period of time.

Preparation of Grant Applications

The grant application, review, and award process used by the NIH is complex and lengthy. The description below provides a brief review of the process. The following

³Orthotics and Prosthetics Research, RFA: HD-92-08. NIH Guide to Grants and Contracts, Vol. 21 (No. 4), January 31, 1992.

⁴Bowel and Bladder Management, RFA: HD-93-05. NIH Guide to Grants and Contracts, Vol. 21 (No. 21), June 5, 1992.

⁵Assistive Devices and Skin Integrity, RFA: HD-93-12. NIH Guide to Grants and Contracts, Vol 22 (No. 3), January 29, 1993.

⁶Biomaterials to Restore Function in People with Physical Disabilities, RFA: HD-93-11. NIH Guide to Grants and Contracts, Vol. 22 (No. 4), February 5, 1993.

organizations are eligible to apply: profit and non-profit organizations and institutions; state and local governments and their agencies; and authorized Federal institutions. Public Health Service Form 398 is used by the applicant to submit an application for NIH funding. This form is available from the office of sponsored research in many organizations, or it may be obtained by writing or calling the Office of Grants Inquiry at the NIH (Division of Research Grants, Office of Grants Inquiries, 6701 Rockledge Drive, MSC, Bethesda, MD 20892; 301/435-0714). All grant applications are received by the DRG. Receipt dates for making application for support of research are set by the DRG (generally October 1, February 1, and June 1). See the PHS 398 application kit for details.

One of the main functions of the program staff is to work with applicants in developing their ideas and to help them understand the application process. The potential applicant is encouraged to call and describe his/her idea for research with a member of the program staff. After a grant application is received at the DRG, DRG grant referral officers assign the application to one of 21 institutes for funding considerations and to one of more than 100 study sections for assessment of scientific merit. Assignment decisions are based upon the missions of the various institutes and the expertise of the study sections. Applicants may write a one-page cover letter attached to their PHS 398 application requesting assignment to a specific institute or center and initial review group. The cover letter should provide a short, clear statement of how the proposed research fits the mission of the Center. The applicant may also request assignment to a specific study section in the cover letter. One should refer to the NIH Advisory Committees book for descriptions of the mission statements and membership rosters of these review committees. Study sections to consider include Geriatrics and Rehabilitation Medicine, Human Development and Aging, Behavioral Medicine, Epidemiology, and those related to specific organ systems that describe clinical research as a portion of the study section's review responsibility.

Review of Grant Applications

The NIH awards funds to support research based on the scientific merit of the proposed research and the relevance of the proposed research to the mission of NIH. Reviewers are selected for study section by the DRG. Descriptions of the scientific areas reviewed by study sections and the names of the current members can be found in a book published by the DRG entitled NIH Advisory Committees. These committees are managed by scientific review administrators and meet three times each year to review grant applications. These initial review groups are composed of experienced scientists who read the grant application, discuss it with other members of the initial review group, and score the proposal on a merit basis. If the grant application is not deemed to have sufficient scientific merit, then the applicant receives a summary of the review group's comments, but the grant is not considered for funding. If the grant application is judged to have scientific merit, then it is

assigned a score. The score range is from 100 (best) to 500. The applications are then reviewed by a second committee, the National Advisory Child Health and Human Development (NACHHD) Council, that makes recommendations to the NCMRR, NICHD, and NIH on the relative merit of the application(s) within the context of the mission of the NICHD.

Grants Management

If the grant application is recommended for funding by the NICHD, then the applicant (principal investigator) and agency fiscal agent are contacted by NICHD's Office of Grants and Contracts. The NICHD grants management staff reviews each application for adherence to special Federal regulations in the areas of minority and women representation in the study sample, animal welfare, substance abuse, and other institutional assurances of compliance with governmental regulation. If an award is made for more than one year, then the grants management staff reviews expenditures for the past year and those planned for future years to determine adherence to the award agreement.

Conclusion

Receiving support for research from NCMRR is a difficult task for even the most experienced scientist. Often, first time applicants seek and receive invaluable advice and support from scientists in their communities who have received research grant awards from NIH. One way to improve one's research skills is to work as a research assistant for currently NIH-funded scientists. NIH makes this possibility attractive to the principal investigator by providing funds to the grant for mentoring persons with disabilities who are qualified and interested in becoming NIH-supported researchers.⁷ Special awards are also available for underrepresented minorities, both for training and for research career development.⁸ Taking the effort to thoroughly examine rehabilitation-related issues amenable to the scientific method will do no harm and may provide an intellectually-stimulating activity.

⁷Research Supplements to Promote the Recruitment of Individuals with Disabilities into Biomedical Research Careers. NIH Guide to Grants and Contracts, Vol. 23 (No. 3), January 24, 1994.

⁸Research Supplements for Underrepresented Minorities. NIH Guide to Grants and Contracts, Vol. 22 (No. 43), November 26, 1993.

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Making Research Results Useful

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This paper summarizes views based on more than a decade of working to increase the utilization of findings from research funded by the National Institute on Disability and Rehabilitation Research. Most projects are "applied" rather than "basic" research, so findings should be of use to consumers and providers of disability services and products. Central to this goal is periodic updating of a research plan. Researchers, providers, and consumers convene to reach agreement on a manageable set of priorities. Such meetings serve as anchoring points for dissemination and utilization efforts. Priorities point toward target audiences for dissemination, and participants, top experts in the research areas, play key roles in utilization.

The Rehabilitation Research and Training Centers (RRTC's) were an early effort to assure dissemination of research findings. The RRTC's build their findings into training courses for physicians, rehabilitation counselors, occupational therapists, physical therapists, psychologists, and others. Courses are available to pre-service training students and to practitioners in continuing education or in-service training. Applicants for RRTC grants must show that their states' VR agencies look forward to benefitting from the proposed activities.

The Rehab BRIEFs were another early dissemination method introduced by NIDRR's ancestral agency, the National Institute on Handicapped Research. "BRIEF" is an acronym for "bringing research into effective focus." One of the founding goals of the monthly publication was to help practitioners appreciate the value of research to the success of their own efforts. Each BRIEF summarizes, in reader-friendly, journalistic language and style, the most applicable highlights from research reports of interest mainly to other researchers.

Researchers have historically done a good job of reaching other researchers, academicians who train rehabilitation professionals, and the university-trained rehabilitation professionals themselves. They read the journals to which researchers submit their reports and attend the conferences/training functions put on to disseminate research information. The success of researchers in reaching other audiences has been dappled. Dissemination and utilization processes require skills that differ from theirs. Also, once research is completed, a project may end just when dissemination should begin in earnest.

Experience shows that possession of information by targeted audiences does not mean that it will be used. A familiar example is the movement of educational institutions away from semester systems toward shorter teaching terms in spite of replicated findings that distributed practice aids learning more effectively than massed practice (Dempster, 1988). Use of research findings requires more than dissemination. An effort to promote utilization of research/demonstration findings by vocational rehabilitation (VR) personnel took place in the early 1970's. Research utilization specialists (RUSs) were funded to serve as knowledge brokers in public VR agencies. They strove to influence counselors, supervisors, and administrators to apply new knowledge from research and to implement service approaches supported by demonstration outcomes. A critical factor was agency support for the idea of research utilization. Often, the RUS's time was diverted to research duties given higher priority, but the project formed a foundation on which other utilization programs' approaches could be tested.

At about the same time, the Rehabilitation Services Administration instituted its Regional Rehabilitation Continuing Education Projects (RRCEPs). They provide in-service training to state VR agency employees and continuing education to additional disability-services providers and, thus, serve as conduits for new knowledge from rehabilitation research. Feeding research findings to practitioners through training may increase utilization over less focused techniques, but it offers no assurances. Most practitioners work in organizations, and organizational dynamics determine whether new knowledge and innovations will be used. The impact of change on all stakeholders must be addressed. The RU project recognized this and placed RUSs within VR organizations in the hope that they could influence organizational attitudes. It seldom proved to be the case; outside consultants seem to enjoy greater influence.

Research projects produce findings with varying degrees of importance and generalizability. Knowledge-brokers evaluate which findings are most urgently needed by which potential users. By fostering technical assistance and consultative relationships between producers and adopters, they determine the suitability of transfer to new settings. When indicated, they facilitate adoption or adaption. The processes are embodied in the Regional Information Exchange (RIE) model which has now been tested in all ten federal regions.

The purpose of RIEs is to maximize utilization of effective disability-service techniques and technology. RIEs choose core areas in which they serve as knowledge brokers for providers throughout the region. Information is sought about exemplary programs, promising practices, or safe/effective products that might be nominated for evaluation. Expert judges review the information to determine whether research, program-evaluation, or informal clinical evidence is sufficient to judge them "validated," "promising," or "not meeting minimum standards" for gaining a RIE's utilization efforts. Once a program, practice, or product has been approved for

promotion, RIE staff foster alliances between originators, potential adopters, and others who might facilitate transfer to new settings.

RIEs have received mixed reviews from providers. No formal evaluation of the overall model has yet been conducted, but one problem has emerged. Limitation to core topics limits participation to potential adopters who happen to be interested in that limited domain--e.g., job development techniques or computer applications. The larger segment of providers then feels left out because a publicized resource proves to have nothing to offer them. Future variants might get better reviews by adding knowledge-brokerage services to full-range Regional clearinghouse operations.

The Consensus Validation Project (CVP) attempted to validate the wisdom of its previous funding decisions as well as to increase dissemination and utilization. The CVP sought to identify the best practices in selected areas of disability services, as indicated by research and demonstration findings, and to spread the word about them to providers and consumers--especially those living in isolated, rural areas with little access to the experts and information resources available in urban communities.

Familiar dissemination techniques were used. Ten thousand copies of Consensus Statements resulting from Consensus Validation Conferences were distributed. Summarizations were published in Rehab BRIEFs. Re-publications in targeted journals were promoted. And a new goal of reaching the mass media was set. An initial plan was to hold press conferences when each Consensus Statement was issued, but the subject matter proved to have an impact on too small a fragment of the general population to attract public press. This experience does not eliminate the press conference as a technique with potential; other topics might have wider public interest. For example, a project educated corporate purchasers of packaging systems about problems created for people with hand disabilities and the business they lose to brands with more accessible packaging. Training, video, and print materials produced have interest-catching titles (e.g., "An Opening Act," "Humpty Dumpty in Reverse"), and the content has human-interest value without being cloying. Hand disabilities affect 40 million people. A Consensus Statement on this topic would enjoy more public interest than those addressed by the CVP (e.g., urinary tract infections among people with spinal cord injuries).

Moreover, it seems intuitively clear that foreknowledge will ease the trauma for people who experience disablement later. The task is to find more effective ways to get information into the mass communications media. People receiving disability services generally access new knowledge through service-delivery contacts. People living without services might benefit from new knowledge, but they are little more likely to get it than the general population. To reach them reliably, the mass media must be utilized. Cable TV programs on disability, New Mobility, Mainstream, and local giveaway newspapers that run features on human needs are low-risk approaches. Higher-risk approaches, such as investing time and effort in trying to interest

mainstream magazines, syndicated columnists, or TV networks, can be explored as budgets permit.

The Rehabilitation Engineering Research Center on Technology Transfer and Evaluation is disseminating information about assistive devices to consumers before the fact by involving them in evaluating devices. Disability-service organizations are being involved--and thereby informed--through a Request for Participation as regional centers to coordinate evaluation activities. This before-the-fact approach relates to products, but parallel scenarios can be imagined for service approaches. Special attention might be paid to employers, who have unique impact on people with disabilities. Focus might be placed on identifying findings of high import to them, then customizing methods for reaching them to promote wider dissemination through industry publications.

Much of the "magic" in getting research findings (and other disability information) into the mass media is purging it of jargon or pedantry. Another part is who you know. Schmoozing is a dirty job, but you have to do it to access key figures in the public media. The trend is moving toward integrated dissemination and utilization instead of tacking them on at the end of projects. Consumers are being involved and, therefore, informed from the outset, and research is being melded with advocacy to improve the suitability of general-use products and services. (An aside for those who are interested, NIDRR publishes a National Directory of Information Sources on Disability, which can be used in targeting mailings for dissemination purposes.)

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Accuracy and Consistency of Estimates of the Population of People with Disabilities in the United States

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For many members of the community of people who have disabilities, independent living goes only as far as a reliable system of personal assistance providers. Planning such services, as well as planning medical services, requires accurate information about how many people have disabilities. *This research sorts the meaning and accuracy of the many national surveys which have estimated disability prevalence over the past 15 years.*

Currently, only a handful of reports deal with disability prevalence based on multi-study analysis (Corder & Manton, 1991; Czajka, 1984; Kraus & Stoddard, 1989; LaPlante, 1993; McNeil, 1993; Wiener & Hanley, 1989). Table #1 lists all 14 U.S. national data sets collected during the past 15 years which can be used to empirically estimate the number of people with disabilities. These studies were conducted for different purposes, used disparate conceptual definitions, sampled different sub-populations, and/or used different data collection methods. To organize the vast number of possible methodological combinations requires evaluating the available data and studies, classifying studies, and pooling estimates from selected studies which fall into the same class.

Table 1
Collected Data on Disabilities in the United States since 1979

1979-80 Home Care Supplement, National Health Interview Survey (HCSm NHIS)
1980 U.S. Census
1982 National Long Term Care Survey (NLTCs)
1984 National Long Term Care Survey (NLTCs)
1984 Supplement on Aging (SOA, Sponsored by NHIS)
1984 Survey of Income and Program Participation (SIPP)
1984-86 Longitudinal Study of Aging (LSOA, Based on the Original SOA Sample)
1985 National Nursing Home Survey (NNHS)
1987 National Medical Expenditure Survey (NMES)
1989 National Long Term Care Survey (NLTCs)

Table 1 (Continued)

1990 U.S. Census (Decennial)

1990-91 Survey of Income and Program Participation (SIPP)

1992 Current Population Survey (CPS, Annual)

1992 National Health Interview Survey (NHIS, Annual)

Of course, one does not expect to find the same number of people with disabilities among different *populations*. The number of people with disabilities in Florida is not expected to be the same as the number in Alaska. Neither is the proportion of people who are under age 65 with disabilities expected to be the same as the proportion of people who are 65 and older.

The next requirement for being able to compare statistics is a *consistent conceptual definition of "disability."* Conceptual definitions vary with purpose for making an estimate. Purposes for using estimates of the number of people with disabilities have included demonstrating the importance of disability through the number of people it affects, monitoring discrimination, determining the need for work rehabilitation or income supports, and determining the need for personal assistance or medical services. The four definitions most commonly used in the literature are

1. **Basic Life Activity Limitation**--concerned with the ability to perform tasks appropriate to a specific age group (i.e., playing for young children, going to school for older children, working for adults, and living independently for elderly people). These activities involve major life areas such as social, family, work, health, and government participation (Kraus & Stoddard, 1989).
2. **Work Limitation**--people of working age who are limited in ability to work (Kraus & Stoddard, 1989).
3. **Physical Function Limitations**--examples include walking a quarter mile, setting words or letters in newsprint, getting around inside the home, understanding or hearing others (Kraus & Stoddard, 1989).
4. **Limitations in Activities of Daily Living (ADLs) and or Instrumental Activities of Daily Living (IADLs)**. The five most commonly used ADLs are: bathing, dressing, toileting, transferring, and eating (Wiener & Hanley, 1989). The most commonly used IADLs are house cleaning, preparing meals, shopping, doing laundry, using the phone, paying bills, and giving medications (Lawton & Brody, 1969).

As an example of how purpose affects conceptual definition and, then, population estimates, consider estimates of the total number of people with disabilities in the U.S. In the Americans with Disabilities Act, which protects against discrimination, Congress defined disability broadly. Under this broad definition, estimates were made of 43 million people (Czajka, 1984) or 48.9 million people (McNeil, 1993) in the United States living in the community who have a disability. These are the highest estimates of the number of people who have a disability.

The estimated number of people who have a disability for the purpose of estimating service use is much lower, but it still varies considerably. To examine the variation in estimates used for designing PAS or medical service systems, estimates considered here are National U.S. population estimates made for people under age 65 and those for people age 65 and older. ADL and IADL operational definitions are widely established to estimate service use. Estimates of the number of people with a disability from the various *data sets were sorted into categories representing methods* which might affect the estimates. *By comparing the size of estimates in the different categories, researchers can see the relative impact of these different methodological features.* Table #2 lists, in order of priority, variables that actually lead to differences in the number of people with disabilities estimated by various surveys. The first *five elements, in order, are most critical (sample populations, conceptual definitions, question wording, different ADL definitions, and non-response).* Other factors (proxy respondents, data acquisition method, sample design, sampling error, and changes over time) are important, but there are not enough published studies to determine the relative impact of these less powerful factors on estimates. A time series in the National Health Interview Survey (National Center for Health Statistics, 1983-1991, Table 67) suggests that, within recent years, changes over time are not an important factor explaining differences among estimates in various studies.

Within a methodological category, where estimates from different studies may be believed to have the same meaning, pooling the estimates across studies can be similar to increasing the sample size and, thus, can increase confidence in the accuracy of the estimate. These major government surveys, which were methodologically consistent on the orderable categories in Table #2 (the 1987 National Medical Expenditure Survey, the 1990-91 Survey on Income and Program Participation, and the 1982 and 1989 National Long Term Care Survey), were pooled, using a weighted average based on sample sizes. Each study used limitations in 6 similar ADL's to measure disability. The problem caused by failure to report variance in many published statistical reports is by-passed here by examining the proportion of people with disabilities, since each proportion implies a specific variance. For all ages, the pooled estimate is 2.2 % of the population, with a 95 percent confidence interval extending from 2.0% to 2.4 %. For people age 65 and older, the pooled estimate is 9.4%, with a 95 percent confidence interval from 8.7% to 10.1%.

Table 2
Major Causes of Differences in Survey Results
(Listed in order of importance)

Orderable Differences

1. Different sample populations that cannot be compared (i.e., elderly vs. nonelderly, Medicare recipients vs. general population, institutional vs. noninstitutional, etc.)
2. Conceptual definition of disability (work, activity of life, ADL)
3. Wording of question--there are three major components that can vary in disability-related questions:
 - a. Type of assistance (help from another, help from equipment, self-care assistance required, assistance required in any "life area")
 - b. Duration (how long a particular disability has lasted--3 months, 6 months, chronic, etc.)
 - c. Context (the way the questions are phrased, framed, and ordered, e.g., multiple ADLs mentioned in one question, or does each ADL have at least one separate question)
4. Different ADL definitions--the five most commonly used today are eating, toileting, transferring, dressing, and bathing (Weiner, 1989)
5. Non-response

Non-orderable Differences

6. Proxy respondents as opposed to direct response
7. Data acquisition method (questionnaires, phone survey, personal interview)
8. Sample design (cluster vs. stratification)
9. Sampling error*
10. Changes over time*

* These differences seem to be inherent to any study and, therefore, cannot be avoided. They appear, however, to be of little significance.

Similar analyses could be conducted to determine the relative impact of methodological features on the size of estimates in other geographic areas, other population groups, or using other conceptual definitions. When multiple studies are based on the same data set, referencing back to the initial data or to analytic variations and their meanings is most useful in interpreting discrepancies. Wherever multiple studies estimate a population based on multiple data sets, an analysis similar to the one used in this study is valuable for interpreting results. The more data sets available, the greater the number of features which can be definitively sorted in order of importance. Although this study was only able to dismiss change over time as unimportant, given a sufficiently large number of data sets, all methodological characteristics might be ordered, and those which are irrelevant to rates could be ignored. Before attempting a pooled estimate, it is important to sort studies by major methodological differences. Otherwise, pooled estimates capture methodological variations and produce numbers the meaning of which is obscure or non-existent.

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Review of Research on Psychosocial Reactions to Neuromuscular Disorders

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Individuals with neuromuscular disorders face a wide range of daily activity limitations. Included among these limitations are: a) physical difficulties that interfere with mobility, sensory, communicative, and manipulative activities; b) cognitive difficulties that often affect memory, alertness, attention, and concentration; and c) emotional reactions that may include anxiety, depression, anger, and lowered self-esteem. These and other symptoms (e.g., pain, fatigue, weakness) vary widely, and the disorders are often life-threatening.

Examination of the existing literature reveals only little consensus among researchers as to the nature, content, correlates, and temporal sequencing of psychosocial reactions to chronic illness and disability (Livneh & Antonak, 1994; Shontz, 1975; Wright, 1983). This paper provides a review of the research on psychosocial reactions to eight major neuromuscular disorders, a commentary on the soundness of the research to date, and recommendations for addressing the research problems identified. Specific disabilities were selected which represent both congenital and early onset disorders (e.g., amyotrophic lateral sclerosis, Parkinson's disease) and disabilities that are stable in nature (e.g., cerebral palsy), variable (e.g., multiple sclerosis), and progressive (e.g., myasthenia gravis, muscular dystrophy).

Cerebral palsy refers to a family of impairments of muscle tone, muscle control, or locomotion resulting from permanent, nonprogressive defects or lesions of the immature brain (Falvo, 1991). Reported psychosocial reactions include: a) difficulties in dealing with parental overprotection and pressure to achieve; b) feelings of inferiority, rejection, and self-consciousness; c) feelings of anxiety and isolation; and d) behavioral problems.

Spina Bifida represents a group of congenital spinal column disorders in which one or more of the vertebral arches fail to close during development of the embryo (Menolascino & Egger, 1978). Reported psychosocial reactions include: a) reduced self-esteem; b) feelings of social isolation, embarrassment, and maladjustment; c) feelings of anxiety and depression; and d) behavioral problems. A few studies (e.g., Spaulding & Morgan, 1986) revealed no differences between nondisabled children and children with spina bifida on measure of self-concept and overall adjustment.

Muscular Dystrophy pertains to a group of inherited, early onset, and progressive neuromuscular disorders (Ilan & Friedmann, 1993). Reported psychosocial reactions include: a) feelings of depression, especially when a wheelchair is required for ambulation; b) dependency related to parental overprotection; c) social isolation and feelings of helplessness; d) negative body image and lowered self-concept; and e) feelings of anxiety, typically related to physical deterioration and impending death.

Neurofibromatosis (commonly known as the "Elephant Man's disease") refers to a group of progressive, mostly inherited neurocutaneous disorders (Berkow, 1992). Reported psychosocial reactions include: a) anxiety associated with uncertain prognosis and future; b) distorted self-concept; and c) feelings of isolation, hopelessness, and resignation. The above, mainly clinical, impressions lack empirical documentation.

Multiple Sclerosis is a progressive disability with onset commonly between ages 20 and 40 years. While the cause remains unknown, the disease is thought to be autoimmune in nature (Falvo, 1991). Reported psychosocial reactions include: a) feelings of depression; b) changes in body image and self-concept; and c) feelings of anxiety associated with uncertain prognosis and future. Other studies (e.g., Pollock, Christian, & Sands, 1990) found no differences in psychological adaptation between people with multiple sclerosis and those with other disabilities.

Amyotrophic Lateral Sclerosis (also known as "Lou Gehrig's Disease") is a rapidly progressive motor neuron disease of unknown etiology (Berkow, 1992). Reported psychosocial reactions include: a) feelings of despair and depression; b) feelings of hopelessness and powerlessness; c) anxiety associated with increased dependency on others and with impending death; and d) denial, used to ward off anxiety.

Myasthenia Gravis is a generally progressive disease caused by an autoimmune attack on acetylcholine receptors within the neuromuscular system (Berkow, 1992). Reported psychosocial reactions include: a) feelings of anger and frustration; b) feelings of depression; and c) feelings of anxiety.

Parkinson's Disease is an idiopathic, degenerative disorder of the central nervous system, most notable for its late age of onset and slow progression of symptoms (Cummings, 1992). Reported psychosocial reactions include: a) increased dependency on others; b) increased withdrawal from interpersonal relations; and c) feelings of depression and anxiety.

Research Problems and Recommendations

Definition of psychosocial adaptation. Problems include: a) reliance on psychological constructs that require inference; b) inconsistent definitions of adaptation to disability; c) unidimensional conception that ignores multiple antecedents and facets

of adaptation. Recommendations include: a) obtaining observable, low-inference behavioral data; b) using multitrait-multimethod data collection approach for broader definition of adaptation; c) selecting a psychometrically sound multidimensional instrument.

Absent or inadequate control groups. Absent or inadequate control groups limit internal validity and preclude identification of psychosocial profiles of persons with different disorders. Comparison groups should be constructed which include people with various types of disabilities.

Disorder group composition. Problems include: a) little consistency in methods and criteria used to define and diagnose neuromuscular disorders; b) heterogeneity of subjects; characteristics (e.g., diagnostic status, severity of disability); c) failure to examine separately individuals at different disease stages or receiving different types of medical treatment. The use of careful sampling, longitudinal design, and multivariate statistical procedures will clarify outcomes of research with heterogeneous populations and increase comparability of results of studies.

Failure to explore coping. There is a lack of information on how coping strategies used by an individual influence adaptation to onset of disease and confirmation of diagnosis. Longitudinal research is needed on the relationships between disorder-related and sociodemographic stressors and use of coping strategies.

Concomitant confounding variables. There is confounding of measures of affectivity, especially depression and cognitive functioning, with extraneous (e.g., sociodemographic, disease-related, situational) variables. After collection of necessary data on extraneous variables, analysis of covariance, multiple regression, or multivariate techniques can be used to investigate and to remove confounding with outcome variable(s).

Confusion of cause and effect. The cause and effect relationship between somatic symptoms and psychosocial reactions is often confounded (e.g., depression following onset of symptoms may exacerbate symptoms of MS). These relationships and their interactive effects must be thoughtfully researched in longitudinal investigations.

Sample selection biases. The use of hospitalized patients and volunteers at specialized clinics precludes generalizability to person with disorders in the general population. Samples of persons with disabilities from diverse settings to which the researcher hopes to generalize results should be included.

Self-selected samples. Data from small self-selected or volunteers limits ability to detect true differences in dependent variable(s) and has led to contradictory research findings. Increase sample size and diversity; report attrition; adjust for attrition statistically prior to interpretation of results.

Subjective self-report data. Problems include: a) data from behavior or symptom checklists or from mail surveys with poor response rate introduce biases of subjects' premorbid personalities and response styles that limit internal validity; b) data from clinical interviews or informant reports introduce experimenter biases that limit external validity. Recommendations include: a) control influences experimentally, use outcome measures free of biases (e.g., observations of behavior in natural environments), or measure and report biasing influences; b) use raters blind to investigation or characteristics of individuals studied, and report indices of interrater reliability.

Reliance on MMPI data. Many MMPI items are saturated with symptoms of disorders (e.g., "I do not tire quickly"), biasing the results toward a finding of maladaptation. Use a psychometrically sound objective measure of psychosocial adaptation without symptom-saturated items.

Experimental instruments. Problems include: a) constructing measures of adaptation for a study and failing to investigate their psychometric properties; b) changing an existing instrument by replacing original referent and assuming data are reliable and valid. Recommendations include: a) select suitable instrument or provide data supporting the psychometric adequacy of measure constructed; b) significant changes to instrument necessitate psychometric investigation and revalidation of the instrument.

Incorrect statistical analyses. Problems include: a) samples that are not randomly drawn or are not randomly assigned to study groups; b) nominal data are analyzed as if they were interval; c) test of normality of distribution, homogeneity of sample variances, or linearity of regressions are not done. Recommendations include: a) use large random samples; b) select conservative probability levels for hypothesis testing; c) test and report assumptions; d) use distribution-free statistical analyses; e) transform data to approximate a normal distribution.

Simplistic designs and analyses. Problems include: a) case-study and unsophisticated group designs cannot yield generalizable answers to complex questions; b) timing of onset or disappearance of specific adaptation reaction phases cannot be delineated with cross-sectional designs; c) traditional unidimensional analysis methods cannot investigate commonalties or differences in process of adaptation to various disorder. Recommendations include: a) use complex designs to answer complex questions; b) investigate nature and stability of reactions as process of adaptation unfolds over time with longitudinal design; c) explore salient dimensions of adaptation, using sophisticated multivariate techniques.

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Managing the Interface between Treatment Technology and Children with Disabilities

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Medical knowledge and technology are rapidly advancing, but medical procedures can be frightening and behaviorally demanding, especially for children with developmental disabilities. These children may have difficulty understanding the reason for procedures, and they may take longer to learn (and to perform) behaviors necessary for cooperation with medical treatment. They may have limited ability to communicate about their symptoms, discomfort, and fear. As a result, children with disabilities are more likely to be denied the benefits of available technology or to be exposed to the risks associated with sedation or general anesthesia to manage their behavior during medical treatment (Kedesdy & Russo, 1988). Our clinical work and research are devoted to removing barriers to high quality medical care for children with disabilities and chronic medical disorders.

Forty years of research on the experimental analysis of behavior have been applied to the educational and behavioral problems of children, with great generality across populations and clinical situations (Cooper, Heron, & Heward, 1987). These techniques can also be applied to the unique problems confronted by children in medical settings, consequently increasing their opportunities to benefit from medical technology. Behavior therapy techniques are available for counterconditioning anticipatory anxiety, teaching specific coping skills, and supplementing medical management of pain and distress associated with medical care (LaGreca, Siegel, Wallander, & Walker, 1992). A summary of the behavioral model developed and employed by our Pediatric Psychology Consultation Service is presented below.

The medical procedure is first partitioned into its basic components for analysis. This facilitates individualized teaching and the measurement of progress. Next, the child's preferred activities (toys, prizes, snacks, cartoons, etc.) are identified and integrated into the medical routine. Whenever possible, the medical environment is modified with engaging artwork and adaptive equipment to make it less frightening and more comfortable for the child. The child is given frequent opportunities to make choices and to control aspects of the environment that will not disrupt quality medical care.

Necessary materials are developed to simulate medical procedures, thereby providing opportunities for training the child without expending medical staff time and resources.

Basic behavior analysis techniques, such as differential positive reinforcement and counterconditioning, are used to teach the child the new skills necessary for cooperation and coping with required medical procedures.

Using this general model, young children with developmental disabilities and disruptive behavior have been taught to lie still for MRI scans without sedation (Slifer, Cataldo, Cataldo, & Burke, 1989). In a controlled experiment, 5- and 6-year olds easily learned to cooperate with simulated MRI scans (Slifer, Cataldo, Cataldo, Llorente, & Gerson, 1993). Before behavioral intervention, the children had high movement rates, but after behavioral training, all were able to lie essentially motionless. Similarly, 4- and 5-year olds have been taught to cooperate with the movement restrictions necessary for radiation treatment without sedation (Slifer, Bucholtz, & Cataldo, 1994).

Through these types of demonstrations, the effectiveness of behavior analysis techniques in pediatric care are being presented to the medical community and to consumers of child health care. With ongoing consultation and training, health care providers can be taught to implement these procedures and to integrate them into their daily routines.

Another significant problem for children with neurological disorders, such as myelomeningocele, is bowel continence. Many of these children have been labeled neurologically incapable of bowel control. However, with relatively simple behavioral intervention, many have become continent or have improved their bowel control (Whitehead, Parker, Bosmajian, Morrill-Corbin, Middaugh, Garwood, Cataldo, & Freeman, 1986). This requires teaching self-monitoring, modifying the child's diet, scheduling routine toilet use, and providing appropriate incentives. Other motorically and psychologically challenging skills, such as urinary self-catherization, can also be taught to many children using Behavior Analysis techniques (Neef, Parrish, Hannigan, Page, & Iwata, 1989). This requires a systematic approach, opportunities to learn and practice skills, and the identification of powerful incentives.

Unfortunately, individuals with disabilities across all ages and ability levels are too often labeled incapable or noncompliant. Health care systems spend massive resources on mechanical or biochemical solutions to medical challenges, while spending relatively little on teaching the behaviors necessary to cooperate and cope with the demands of medical technology. This is particularly striking with respect to medication use. Billions of dollars are spent researching and developing new drugs, yet a child will not benefit from medication that is not taken. Relatively few resources are expended on discovering the reasons why, for example, parents might

forget to give the medicine or might be unable to get the child to swallow it. The child may not be motivated to ingest the medication because of its taste or smell, and he or she may not have the skill to swallow a pill or capsule. Many children can begin with tiny placebo pills and gradually learn to swallow larger and larger ones until they reach the same size as the actual pills (Babbitt, Parrish, Brierly, & Kohr, 1991).

For those children who are capable, but who refuse to ingest medication consistently when presented, a compliance training program can be implemented (Babbitt, Cataldo, & Gerson, 1994). This involves preventing the child from using disruptive behavior to avoid medication, and providing positive consequences (praise, snacks, prizes, games) for accepting and swallowing medication. If parents forget to give medicine or cannot manage their child's disruptive behavior when medication is presented, behavioral parent training can be provided to teach parents the needed skills (Gerson, Pegelow, Armstrong, & Faust, 1992).

Even procedures that are painful and require sedation or anesthesia can be improved by the addition of behavior therapy techniques during stages of anesthesia induction, conscious sedation, and post-procedural or post-operative recovery (LaGreca et al., 1992). The behavioral approach can be used to teach children to report pain or other symptoms to medical staff, to teach them distraction and relaxation strategies, and to gradually expose them in advance to the medical stimuli they will encounter when they undergo procedures or awaken from surgery. For example, a 3-year old with developmental delays recently required tracheostomy tube placement due to sleep apnea. The routines and sensations involved in daily tracheostomy care were simulated as accurately as possible. Positive reinforcement and counterconditioning were used to teach the child not to touch or disrupt his tube. In this way, the need for post-operative sedation and restraint was reduced, and the child's discharge to home health care was accelerated (Slifer, Babbitt, & Cataldo, 1995).

This paper highlights many situations in which Applied Behavior Analysis and Behavior Therapy can facilitate children's adaptations to medical stressors and routines. We advocate pursuing every opportunity to integrate behavioral and medical science for collaborative research aimed at improving access to quality health care for children with disabilities.

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Section VIII

Expanding Approaches to Disability

The four chapters in this section review past and present understandings of disability, and explore redefinitions of disability experiences. James Ferris examines ways in which performance studies does/does not offer a perspective that is relevant for disability studies in his paper, "The Ghost in the Machine: Limiting Concepts of the Body in Speech Communication/Performance Studies Textbooks." Both performance studies and disability studies encourage interdisciplinary research; both explicitly take, rather than disavow, political perspectives; and both include the body and embodiment as key elements in social life. Ferris reviews major texts in performance studies and, in so doing, clarifies ways in which, despite its "inclusionary attitude" (p. 205), performance studies makes assumptions about the "normative body" that serve "to alienate and marginalize members of the country's largest minority, people with disabilities" (p. 208). Ferris challenges performance studies scholars and teachers to examine how their own practices may further, rather than eradicate, exclusivity and stigmatization.

David Mitchell and Sharon Snyder address ways in which disability, unlike other signs of "displaced populations," is characterized by its "seemingly endless circulation in narrative" (p. 212), rather than by its absence. In their chapter, "Narrative Prosthesis: Idiosyncrasy and Incapacity in Postmodern Discourses of Disability," the authors challenge contemporary scholars who pursue theories of the body and of difference, to critically consider ways in which disability in narrative, visual representations, and experience occupies a "unique status" (p. 212). The questions Mitchell and Snyder pose have implications that extend to considerations of humanness and social interactions.

Like Mitchell and Snyder, Marcy J. Epstein draws on contemporary theories (e.g., discourse analysis, feminist theories, post-structuralism) in her paper, "Dis/ability as Dis/course: Eating Dis/order and the Challenged Culture." Using the example of eating disorders, Epstein examines ways in which the "body language" of eating disorders is similar to/different than other discourses of disability. In discussions of identity politics, Epstein cautions us to consider: "Who is being challenged, to what, and to what end?" (p. 215).

No one method or theoretical model can fully answer all of our questions about disability. As the chapters in this book illustrate, a carefully considered use of a variety of techniques, concepts, etc., furthers our understanding of disability-related issues. In "My Good Leg Doesn't Like Me Anymore': Interpretations of the Disablement Process," Jessica Scheer, Mark Luborsky, Monika Deppen, and Kathryn

McGowan employ three cultural frameworks in order to more fully understand disability experiences. Their presentation of one case, and the application of these frameworks (stigma, liminality, and acculturation) affirm living with a disability as a complex process. As all of the papers in this section have asserted, disability is profoundly cultural in definition and experience. The final sentence in Scheer, et al., could be considered a general challenge to disability researchers: "We expect our work will result in significant refinement of the use of values in defining impairment, disability, and handicap" (p. 223).

The Ghost in the Machine: Limiting Concepts of the Body in Speech Communication/Performance Studies Textbooks

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The emerging fields of disability studies and performance studies have a number of commonalities. Both draw on the resources of other academic disciplines to examine issues that tend not to respect traditional scholarly boundaries, both are relatively new to campuses, and both imply a certain political stance. Perhaps most importantly, both fields recognize the centrality of the body in human experience: disability studies argues that physical characteristics have a great deal to do with how people are perceived, identified, and treated; and performance studies contends that a normative body is an essential attribute for a performer--and that we are all performers.

Since all human communication can be considered an act of performance, performance studies is generally situated within the discipline of speech communication or human communication studies, yet it is enriched by a wide range of fields, including anthropology, sociology, theatre, literature, popular culture, and folklore. Performance studies can be seen as both an evolution and an expansion of the long tradition of the oral interpretation of literature, reaching back to the rhapsodes of ancient Greece. The field takes as its central concern the analysis of aesthetic communication through the act of performance (Pelias, 1992). Performance studies is based upon the conviction that there is no better way to understand a text than to get inside it, to inhabit it as you seek to embody it, and to bring it to life in performance.

One of the most important characteristics of performance studies is its inclusionary attitude toward performers, texts, and audiences. Pelias and VanOosting (1987) contend that "an inclusionary impulse toward performers and audiences and a noncanonical attitude toward texts" are the "root orientations" of performance studies (p. 227). They describe a "radically democratic and counterelitist" (p. 221) ideology which calls into question "the assumed authority of literary and artistic 'experts'" and which authorizes all members of the community "as potential artists, all utterances as potentially aesthetic, all events as potentially theatrical, and all audiences as potentially active participants who can authorize artistic experience" (p. 221).

But this laudatory impulse is undercut by assumptions the field makes about the performing body. Although performance studies valorizes an inclusive attitude to performers as well as texts and audiences, the way scholars and practitioners talk and write about the performing body serves to exclude at least some of the marginalized

people this "radically democratic and counterelitist" ideology seeks to enfranchise. Performance studies discourse implicitly posits a normative body, one which stands, walks, talks, runs, breathes easily, sees, and hears, an assumption which opposes the field's own aspirations to inclusiveness. This normative body excludes people with physical disabilities, who have impairments in one or more of the very functions taken for granted by performance studies discourse.

How members of the performance studies community introduce novices to the act of performance provides a clear picture of the normative body. I examined the ways selected authors discuss the body of the performer in six of the most influential textbooks from the past twenty years: books by Bacon (1979), Lee and Gura (1992), Roloff (1973), Long and Hopkins (1982), Yordon (1993), and Pelias (1992). I considered the type of body their writing assumes, and the types of bodies which may be excluded.

"Everyone's physical presence is open to interpretation by others," Pelias (1992, p. 74) notes; "performers cannot escape their own physical presence" (p. 161). Bodies cannot help but influence a performance. Indeed, physical presence--a body--is an open invitation to others to begin making meaning of our presentation in the world. This happens, Roloff (1973) notes, whether we desire it or not.

Lee and Gura (1992) describe how the body "performs" even before the first word is spoken: "From the moment the audience becomes aware of your physical presence, you are arousing a response. . . . By your bodily actions you give intimations of a particular mental attitude toward yourself, the audience, and the material" (p. 116). So, the authors suggest, performers--and their bodies--should be careful not to overshadow the texts they are performing: "The style of performance in the art of oral interpretation must be unobtrusive" (p. 115). A major concern, Roloff (1973) says, is to eliminate behaviors and mannerisms that might call attention to the performer and take away from the audience's enjoyment of the text. "To do otherwise can only result in a distracting conflict between [the performer's] personal life style and his [or her] performing style" (pp. 99-100). But the body is inescapable, and even more so for performers with visible physical disabilities who, try as they might, cannot avoid the fact that, in a world of bodies, theirs are more obtrusive because of their noticeable difference.

There are many other assumptions that make up this normative body. Roloff (1973) asserts that the performer "is obligated to be free of idiosyncratic behaviors of all kinds" (p. 104). This effectively eliminates many people with disabilities who may well have idiosyncratic ways of walking (or not walking), sitting, talking, and gesturing, for example. He argues that there are normative standards and offers a checklist of questions for the beginning performer, focusing on the suitability of the body and voice as instruments of expression. Roloff suggests that the performer's body should be supple and move freely, be responsive to rhythm and movement, and

that the performer's voice' should be flexible in tone and rate, vocally responsive, and capable of effortless projection.

Although Bacon's (1979) concept of matching emphasizes congruence between the inner forms of poem and performer, the performer's body is still important to him:

The whole body participates, whether or not overtly, in the emotional state of the individual--but it is from the overt behavior that we as audience get some sense of the inner state. The outer form must lead us to the inner form. (p. 117)

The interpreter must have "a flexible and sensitive" voice and body, and "the broader the interpreter's lexicon of behaviors, the better" (p. 38). Bacon contends that

No performance can reach the ears of the audience without the careful participation of the performer's whole body. . . . The reader reads from head to foot, and a slackness of tension in the lower part of the body . . . will betray inadequate responsiveness just as much as a meaningless gesture of the hand. (pp. 71-72)

For Lee and Gura (1992), who devote a chapter each to the use of the body and the voice,

The basis of effective bodily action is good posture, which is . . . the arrangement of the bones and muscles that puts the body in its perfect alignment so that each unit does its job of supporting and controlling the bodily structure without undue tension or strain. . . . Good posture requires nothing more complicated than standing straight and easy from the ankle bone to the crown of the head, so that the various parts of the skeletal structure fall naturally into place. (p. 117)

Long and Hopkins (1982) do not focus much attention on the performing body. Yet they clearly assume a certain kind of body when they offer directions for warm-up activities, including running in place.

Standing and walking are functions of the normative body. They are not only used metaphorically (as when the student is advised to walk around in a text or a character's shoes); they are commonly part of the directions or suggestions: "As you tell the story," Yordon (1993) suggests, "you will probably want to stand" (p. 36).

Roloff's (1973) checklist assumes a normative body that is supple and free-moving, with a voice that is responsive and flexible. Adequate breathing and a capacity for effortless projection are also assumed. For Bacon (1979), the performer needs a body which can respond head to foot, a flexible and sensitive voice and body, and a wide behavioral repertoire. Lee and Gura (1992) call for uncomplicated good posture and

proper breathing. Although the aim of each of these books is not to train stage performers, but to teach beginners in introductory classrooms, this normative body established by the field's discourse serves to alienate and marginalize members of the country's largest minority, people with disabilities.

The textbook authors suggest that inability to meet the specifications of the normative body means that performers need to develop those capacities. According to Pelias (1992), performers "often learn what skills they need through their encounters with personae who demand certain vocal or bodily behavior for portrayal. Being unable to present these behaviors specifies for performers the technical skills they should develop" (pp. 82-83). Those whose bodies are not able to develop those skills are likely to feel excluded from a pursuit which hopes to be inclusive and empowering.

Even when people with disabilities are mentioned, the normative body is not only assumed, but reinforced. Lee and Gura (1992) address the problem a performer, assumed to be free of disabilities, might face in trying to portray a character with an "infirmity": "Sometimes characters with physical infirmities pose special problems. The best way to deal with these characters is to examine how the infirmity affects their living in the scene" (p. 310). But nowhere do Lee and Gura address the problems a performer with a disability might have in portraying a nondisabled character. People with disabilities are apparently not part of the audience of potential performers.

In an appendix, Yordon (1993) mentions people with disabilities as offering a possible career for her students: "There are many outlets for the interpreter's work with handicapped persons. You can work as a teacher or as an activities therapist in schools, hospitals, or community centers" (p. 434). Although she asserts that "the physical limitations of physically handicapped people do not inhibit their involvement" in performance activities (pp. 434-435), her book otherwise excludes this population, suggesting that people with disabilities have less status, and that people with performance studies/interpretation training are required to help them "express and deal with their problems" (p. 435). If people with physical disabilities can participate successfully, why relegate them to the back of the book? This treatment continues the marginalization and devaluation of people with disabilities.

Because of this unquestioned conceptual framework, persons with disabilities can be accommodated in practice in the classroom and the theater, but still be excluded from full participation because their bodies do not fit the fundamental definition of performance. We make some accommodations, for example, by adjusting an exercise, by reblocking, or by changing our immediate expectations, but, without rethinking our underlying assumptions, we continue to marginalize those who present other bodies. If we continue to accommodate without rethinking the normative body, we engage in tokenism, allowing one person partway in at a time, instead of throwing open the doors in a truly democratic and counterelitist way.

Performance studies has much to offer people with disabilities. This field, with its rich traditions of performance and analysis, offers tools vital for resisting the devaluation and marginalization inherent in the normative body. But, in order to make these tools more readily available, performance scholars must first carefully assess how they themselves may be reproducing this oppression in their own thinking and practice.

Performance studies practitioners, instructors, and scholars are challenged to take their historical attention to the performing body a step further. Only in this way can the field truly make good on its "radically democratic and counterelitist" promise.

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Narrative Prosthesis: Idiosyncrasy and Incapacity in Postmodern Discourses of Disability

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If we are to ask the question--"What can literature, film, and narrative theory do for the development of disability studies and disabled psyches?"--then we simultaneously encounter the parallel difficulty of understanding that, at least in literary circles, disability can mean anything at all but itself. In other words, tropes of disability such as amputation, immobility, disfiguration, congenital malfunction, and sensory deprivation or breakdown, all "enjoy" a preponderance of "air time" on the wavelength of the literary, and, at the same, that perpetual circulation deploys the category of "disability" as a metaphor never quite bound to the physical landscape/terrain. Instead, the idiosyncrasy that physical deformity provides proves to be one of the most significant and often-used tools of character development. Since the sign of disability provides a kind of accent to the geography of the body, literary narrative and poesis has consistently gone to the visible landmark of the physical in order to highlight and individuate character.

This project of narrative individuation can be understood as a kind of shorthand methodology to the study of character, and nowhere can this be seen better than in film. Because of the visual nature of the medium, the contours of character--the art of outlining the narrative focal point against the anonymity of the crowd--inevitably privileges the realm of the physical as the antidote to the psychological interior that is available in print. D. W. Griffiths' pioneering films of the early twentieth century founded our visual notions of character development in film (and borrowed from Victorian melodrama in doing so) upon the premises of disability as the mediating device of audience response. The very tag of villainy is almost synonymous with the visual phenomenon of the limp. Of course, villains with impairments can become the most interesting characters, as in Orson Welles' creation of Quinlan, the Texas police officer in his classic, Touch of Evil (1958). In Touch of Evil, Quinlan's grandiose, unmaneuverable size, his limp, and a humorously lost cane provide the basis for an allure that such mythic villains afford us. In this paradigm we can represent the history and development of physical "deformity" as the central metaphor for the relatively inaccessible psyche. Here the idiosyncratic promise of the exterior is displaced in the logic of a deformed interior fully essentialized in the visual correlative of physical geography.

Unlike the recent spate of critical models that endeavor to rescue the socially disenfranchised from "representational obscurity," we are interested in marking a distinct reformulation of a concept of marginality through the category. Instead of arguing that disabled populations have been relegated to the oblivion of cultural disinterest and silence, we argue that physical deformity--in its omnipresent service to the engine of narrative--ironically enjoys an endlessly textualized existence. In other words, while most discussions of displaced populations begin with the fact of their displacement (their literal unrecognizability in the eyes of the world), "disability" troubles this critical predisposition because its marginalization occurs in the midst of its seemingly endless circulation in narrative.

The import of this formulation suggests that literary and philosophical studies need to undergo a formative shift in the understanding of the processes of political and social ostracization because narrative operations depend upon the repetitive invention of displaced populations as the definitional essence of consolidating a hegemony of the "norm." What this saturation of disability in the contemporary marketplace of ideas and images signals is that the "other" is consolidated, not in its banishment, but rather in the fury of its perpetual location. Thus, while we would like to draw comparisons between disabled populations and the disenfranchisement of racial and gendered communities (social categories that also depend upon the imposition of a physical trait to segregate and mark the object of social exclusion), we also want to foreground the challenge that disability, in its conceptual sense, poses to the academy's current scholarly conversations regarding the psychological, sociopolitical, and physiological matrix that comprises social identity.

Toward this end, we seek to seriously explore a key question that has surfaced over the past few years in discussions of disability: Is there such a thing as a limited body? Deconstructionists, social constructivists, feminists, and theorists of the body have justifiably answered this question with a resounding "no," by posing an alternative rhetorical question: Should physical impairment be perpetuated as social limitation and constraint? We want to argue that such an impulse, while significant, forecloses some crucial areas of inquiry that must be pursued. In the push to "re/member" the disabled body into the semblance of a more human creation, philosophy has endeavored to "transcend" the life of the bodily as the material of a stubborn recalcitrance. Through strategies that lay waste to the monolithic pretense of health and wholeness, we have come upon the "hard calculus" of a corporeal phantasm: a residue that continues to buttress the social categories of "grotesque" and "abject" deviance.

The experience of physical impairment does not lend itself readily to the utopian promise of disability as another difference in a democratic sea of variegated identities. We are endeavoring to inquire after the causes and rationale of disability's unique status in this regard. We would like to end this paper with some questions that are difficult to answer. How do we explain and theorize the implications of disability's

recalcitrance? How do we understand the pleasurable investment that informs a desire to "closet" the threat of disability (both individually and as a society) by producing and reproducing its very visibility as exceptionality? Finally, how do we respond to impairment as limitation without simultaneously disqualifying and denigrating the recipient of necessary social accommodations?

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Dis/ability as Dis/course: Eating Dis/order and the Challenged Culture

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Like many identity-political discourses, disability as a discourse in its own right appears an anomaly, but one used to express identities or forge timely political coalitions. Yet, in shaping language, the rubric of the "challenged" often leads to confusion. Part of a larger project on cultural anxieties which emerge from discourses of disability, this paper explores a "disabled" relation between material bodies and cultural sensibilities in a range of cultural and feminist theories which themselves draw from discourses on disability. I re-theorize the subject with eating disorders alongside disability to offer at least one strategy for linking together "definitions" and theories to "metaphors" and configurations of the so-called "challenged." Who is being challenged, to what, and to what end? For example, a person with paraplegia may join another with visual impairment and barrage the steps of the Capitol in order to promote public and media awareness, but the physical appearance of these bodies also has a *discursive* consequence. Specifically, political strategies can rationalize the gross, even grotesque simplification of our conditions--a body with variable motor skills becomes comingled with a body with variable sight. Such strategies reveal a paradox: the more bodies with disabilities added into the equation of discourse and representation, the more disability is defined through loss, disrepair, or incompleteness. Without use of limbs and eyes, people who are blind and those with paraplegia meld into one spectacular "disabled" body of a discursive and political nature, a body of many afflictions, a body thus beyond any real hope of breaking free of another physical challenge: language itself. Somehow these bodies find a polity and language of disability turned against them.

A recent discovery, this is not. Disability has evolved through terms such as "discourse" and "culture," but it has also preceded them. Michel Foucault (1986) deduces that discourse comes from a need to avoid punishment for being in a body at odds with cultural standards. To matriculate safely into culture, according to Foucault, to attain the "art of existence--the *techné tou biou*-- . . . one must 'take care of oneself'" and--importantly--"attend to oneself" (p. 42). These mandates for self-care deal with washing, diet, urinating, sex, sports, disease, movement, death, and--this seems anomalous in itself--philosophy. Foucault describes antiquated cultural regulations, aesthetics, and standards which the citizen's body should practice, emphasizing how difficult and painstaking this regimentation of body instincts, desires, and irregularities would be. Foremost, a discourse of ability depends on developing the *right* balance of the senses and skills, a "sense/ability" to define one's sensibility, a cautious reworking of body meaning to serve a social standard in lieu of the body's own way of accomplishment.

Taking care of ourselves, then, defines the compromise between the body and the status of an "able" subject; these equivocations in language keep us "careful" with sexual and moral practices, scientific inquiry, relegation of power, in short, the lending of material substance to cultural value of ability by avoiding wrong ideas, wrong bodies, wrong habits. Moreover, some of the body's nature must be vacated for this new preoccupation with material well-being; the citizen's body holds a set of impractical senses and properties which supposedly *dis/able* the subject from caring for herself/himself and "*taking in*," or as my illustration will show--*ingesting*--cultural discourses which would ensure personal advancement. So, understanding one's abilities means not only consuming the right ideas for the body, but also purging oneself and one's body of its impurities and disabling ideas. It follows that disability not only threatens cultural order, but also serves as its integral source of nourishment; "ability," then, is not, in Foucault (and, thus, Seneca's terms), always a "reparation" or "freedom," but the proactive term of regulating the body in *constrictive* institutional status (Foucault, p. 51).¹

But does the challenge to exist lay entirely on the individual, and is this economy of body-traits and consumption all inclusive? Judith Butler (1990) observes that physical features and some material bodies "appear to be in some sense *there* on the far side of language, unmarked by a social system" (p. 130). Similarly "passing unmarked" in a social system, eating disorders represent disabilities which often are not visible, but which pass dangerously into "the other side" of a consumer-consumed economy, a disability of language and motive. Already we have a citizen bent on a discourse of purposeful consumption and purging. But experts on the condition of compulsive bodies and eating disorders--Susie Orbach, Kim Chernin, Geneen Roth, or Roberta Seid--do not document a generic predisposition for eating disorder, but rather how their subjects invent the terms of their incapacitation, become known later as "disordered," and sometimes face permanently challenged mobility, dire weakness, even death. Rather, discursive disability infuses "eating disorder" with the term's naturally deconstructive language for resituating actual bodies at the margin of ability and material articulation. Their bodies may be sacrificed for self-survival, but eating disordered subjects, in such way, also find "body language."

In her study of anorexia and critical theory, "The Body and the Reproduction of Femininity: A Feminist Appropriation of Foucault," Susan Bordo (1989) suggests the

¹Foucault does evidence a relation between manufactured discourses of sex and ability. He seems less concerned with the cultural threat to/of proper sex or sense/ability as much as to the discourses which constitute those threats in the first place. By using the term "disorder," I do not mean to imply that same sociopathologizing of people with disabilities. On the contrary, I mean "disorder" to represent a specular alternative to restrictive social orders, a position not of bodies but in language, a political effect of oppression and the randomization of the concrete orders this "disabled" subject position is thought to oppose.

following to relate the body with eating disorder metaphorically to cultural definitions of adequate bodies: "The body may operate as a metaphor for culture . . . an imagination of body-morphology has provided a blueprint for diagnosis and/or vision of social and political life" (p. 13). Bordo's "body-morphology"--a term which aligns *material* bodies and *defined* morphologies--re-theorizes Foucault's practiced, normalized, and acculturated body. However, this body-subject is female and feminine. In light of this realignment, her cross-semination between gender and body ability allows the objective analysis of power relations as well as the agency necessary for her subject to comprehend her own abjection. By claiming that the body is a morphological and aggressive "text of culture," Bordo might agree that disorderly, consuming, feminine bodies and those with disabilities provide the blueprint, the inverse image which gives us our institutions of femininity, compulsory heterosexuality, whiteness, ability, and--significantly--*disability*. With or without a disability, colluding with institutions or appearing to subvert the will of powers that be, above all, the body lays open, textual, and interpretive.

We must address, however, the aggressive *will* of those with eating disorders to fail in material or interpretative self-care, the *techné tou biou*, when disability is so oft depleted and incapacitated in language. No matter how ravaged and "disabled" the eating disordered body becomes, its person nonetheless possesses a reservoir of choice which, then, swells into compulsion. Options to eat or to not eat, what to eat and how much, what symptoms to hide or to show exercise a complex material politics. Eating disorders may be dissimilar to some disabilities, but they similarly challenge our culture's anxiety about producing materially-able bodies at all. The anorexic, obese, bulimic, or food-fetished habituate makes *literal* a disposal of the material body at the border between cultural sensibility and cultural language. As Edwina Franchild (1990) writes, "able" people are not those who can see, but those who are enfranchised. Unlike Franchild, who seeks a place between able and lesbian communities, the eating-disordered subject--for all her passability and subversive stratagem--seeks no enfranchised category based on her material state--the *state* could never meet her body's self-exacting criteria.

Indeed, bulimia, anorexia, and compulsive eating suggest radically private body conditions, as disability represents the grotesquely public one; one rarely finds societies of women who get together to discuss their rights as fast disappearing bodies, or, even more unlikely, friends who throw up together. The *body language* of eating disorder redirects our attention away from the impossible singular body with a disability, and toward a new subject of an impossible "culture with a disability." In its broadest terms, this reevaluation of challenged sense/ability in terms of compulsion, policy, and discourse may enable disability scholars to confront their most formidable barriers for determining "ability" and a unidirectional access within greater discourses of cultural studies and identity politics.

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"My Good Leg Doesn't Like Me Anymore": Interpretations of the Disablement Process

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For us, doing fieldwork is the heart and soul of being cultural anthropologists. It is our practice to get to know people over an extended period of research time, talk with them in depth, and listen for ways in which cultural forces shape an individual's beliefs, experiences, and actions. For the past several years, our fieldwork has been among people who had polio; for analytic purposes, people who had polio represent the increasingly large group of individuals who have had lifetime disability experiences. Our current study, funded in 1993 by the National Center for Medical Rehabilitation Research, contrasts a total of 156 men and women who previously had polio and are now at mid and late life. We compare individuals who have followed three pathways of lifetime experience: those who recovered from polio without impairments, those who recovered with stable impairments which have remained stable, and those who recovered with stable impairments that have unexpectedly converted to become progressive due to the late effects of polio or post-polio syndrome.

In this paper we will explore how the lived experience of one of our research subjects or informants is an expression of the dilemmas posed by common solutions to the sociocultural problem of having a disability in American society. We suggest that using a combination of three cultural frameworks provides a more complete understanding of the dilemmas presented in Max's story.

Max's Story

Recently I visited Max, a down-to-earth retired man in his late sixties who had polio as a child and had walked with a moderate limp since then. Max was most proud of his working days and the years he spent with his charming and loving wife. Both of these dimensions of his life had been unexpectedly cut short--his wife had died ten

years before from cancer in her early fifties, and Max was forced to take an early retirement due to severe leg and hip pain and weakness from the late effects of polio.

As a young boy Max had a paper route; during his teenage years he learned how to cut meat while working for a butcher; during World War II he operated a lathe on a tool and dye assembly line for a munitions firm. Max spent most of his working days putting in long hours in the neighborhood grocery store he and his parents owned, and, when he sold the store because the neighborhood had changed, he got into real estate sales in a big way, moving up quickly to District Manager, training other agents and, as he said, "having a ball." He deeply regretted having to retire early because he could no longer climb steps and put in the long days required. Within the same year, he lost his wife to cancer.

One of Max's life themes was the pride he felt in having successfully met the challenge of working hard and earning money, one avenue to achieve the social acceptance he felt had been denied to him by childhood playmates who teased him for not being able to run and play ball. At the beach Max hid his weakened and withered leg with a towel, his attempt to be accepted for who he felt he was, an equal to others. By the time he was ten years old he had started to earn money. As a result, he could afford to buy his own car as a teenager, which was not common in the late 1930's. He reveled in the fact that the same boys who had teased him and excluded him from ball games then begged him to use his car to double date with them. In one of our first interviews, Max told me that the thrill of owning a new car had never left him. Max's "pride in work" life theme illustrates the special significance that the work ethic, a strong cultural ideal, has for many Americans with disabilities. Like other devalued groups, practicing the work ethic and achieving success is an important passage to social acceptance and a way to counter the low self-esteem generated by internalized negative social messages of being different and inferior. Cultural ideals provide anchor points for framing life experiences; and, for people with limited avenues for social integration, achievable cultural ideals have a heightened significance.

Getting back to Max's story, when I arrived at Max's house, the first thing I noticed was a shiny new silver gray Cadillac sitting in his driveway. But Max was subdued. He said he had had the car for a week. And he reminded me of how every other time in his life when he had bought a new car he had jumped out of bed first thing in the morning to sit in the car and see if the car was "for real." But with this car, he did not do it. He lived in a two-story house, and his post-polio pain and weakness made the effort of going downstairs more times than absolutely necessary too great. He asked me, this man who had already lost the two major joys in life, "Am I getting too old to enjoy the simple things in life? What's the matter with me?" In his frame of reference "the matters" were not physical but, instead, referred to a set of negative psychological characteristics, something that was wrong with Max, intrinsic to Max himself. The purpose of our work as anthropologists is to try to make sense of the

influence that culture has in shaping the meaning people attach to events. Max was blaming himself for not being able to "be himself" and to enjoy his car in his own way. He felt he was becoming someone else, maybe joining the ranks of the "old" and "depressed." But Max could not "be himself" because he could not easily climb down the stairs in his inaccessible home. Max's early solution to the dilemma of having a disability in our society did not last a lifetime, and the psychological cost was becoming expensive.

Max described his new post-polio disabilities as something he now has to consider when planning his day, when deciding the restaurants to which he can go with his friends. He said, in summary, "my good leg doesn't like me anymore." Once again, he blamed himself for not being able to do what he could not do. Max had learned during his initial polio rehabilitation as a child that he had a withered "bad" leg which stopped him from being able to run and a strong muscular "good" leg which became his solace. By objectifying his limbs as being either "good" or "bad," Max had effectively externalized a personal imperfection. It was not Max who was good or bad, but his legs. Still, the objectification of a part of himself replicated the negative social evaluation of impairment. Objectification is a common strategy that has the potential of not lasting a lifetime, and the betrayal later in life is painful to bear. The person ends up blaming himself or herself for the negative social evaluation of impairment.

Three Cultural Frameworks for Understanding the Disablement Process

Attention to three sociocultural frameworks adds insights to Max's disability-related life experiences: first, stigma; then, liminality; and, finally, acculturation.

What does the stigma framework tell us about Max at this point in his life? Stigma defines disability as a socially-ascribed undesirable difference. Stigma theory has contributed concepts of the stigmatized role, spoiled identity management, and deviance disavowal to disability studies (Wright 1960; Davis 1963; Goffman 1963). A deficit of the stigma model is that it focuses on an individual's responsibility for success or failure in adapting to labels and environments. Management of the social stigma by self and family is as much a focus as management of impairments. Max used deviance disavowal as a reaction against negative social labels, a strategy that, we see, did not last a lifetime. In fact, it backfired when new disabilities emerged, and the stigma was left exposed once again, and internalized.

Another cultural framework, liminality, defines persons with disabilities as members of a social category of liminal persons, stranded "betwixt and between" the categories of health and illness. Although not perceived as being actually sick, people with disabilities are also not perceived as being fully well. The marginality and isolation of people with disabilities is attributed to their being socially structurally arrested, "neither here nor there." As a result, they do not gain full presented or social

acceptance. Liminality is characterized by feelings of anomie, uncertainty, and ambiguity. Aversion or avoidance of people "betwixt and between" social statuses is a cross-cultural universal; they are secluded and believed to be polluting because they represent an "anti-structure" that contradicts normal social structure and categories. Actions, such as employment, parenthood, and other forms of engagement, can modify the symbolic barrier to some degree. Max's underlying feelings of isolation and uncertainty about the present and future emerged again in late life as he acquired new disabilities. Not yet moving towards a new value orientation in response to a changing physical situation, we find Max frozen in ambiguity. We see that, when efforts to disavow the stigma or to modify the symbolic barrier of liminality no longer work, the individual is left without cultural anchors, and he or she resorts to self-blame.

Both stigma and liminality are incomplete, in themselves, for understanding the complexity of Max's lived disability-related life experience. Stigma and liminality are static frameworks, not conducive to issues of personal and wider social change. We turned to another anthropological concept to gain insight into the value re-orientation process so intrinsic to personal life. The study of acculturation in anthropology attends to the changes in cultural value systems due to historical change or contact between cultures or subcultures. Feelings of obsolescence to personal and social ways of life and core values, as well as a sense of disjunction from prior systems of values and lifeways, are very much present for individuals immersed in cultural or subcultural change. We found that acculturation-like dynamics are present in people who have lived lifetimes with disabilities, especially as the nature of their disabilities change over the life span. Because the value orientation developed by Max in response to the challenge of living with his disabilities in American society did not continue in the face of new disabilities, a new value orientation is in order, one which Max, perhaps, is not ready to consider.

Cultural frameworks provide fundamental value orientations that instill deep motivations in people, shaping their perceptions, feelings, and patterns of behavior. As we have seen from Max's story, cultural frameworks themselves can present multiple conflicting dilemmas that induce distress or tension in the person. Culture is both a source and a resource for stability, and it provides elements that function to produce individuals' experiences of distress and tension. These are not psychological problems in the individual, but system level tensions.

Our current project, now in the beginning data collection phase, seeks to gather (1) an accurate and detailed description of the types of personal concerns, values, and perceptions held by people with lifelong disabilities at mid and late life about their physical and social lives; and (2) to refine and expand frameworks of the cultural construction of disability-related life experiences. One of our goals is to help refine the definitional work undertaken by the ICIDH and the Disablement Process Research Model suggested by Verbrugge and Jette (1994). These models refer to the

importance of values in mediating handicap, in the case of the WHO and IOM Models; or in slowing down or speeding up the disablement process, in the Disablement Process model. But in neither instance is the cultural context of disability-related value orientations considered. Each of the cultural frameworks discussed in this paper is incomplete in and of itself, but, when used together, we find a fresh view of lifetime disability experiences. We expect our work will result in a significant refinement of the use of values in defining impairment, disability, and handicap.

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Section IX

Contact and Communication as Vehicles for Change

The six chapters in this section provide support for the idea that increased contact between people with and without disabilities can facilitate better understanding and decreased stigmatization. Renata Staron describes her study of 50 sixth graders in "Does Contact Influence Boys' and Girls' Attitudes toward Children with Disabilities?" Results from this study show that those children who had had more contact with peers who have disabilities exhibited more favorable attitudes towards other children with disabilities. Interestingly, the results varied by gender, which may be explained in part by differences in gender socialization.

"Disability Across the Life Span: Common Themes and Issues, A Roundtable Discussion" is a summary of issues raised at a 1994 Society for Disability Studies roundtable co-led by Rosalyn Benjamin Darling, Karen Hirsch, and Jennifer Stepanek. (Other roundtable discussants included Devva Kasnitz, Alice Rager, Ruth Ricker, and Judith Sandys.) This session, a follow-up to the Fall 1993 issue of Disability Studies Quarterly co-edited by Rosalyn Darling, was designed "to suggest some initiatives for promoting increased communication" (p. 233) between people with and without disabilities. The session focused in particular on communication among children with disabilities, adults with disabilities, parents of children with disabilities, special education professionals, and disability rights representatives. Session participants suggested several possible ways to improve communication at the community, state, and national levels.

The next three chapters address issues related to disability and education. Carol J. Gill and Larry A. Voss add a typically unconsidered perspective to debates about inclusive and segregated educational settings in their paper, "Inclusion Beyond the Classroom: Asking Persons with Disabilities about Education." Using a survey and in-depth interviews, Gill and Voss asked adults with disabilities to share recollections about school experiences and to describe their current lives. The results show that simply measuring contact does not provide an accurate understanding of how different educational settings affect people with disabilities during their education and over time.

Betty Aune and Jeff Porter describe two studies that examined "Disability in Higher Education: Alternative Organizational Approaches." Aune and Porter define disability from an interactionist perspective, "contingent on the specific interactions among the learner, the task, and the instructional approach" (p. 241). In the first study, the authors met with members of a university community to explore definitions of disability, treatment of faculty/staff/students with disabilities, and responsibilities

within the university. The second study evaluated a program designed to create "partnerships" at campuses in a state college system. Special services staff and faculty worked together with students who had disabilities in order to meet the latter's needs. In effect, this program was an attempt to realize an "interactionist" approach to disability, rather than a medical approach. Results indicate that change is possible if participants are given control, and if they are able to deal with the ambiguity inherent in change.

In "Disability Studies in the Teacher Education Curriculum," Parnel Wickham-Searl shares a course synopsis and competency goals/objectives that she has developed in order to educate students and colleagues about a "social systems" approach to special education. Wickham-Searl writes that a social systems or "ecological perspective attributes children's behavior to the interaction of children with other individuals and institutions" (p. 247). In content and in method, she has revised the curriculum to include multidisciplinary approaches to disability, rather than relying solely on clinical perspectives. The set of competencies and the reading list that Wickham-Searl includes are useful guides for anyone seeking to incorporate disability studies in syllabi and/or curriculum planning.

Catherine A. Marshall's chapter, "A National Survey of Indian Health Service Employees and the Development of a Model Job Training Demonstration Project: Identifying Work Opportunities for American Indians and Alaska Natives with Disabilities," ends this section. Marshall reports on the development, implementation, and results of a collaborative project between the American Indian Rehabilitation Research and Training Center (AIRRTC) and the Indian Health Service (IHS). The project included three phases: a national survey of IHS employees (with and without disabilities in supervisory and nonsupervisory jobs), a pilot job training project, and a replication of the job training model. Marshall presents the results of Phases I and II, each of which indicated a need to further address attitudinal barriers to accessibility.

Does Contact Influence Boys' and Girls' Attitudes toward Children with Disabilities?

**Renata Staron, B.A.
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The integration of people with disabilities into all aspects of society is important both for persons who have disabilities and for those who do not. Many questions remain, however, as to the impact of prior contact with individuals who have disabilities on attitudes toward people with disabilities as a group. Although the research generally supports the hypothesis that contact can positively influence the attitudes of nondisabled people, it is clear that the nature of the contact (e.g., its pleasantness, its degree of intimacy) plays a role in the types of attitudes formed (Esposito & Reed, 1986; Makas, 1989; Yuker, 1988). It is also important to note that the research investigating this relationship between contact and attitudes among children has produced particularly mixed results (Esposito & Reed, 1986).

My research focuses on the attitudes of elementary school children. I chose sixth graders as a sample for study because I believe that it is easier to avoid the stigmatization of people with disabilities in the first place than it is to remove the stigma later. One very effective way to do this may be the mainstreaming of children with disabilities into the schools when they and their classmates are very young.

For the purposes of this study, I will define "contact" using Cook and Selltiz's (1955) definition in which they make an initial distinction between a "contact situation," which refers to proximity that makes interaction more likely, and "contact," which refers to actual interaction between people. This definition includes types of "contact" which range from observation of out-group members without communication to direct, prolonged, and intimate interaction. To define "disability," I will use the definition from the Americans with Disabilities Act (cited in Kemp, 1991). This definition states that a person is "handicapped" if he or she "has a physical or mental impairment that substantially limits one or more of the major life activities." The type of disability on which my study focusses will be mild to moderate cognitive impairment. The term "cognitive impairment" includes such disabilities as autism, learning disability, and Down Syndrome. The attitudes which I will investigate are nondisabled children's opinions about children who have cognitive impairments.

The theory on which this study is based is symbolic interactionist theory (Stryker, 1980), which suggests that, if a nondisabled child interacts extensively with a child who has a disability, then the nondisabled child will begin to perceive the child with the disability to be "normal." Because of this interaction, the nondisabled child should manifest favorable attitudes toward other people who have disabilities.

Ideally, this will result in neither the nondisabled child nor the child with the disability putting much emphasis on the disability.

Method

I used the survey method and a purposive sample to test my hypothesis that nondisabled children who had had some contact with peers who had disabilities, compared to those with little or no contact, would exhibit more positive attitudes toward two children with cognitive impairments who were described in a vignette. My sample was composed of 50 sixth grade students, 26 girls and 24 boys, who attended an elementary school in New Hampshire which mainstreams children with disabilities.

The survey which I used consisted of two parts. The first part addressed contact. I asked questions which measured the amount of contact students had at that time or had had in the past with children identified as having "special needs." (Sixth graders are aware that the term "special needs" refers to children who have disabilities.) The questions were worded to measure "no contact," "low contact," and "high contact" since I had anticipated finding students at each of these levels of contact. However, none of the students indicated that they had had no contact. I believe this is the result of New Hampshire's success in mainstreaming children with disabilities into regular schools and classrooms.

The second part of my survey featured two vignettes designed to assess the students' attitudes toward children who have cognitive impairments. One vignette was about a girl named Susan who was the same age as the subjects and who had a cognitive impairment; the other was about a boy named Joey who was also their age and who also had a cognitive impairment. I explained to the students that a child having a cognitive impairment is "someone who can go to school like you, but it takes them longer to learn some things."

I used a Social Distance Scale and asked questions regarding whether or not the respondents would like it if Joey or Susan lived in their community, went to the same school with them, was in their social group, and was their best friend. The students' answers were recorded on a Likert-type scale.

I analyzed the children's responses using Pearson's r to calculate four correlation coefficients measuring the relationship between contact and attitudes. I found that the more contact the boys had had with individuals who had disabilities, the more favorable their attitudes were toward the children in the vignettes. In general, I found that the boys' attitudes were more favorable toward Joey than toward Susan.

The results for the girls were higher on each variable. That is, they had higher scores than the boys for contact, and they also had higher scores on the attitudinal measure.

The girls' attitudes toward Joey were high and favorable, and their attitudes toward Susan were even higher and more favorable.

Discussion

In response to the first part of my survey, which measured contact, I found that contact was higher among girls than among boys because more girls indicated that they had a friend with special needs with whom they talked on a regular basis. This may have been the result of the way girls are socialized. Girls are taught to be polite, and there is more social pressure on them than on boys to be nice (e.g., Basow, 1986). This may explain why the girls had generally favorable attitudes toward the children in the vignettes, even when previous contact was low. Boys are not socialized in the same way. As a result, their attitudes toward the children were favorable only if they had had a high amount of contact. Therefore, contact influenced the boys more than the girls, resulting in a higher correlation between contact and attitudes.

In addition, girls tend to interact with friends in many different activities, such as talking, reading, playing cards, and dancing; whereas boys tend to interact with friends primarily in one activity, which is sports (e.g., Sargent, 1977). In this sense, there is likely to be less opportunity for boys than for girls to have contact and to become friends with people who have disabilities. Since girls have more friends who have disabilities, and the more friends, the more contact they have, the better their attitudes are likely to be.

I also found that sixth grade boys and girls had more favorable attitudes toward members of their own sex. The most likely interpretation for this finding is that children at that age tend to be shy around persons of the opposite sex because they are just starting to become interested in them.

The results of all four correlations support my hypothesis that the higher the amount of prior contact is with children who have disabilities, the more favorable are the attitudes toward other children with disabilities. The more contact a nondisabled child has with someone who has a disability, the more she or he will be able to see past the disability and become aware that a person with a disability has feelings and hopes and likes and dislikes just like everybody else.

Contact breaks down barriers and removes stigma. Mook (cited in Makas, 1993) suggested that repeated exposures to persons who have disabilities are likely to make a nondisabled person more accustomed to that sensory stimulus. Langer, Fiske, Taylor, and Chanowitz (1976) noted that repeated exposures are likely to comfortably satisfy the nondisabled individual's curiosity. And Kleck and his colleagues (Kleck, 1968; Kleck, Ono, & Hastorf, 1966) suggested that repeated exposures are likely to reduce the nondisabled person's fear of saying or doing the wrong thing. Contact also negates stereotyping in that the more contact a person has with someone who has a

disability, the more the person with a disability becomes part of the "in-group," and the nondisabled individual sees the person with a disability as more like himself or herself (Makas, 1993).

In conclusion, I set out to study whether contact influences school-aged children's attitudes toward people with disabilities. I found that, for both boys and girls, the more contact a sixth grade student had had with individuals who had disabilities, the more favorable attitudes he or she had toward other children with disabilities. Contact breaks down barriers and removes stigma because repeated exposures make a person more comfortable around people who have disabilities. The implication of this study is that educational mainstreaming is very important because it benefits everyone in society, both people with disabilities and those without disabilities.

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Disability Across the Life Span: Common Themes and Issues A Roundtable Discussion

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Background

The Fall 1993 issue of Disability Studies Quarterly, co-edited by the Session Leader, contained a section on the relative lack of communication among (1) adults with disabilities, (2) parents of children with disabilities, (3) children with disabilities, (4) special education professionals, and (5) professionals working with adults who have disabilities. The section included two essays, one by Karen Hirsch and one by Ann and Rud Turnbull, addressing this issue and suggesting reasons for and means of increasing interaction among these groups and their individual members. The purpose of this session was to further explore these reasons and means, and to suggest some initiatives for promoting increased communication in the future. Participants included adults with disabilities, a parent of children with disabilities, special education professionals, and professionals working with adults who have disabilities. (These categories were not mutually exclusive.)

Themes and Issues Discussed

The following issues were addressed in the course of the discussion:

- 1. Lack of communication between**
 - a. Adults with disabilities and parents of children with disabilities.**
 - b. Children with disabilities and adults with disabilities.**
 - c. Special education and adult rehabilitation professionals.**
 - d. Special education professionals and members of independent living/disability rights movements.**
- 2. Animosity between the parent movement and the independent living/disability rights movements, especially around issues of independence for adult children.**
- 3. Reasons for increasing communication.**
 - a. Adults as role models (children as future adults).**
 - b. Adults as former children.**
 - c. Common issues (e.g., inclusion and ADA).**
- 4. Strategies for increasing communication.**
 - a. Adults in the schools.**
 - b. Adults on state interagency coordinating councils for early intervention (ICCs).**
 - c. Jointly taught disability studies courses.**
 - d. Regularly scheduled meetings between parent and adult movements.**
 - e. Joint sessions at conferences such as those of the Council for Exceptional Children (CEC), the Society for Disability Studies (SDS), and others.**

Several participants mentioned initiatives that already exist in a number of states for increasing linkages. One participant (an adult with a disability) said that, prior to this discussion, she had never thought of herself as a mentor for children.

Outcomes

As a result of this discussion, the participants agreed to work toward the development of two products:

1. A session to be presented at the next SDS meeting in Rockville (in 1996) on cross-generational approaches that have worked. Everyone agreed to do some research on models with which they were familiar, including the Massachusetts project, Partners for Disabled Youth, and a new mentoring project being undertaken by the Association for the Care of Children's Health (ACCH). The group also discussed presenting this session at other conferences, such as those sponsored by CEC or ACCH.
2. An article to be published in the ACCH newsletter and possibly the newsletters of other associations.

The group also discussed the possibility of meetings with other associations (e.g., CEC, national disability organizations) but made no definite plans.

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Inclusion beyond the Classroom: Asking Persons with Disabilities about Education

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The special education literature burgeons with articles discussing the pros and cons of models for the inclusion of students with disabilities in mainstream settings. Well-represented are studies documenting the thoughts of educators, administrators, parents, and even nondisabled students. However, a key voice is missing. Largely overlooked is the crucial input of persons with disabilities--this oversight constituting yet another instance of exclusion (Davis, 1989; Lipsky & Gartner, 1987).

The current study was an effort to begin documenting the psychosocial educational histories of a sample of adults with disabilities. The responses of persons educated in integrated or "mainstream" settings were contrasted with those of persons educated predominantly in segregated special education settings. Because a major concern of educators in implementing integration is insuring students' social and psychological well-being, we focused on psychosocial variables, including self-image, emotional well-being, experience of stigma, relationships, social roles, developmental tasks, school behavior, satisfaction with school, and perceived links between childhood educational experiences and success in adult adjustment. We analyzed participants' responses by comparing consistent patterns in the two groups (integrated versus special education) to see if they suggested an optimal blend of educational experiences for successful development.

Method

Twenty-one women and men with childhood physical disabilities were asked to report their psychosocial experiences from early elementary school through high school on a self-administered survey followed by an in-depth personal interview. Subsequently, some of the respondents were brought together in a group discussion to test the utility of this format in eliciting further information.

The ages of the "integrated" group ranged from 21 to 52 with a mean age of 38.8. There were eight women and two men. The ethnic/racial composition was seven white, two African-American, and one Latino. The ages of the "segregated" group ranged from 26 to 56 with a mean age of 42.5. There were six women and five men. The ethnic/racial composition was eight white, two African-American, and one Latino.

Results

The profiles emerging from the two groups produce a complex view of the ways in which educational setting may affect psychosocial development. Among the most consistent, yet disheartening findings is that the integrated group reported experiences of increasing social isolation and marginalization throughout the school years. Although many deliberately developed an outwardly confident social presentation, depression and low self-esteem marred their high school experiences. Suicidal impulses plagued some of the women during high school. Most of the integrated group reported having felt discomfort in contacts with children who have disabilities. They were encouraged by parents and teachers to see their "healthy" minds as separate from their disabled bodies. Incidents of physical and emotional abuse from nondisabled classmates were common in elementary, junior high, and high school. A substantial proportion of the integrated group recalled not belonging to a group of friends in school and having no dating experiences. Typically, they felt school pride but did not feel part of the student body.

In contrast, the special education group reported positive social experiences throughout the school years and virtually no drop in emotional well-being in high school. Almost all respondents had affiliated with a group of friends and had dated during high school. They reported feeling mostly sympathy, but little discomfort, in the presence of other children with disabilities. There were no reports of abuse from classmates in this group. Reversing the pattern experienced by the integrated group, these students typically felt part of the student body but were not proud of their special education schools.

Both groups recalled engaging in typical childhood activities, such as scouting, chorus, and student council. The integrated group, however, reported slightly more involvement in such activities.

In current life, both groups, despite their differing exposure to nondisabled classmates, reported comfort both with friends who have disabilities and those who do not. The special education group appeared more socially-oriented in general than the integrated group, reporting more close friends and staying in touch with more friends from their school days. Although employment patterns did not differentiate the two groups, special education respondents seemed more invested in family than in work or academic achievements, while the opposite held true for the integrated group. Similarly, the special education group generally described themselves in social and positive affective terms, while the integrated group portrayed themselves as intense and achievement-oriented. The majority in both groups belonged to disability organizations, but the integrated group appeared to be more actively involved in disability rights.

Special education respondents expressed less concern than integrated respondents for the importance of role models for children with disabilities. A confounding factor is that special education respondents, compared to integrated respondents, had more contact in childhood with adults who had disabilities, a variable which may have satisfied their need for role models. Alternatively, belonging to a community of peers who also had disabilities may have substituted for the potential benefits of a mentor. Finally, it is possible that the need for a role model is felt in proportion to one's sense of isolation, which was greater for the integrated students.

This study underscores the distinct power of parental words, attitudes, and actions in the lives of students who have disabilities. According to respondents in both groups, children with disabilities can carry far into adulthood the emotional pain of feeling like the family burden. If ever there were a compelling argument for the funding of personal assistance services for children with disabilities, it would be the weeping of our middle-aged respondents when they recalled their parents' overwhelming responsibilities. Parents' acceptance of disability both in their own children and in their children's acquaintances appears to have affected profoundly their children's self-acceptance and comfort with others who have disabilities. Respondents expressed heartfelt appreciation for parents who had held reasonably high expectations of them, who had offered them a meaningful role for contributing to family life, who had fought for their rights, and who had affirmed their social value and facilitated their social activities.

Regardless of educational background, participants in this study registered a strong vote for inclusive education. Their model of ideal integration, however, is quite different from the one actually experienced by the respondents in the integrated group. Instead, they recommended placing more than one child with a disability in a setting to preserve the opportunity for peer contact. They wanted discrimination and disability attitudes monitored. They called for disability awareness training for nondisabled students and teachers. Some suggested that disability history and culture be celebrated in the schools. Those who sometimes felt lost in the mainstream believed the greater presence of powerful adults with disabilities can help students who have disabilities to see a future.

According to integrated group respondents, encouraging their academic development was not enough. They needed better access to informal social opportunities. They needed their classmates restrained from assaulting them. They wanted respect and sensitivity to replace the ignorance and devaluation surrounding them. Some said they needed counseling. The arts were important for expression and socializing; sports should have been more open to them. Transportation problems were a central limitation in social activities.

According to special education respondents, separate is never equal. Although their responses indicated that they enjoyed more relationships and social interaction than

students with disabilities in the "mainstream," many still felt cheated of social opportunities due to their consignment to a segregated facility. Although they appear to have been spared much of the abuse and rejection of the mainstream, and, although they ended up equally likely to be employed and partnered in adulthood as integrated students, they would have preferred to attend school with their siblings and neighbors. The apparent absence of discomfort in their lives when compared to the integrated group, then, may not be adequate compensation for their sense of exclusion.

This research project has demonstrated the utility of survey and interview measures to elicit valuable information and consistent patterns of responses. The study should be repeated and expanded to include comparisons of geographic regions and more respondents. Questions should be refined to test alternative interpretations of some of the findings discussed above. More discussion groups should be arranged to assess the value of this format for producing additional data. After replication, more specific formal recommendations can be offered for improving inclusive education for students with physical disabilities.

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Disability in Higher Education: Alternative Organizational Approaches

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The traditional view of disability is defined medically in terms of physical, emotional, or intellectual impairments rooted in the person and hindering normal functioning across a wide variety of settings (Hahn, 1985). But there is an alternative, more educationally-relevant interpretation of disability. This view, consistent with recent theories in the field, defines disability not as rooted in individuals, but as arising out of unsuccessful interactions between individuals and their environments (Booth, Swann, Masterton, & Potts, 1992; Hahn, 1985; Oliver, 1990). By interpreting disability as contingent on the specific interactions among the learner, the task, and the instructional approach, this "interactionist" view of disability holds direct relevance for teachers and learners. It shifts analysis from immutable factors, such as the medical impairments of students, to dynamic processes that are controllable, such as how faculty and students (regardless of assigned labels) can work together to optimize educational progress and to minimize educational disability. From this interactionist perspective, disability is viewed not as existing within the learner, but between the learner and the teacher. Resolving disability does not mean "fixing" an impaired learner, but redesigning the learning task and instructional approach in light of learner characteristics and curricular goals. The teacher and the student working together are the agents responsible for such redesign.

This chapter reports on two studies, one which explored alternative meanings of disability, and another which examined the process of change in responding to new meanings of disability.

Exploring Alternative Meanings

The first study was conducted at a mid-sized private comprehensive university in the Northeast. Informal discussions, through individual face-to-face meetings, were conducted with members of the academic community regarding the experience of enrolled students with disabilities. The discussant pool included twelve administrators, thirteen faculty/staff, and one student. Throughout the discussions, disability was referenced broadly to include physical, learning, sensory, and emotional domains. Four of the issues addressed in these discussions were

1. Does disability contribute to or detract from the educational community?
2. Are faculty/staff generally understanding and sensitive regarding students with disabilities?
3. Should there be centralized or shared responsibility within our university for working with students with disabilities?
4. Do faculty/staff receive professional development and/or recognition for working with students with disabilities?

Interview results in terms of these four issues can be summarized as follows:

Issue #1: Regarding how discussants, as individuals, view disability, 75% of all comments describe disability as either actually or potentially contributing to the educational community. Regarding how discussants characterize the views of the collective community toward disability, a more differentiated response pattern occurs. From this perspective, 33% of all comments fall into the "actual/potential contribution" categories, with 33% falling into the "actual/potential detraction" categories. Remaining comments fall into the "it depends" category.

Issue #2: Regarding whether or not faculty/staff generally demonstrate understanding and sensitivity towards students with disabilities, 86% of all comments fall into either the "not sure/depends" category or the "no" category.

Issue #3: As to whether there should be "centralized" or "shared" responsibility within the educational community for supporting students with disabilities, comments fall equally into two categories. One category, "necessity of centralized responsibility," emphasizes that students who have disabilities would not be successful without a centralized and accountable special services program. The other category, "goal of shared responsibility," emphasizes that primary responsibility by faculty and staff in general for working with students with disabilities (perhaps as supported by the expertise of a special services program) should be an institutional goal and that, due to the efforts of special services over recent years, there has been some progress in this direction.

Issue #4: In terms of professional development and recognition for faculty/staff working with students with disabilities, discussant comments acknowledge the special services office as the sole source of such support, with no such support offered by home departments or colleges. Related comments emphasize the low priority of disability issues for faculty, given competing interests and existing institutional reward criteria.

These results reveal a university community with mixed views of disability. Still clearly dominant is the conventional interpretation of disability, but traces of a more interactionist interpretation are also evident. Full acceptance of this latter interpretation, by this university in particular, but by higher education generally, would have radical teaching/learning implications, including the following:

1. Disability is interaction-specific rather than person-specific, based on the "goodness of fit" or lack thereof among learner characteristics, learning tasks, and instructional approaches (given the established framework of curricular goals and academic standards).
2. Disability represents an enriching and energizing resource, both in terms of the overall climate of educational diversity and the press for developing innovative alternative instructional strategies and technologies to complement such variety.
3. Faculty responsible for developing and implementing curricula have primary responsibility for teaching all students admitted to the educational community, and for doing so in ways which support optimal academic progress by tailoring instructional approaches to the learning characteristics of individual students (in light of established curricular goals and standards).
4. Special services staff, along with any other academic support resource, should serve as consultants for faculty in fulfilling this primary teaching responsibility for all students.

Examining Alternative Organizational Approaches

The second study examined a state technical college system in the Midwest, which put this interactionist view into practice by adapting its system to students with disabilities. The goal of the state agency that initiated the change was to develop a partnership between special services and faculty who, together, would modify instructional approaches to the needs of individual students. This change required a major shift in the roles of special services staff as they moved from direct service to a consultative model, and of faculty, as they adapted their methods and materials to make their courses more accessible. The purpose of the study was not only to explore the outcomes of the initiative, but also to examine the process by which the change was realized. An alternative view of disability is meaningful only if the institution is able to put it into practice.

One school was studied in depth as a case study in which semi-structured interviews of key faculty and staff (seven special services staff, five program instructors, and three administrators) were conducted. The other 33 campuses in the system were

studied as a group, with focus group discussions held on 19 campuses (106 faculty and staff participating). Participant observations and document analyses were conducted on all 34 campuses.

Each college was encouraged to develop a model that would be workable on its campus. In most schools, the new models replaced or significantly modified existing structures. Most colleges held workshops on ways to modify materials, to provide accommodations, and to teach to students' learning styles. About two-thirds of the campuses formed resource teams, generally consisting of all special services staff, two to twenty instructors, and, occasionally, a counselor or administrator. Some resource teams were project-centered, with each instructor developing modifications for a specific course. Others were student-centered, with an instructor, a special services staff, and a student meeting to discuss accommodations needed. Another approach was the classroom-centered model, in which special services staff spent time in the regular classroom to understand the expectations and the content of the class, to assist students in the classroom, and to suggest ways in which the instructor could work more effectively with students with disabilities.

Some colleges made significant changes in a very short period of time. Others gradually moved from a direct service model to a consultative model. Those involved described personal changes in attitude, behaviors, and relationships with other faculty and staff. Those interviewed noticed an increased awareness of the diversity of their student body and a more positive attitude toward students with disabilities. Instructors began to see special services staff as more approachable for collaborative discussions regarding a particular student. This increased communication resulted in faculty and special services taking joint responsibility for students. Special services was much more visible, and there was more coordination between special services and faculty.

Faculty adapted materials creatively to accommodate students' learning styles. For example, instructors re-wrote handouts and worksheets, had lectures videotaped, purchased adaptive equipment, and developed study materials. Although instructors were less willing to make changes in their tests, some reported giving tests more frequently, offering alternative testing options (such as oral or performance-based tests), and improving the format of tests. Faculty modified their methodology by incorporating more variety, breaking down concepts into smaller steps, providing lecture outlines, and putting main points on the board.

Findings suggested certain factors as influential in effecting the change: (a) perceived need, (b) strong leadership, (c) a culture that was open to change, (d) external factors providing both pressure and support for change, (e) an innovation that was viewed as positive and relevant, and (f) voluntary participation. However, it was also evident that the change process could not be reduced to a set of simple guidelines. Rather,

the complexity, ambiguity, and non-rationality of the change process must be addressed.

The study revealed that a key element of change was the participants' (faculty and staff) affective experience in dealing with the insecurity and ambiguity of the process. During the change process, people felt uncomfortable in new roles, regretted the loss of old meanings, and wished that the ambiguity and uncertainty they experienced would be replaced by certainty and clarity. However, those involved were empowered to become agents of change, giving them control over the process. The state agency gave the colleges in its system the freedom to create their own models to realize a vision, to become authors of the change. Participants had the power to chart the course of the innovation, resulting in an environment in which the status quo was continually questioned and new realities were imagined.

Conclusion

Results of these two studies suggest that the meaning of disability in higher education is only gradually changing, but that institutions can transform themselves based on these new understandings, given the right conditions for change to occur.

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Disability Studies in the Teacher Education Curriculum

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Special education has evolved within the clinical professions of medicine and psychology. Traditionally, special educators have been trained to identify deficits in children, isolate the "problems," diagnose them, and treat children in laboratory settings. By the 1960's, the advocacy of parents of children with disabilities, and the disability rights movement began to challenge special education professional practices. New approaches to understanding children emerged, including alternative views that consider individuals within the context of their environments. Such an ecological perspective attributes children's behavior to the interaction of children with other individuals and institutions.

However, the ecological, or social systems perspective, is still not widely embraced in special education. Curriculum to prepare special education teachers tends to be categorically based and clinically derived. Thus, major curricular revisions are required to prepare teachers to understand students within their environments. And because most teachers in higher education have little or no experience with the social systems approach, they have no reason to revise their views of the profession.

In my work at Dowling College as Assistant Professor and Coordinator of Special Education, I am introducing the social systems perspective into the teacher education programs. To do so, I must first convince my colleagues in special education of the importance of the perspective, and I then have to inform and convince other influential faculty members and administrators at the college. I have conducted a series of informal and formal meetings and have prepared written policy statements and working papers. Furthermore, I have introduced a set of competencies to reorient the entire curriculum. Now I am developing courses that correspond with the specific competencies.

One such course, Multiple Perspectives of Special Education, provides students with an overview of the social systems approach. While the entire revised curriculum has taken on aspects of disability studies, this course, in particular, probably represents the core of disability studies, with its emphasis on history, politics, and sociology. A synopsis of the course, a set of competencies that correspond to the course, and a reading list follow.

Dowling College
Multiple Perspectives of Special Education

A Synopsis of the Course

This course introduces students to multiple perspectives concerning individuals with disabilities. While most educators are familiar with the clinical approaches of the health-related professions and psychology, the perspectives of sociology, history, and politics are less well known. This course, then, focuses on the social and environmental conditions of disability, considers persons with disabilities from a minority-group perspective, and reviews historical dimensions of disabilities. This approach will be applied to understand students with disabilities and their families.

The purpose of the course, broadly, is to understand how students with disabilities learn and grow, and to consider alternative theories that explain their behavior. Traditional theories to understand the behavior of students with disabilities derive from the clinical practices of medicine and psychology, which tend to attribute an individual's problems to certain innate or acquired personal defects. Alternatives to the clinical approach examine the social environment and the interaction between the social environment and individuals to explain an individual's situation.

An ecological view of disabilities recognizes that certain individuals in our society have problems that limit their potential to lead satisfactory and productive lives. But the ecological view also recognizes that the source of those problems is often found within the larger society rather than within the individual who has a disability. Professional educational practices, such as labeling and classification of children in schools, ability grouping or tracking, and the segregation of children with disabilities into separate classrooms or buildings, are often given as examples of social conditions that have detrimental effects on children.

Certain theories provide important ways to understand and explain the social context that shapes the learning and behavior of students with disabilities. Theories of social construction, for example, provide a way to study the social interactions among individuals and the ways in which individual behaviors evolve through those interactions. In related work, theories of social identity explain how individuals change in response to the expectations of others.

More broadly, an understanding of social systems permits insights into the organization of the social world and an individual's relationship to society. Similarly, social role theory describes the identification of individuals within social groups and explains the behavior of individuals within the context of social roles.

Other theoretical perspectives inform our understanding of students with disabilities. Sociopolitical theories, for example, describe the systematic oppression of groups of

individuals by others in society who are more powerful. These theories contend that persons with disabilities form a minority group within the larger social system and that, as minorities, these persons are unable to exert control over their own lives. They often do not, as members of a minority, participate in the decisions that affect their lives.

Finally, theories of history inform an understanding of persons with disabilities and their interactions with others in society. A historical analysis of events concerning persons with disabilities illustrates patterns and trends of social behavior as it occurs over time. Understood within the context of social systems theories and sociopolitical theories, the historical perspective offers insights into problems and issues that might not otherwise emerge.

In addition to the study of these related theories to understand students with disabilities, this course adopts a unique methodology to study their personal development. Rather than relying on the traditional clinical materials of the social sciences, the course draws directly from the lives of persons with disabilities. It assumes that, in order to learn about individuals with disabilities, it is imperative that information be obtained from the individuals themselves rather than from those who attempt to interpret and explain their lives. Thus, this course refers to the writings of people with disabilities and, in some instances, to their parents to promote a full understanding of the experience of disability.

Competencies for Special Educators

Goal: Each graduate will be competent in understanding the unique contributions of special education to the general field of education.

Objective: Each graduate of the Bachelors and Masters programs will demonstrate an ability to describe:

1. Historical developments in special education.

The student will be able to:

- a. Describe the circumstances within regular education which resulted in the development of special education.
- b. Discuss the similarities and differences which have evolved between special education and regular education.
- c. Describe the contributions of special education throughout its evolution.
- d. Discuss the problems associated with special education from its origins.

- e. Describe current best practices for students with special needs.

Objective: In addition, each graduate of the Masters programs will demonstrate an ability to describe:

2. Philosophical orientations in special education.

The student will be able to:

- a. Distinguish among philosophies of education as they pertain to special education.
- b. Articulate a personal philosophical position concerning special education.

3. Sociological perspectives in special education.

The student will be able to:

- a. Recognize social responses to disability in American institutions, including media, business, and culture.
- b. Describe the effects of social interactions on students with disabilities, family members, and educators.
- c. Analyze individual behavior within social systems.
- d. Discuss the processes of educational labeling, classification, and placement from the sociological perspective.

4. Political developments in special education.

The student will be able to:

- a. Distinguish between the sociopolitical and deficit approaches to students with special needs.
- b. Explain the minority group status of persons with disabilities and its implications for special education.
- c. Use language concerning persons with disabilities that demonstrates awareness of political developments.

- d. Identify key litigation and legislation concerning special education and related fields.
- e. Discuss the contributions of special interest groups concerned with special education.

Required Readings

- Bogdan, R., & Knoll, J. (1988). The sociology of disability. In E. L. Meyen & T. M. Skrtic (Eds.), Exceptional children and youth: An introduction (3rd ed.) (pp. 449-477). Denver, CO: Love Publishing Co.
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**A National Survey of Indian Health Service Employees
and the Development of a Model Job Training Demonstration Project:
Identifying Work Opportunities for American Indians
and Alaska Natives with Disabilities**

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In August 1989, the American Indian Rehabilitation Research and Training Center (AIRRTC) collaborated in an action research project with the Indian Health Service (IHS), a major employer of American Indians. This project was funded by the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education. The goal of the research was to increase the number of American Indians with disabilities who are employed. IHS employs a work force of approximately 15,000 people across the United States; the majority of employees are American Indian, yet, at the time the study began, the IHS had a record of less than 1% being American Indians with disabilities. Specifically, according to IHS statistics, the total number of ethnic minorities with "targeted disabilities" employed by IHS as of September 23, 1989, was 32. IHS had no data indicating how many of the 32 were American Indians, or how many persons with disabling conditions other than the targeted disabilities worked for IHS. Further, IHS representatives in Rockville were unaware of the tribal vocational rehabilitation (VR) programs and expressed the desire to have a "direct pipeline" opened between the tribal VR programs and IHS employment opportunities.

Phase I: The National Survey

The first phase of the collaborative project entailed conducting 676 nationwide telephone interviews with IHS employees, including 187 employees with disabilities (of whom, 25 were supervisors), 58 nondisabled supervisors, 105 nondisabled employees whose co-workers included a person with a disability, and 326 other nondisabled staff members. The purpose of the survey was to assess the working environment of IHS facilities, as well as the extent to which IHS employed and provided support services for persons with disabilities. The survey also sought to identify program and consumer service needs in order to enhance the employability of American Indians with disabilities. The survey, completed in Spring 1992, indicated that, while more American Indians with disabilities are employed by IHS than previously believed or documented by the IHS, these employees do not have severe disabilities and have required minimal, if any, accommodation to their disabilities.

Across all categories of respondents, interviewees tended to agree that their work sites, including restrooms, were accessible. Interviewees were least satisfied with the IHS affirmative action recruitment program for persons with disabilities, as well as the type of IHS-sponsored recreational activities available. In terms of "Individual Needs," interviewees agreed that their supervisors were pleased with their work, with all interviewees least satisfied with the career potential of their positions. As regards "IHS Recruitment Efforts," all interviewees agreed that IHS employees needed to learn more about disability issues. Interviewees were most dissatisfied with IHS personnel procedures in assisting potential employees to secure employment and with recruitment efforts that identified American Indians with disabilities for employment with IHS.

A one-way analysis of variance was used to compare the means of Likert-type items across the four respondent groups; statistically significant differences were found between several of the items. Specifically, among the nine items in the category "IHS Working Environment," 67% (n=6) had significant mean differences across respondent categories. For example, regarding the statement, "In general, there is acceptance of employees with disabilities by managers at IHS," a significant difference was found between the mean response of supervisors (3.63) and that of employees with disabilities (3.11; $p=.01$). An independent test of proportions indicated a statistically significant difference between the proportions of respondents in these two categories expressing agreement (combining responses of "Agree" and "Strongly Agree") with a given item; 69% of Supervisors agreed with this statement, while 44% of Employees with Disabilities agreed. (A detailed presentation of significant differences among the respondent groups is given in the Final Report, available from the AIRRTC.)

Overall, the national survey indicated that, while employees generally agreed that their work sites were accessible, they also agreed that IHS employees needed to learn more about disability issues. IHS employees generally agreed that they were satisfied with their work schedules, but a significantly greater proportion of supervisors than employees with disabilities felt competent in setting long-term career goals, reported having a challenging job, reported having the opportunity to be creative on the job, had control of their work assignments--including feeling comfortable in requesting reasonable accommodation, and expressed satisfaction regarding career development and career advancement. A significantly greater proportion of employees with disabilities, compared to supervisors, agreed that IHS needed to take specific steps to recruit persons who have disabilities for employment.

Phase II: The Job Training Demonstration Model

Following completion of the national survey, the second phase, pilot-testing a job training demonstration model, was begun at the Phoenix Indian Medical Center (PIMC) in Phoenix, Arizona. The purpose of the model project was to demonstrate effective practices in hiring and providing support services to American Indians with

disabilities. Supervisors from PIMC, as well as a job coach provided by the Arizona Rehabilitation Services Administration (ARSA), worked with nine trainees identified through ARSA, to provide on-the-job training and to solve any work-related issues that posed barriers to the success of the trainees and the project in general. Of the nine trainees, six (67%) were considered by vocational rehabilitation to have disabilities which were severe.

According to Gottlieb, Vandergoot, and Lutsky (1991), "the specific types of interaction and support . . . that will best meet an individual employer's needs and result in the establishment of a mutually beneficial relationship must be based on a careful assessment and understanding of the company and its workforce" (p. 27). Thus, from the outset of the project, a Hospital Advisory Committee (HAC) was formed to assist in the design and implementation of the training effort. The HAC met on a monthly basis throughout the project to assist the research team in better understanding of the needs of PIMC and with project development activities such as trainee recruitment, evaluation, problem-solving, and dissemination planning.

On-site job analyses were conducted by the ARSA job coach in conjunction with the ARSA rehabilitation counselor and the PIMC supervisors in whose areas the trainees would be placed. One month after trainees were placed in training, supervisors completed a standard employee evaluation assessing each trainee's performance. The evaluations were forwarded to the personnel officer and reviewed by the HAC. Training periods were established for each trainee, based on his or her experience, current performance, and vocational goal. The average length of time recommended for training was eight months. A primary component of the model project involved supported employment. The job coach, Mr. Bryan Longie, functioned also as a peer counselor, providing extensive support both during working hours and in the evenings to some of the trainees.

In general, IHS personnel at PIMC reported being pleased with the outcome of the project; three trainees were hired by PIMC. As the purpose of the model project was to demonstrate effective practices in hiring and providing support services to American Indians with disabilities, it is important to note that one unanticipated outcome was the amount of emotional support trainees would need to sustain their involvement, both while in training and after being hired. Supervisors from PIMC, as well as the job coach/peer counselor, worked closely with the trainees to provide on-the-job training and to solve any work-related issues that posed barriers to the success of the trainees and the project in general. However, it was generally believed that the trainees needed even more intensive and sustained support.

Involvement of the AIRRTC in the model project at PIMC was terminated in September 1993, as funding for the pilot effort came to a close. However, continuation of the project beyond its pilot stage has been strongly supported by the

director of PIMC, Ms. Anna Albert, who requested the continued involvement of ARSA as well.

Based on the results of the Phase II demonstration project, the following recommendations were made regarding future training efforts:

1. Given the extensive periods of training (4-12 months) that may be necessary in order for trainees to meet the minimum requirements for even entry-level positions with IHS, sufficient monies need to be available to pay trainees a stipend that will cover their basic costs of living during training.
2. Psychological counseling should be available on an as-needed basis to the trainees. The job coach at PIMC provided a great deal of psychological and emotional support to the trainee--both on and off the job. Supervisors specifically requested that they be assisted with the psychological needs of the trainees through, for example, trainee group meetings with a psychologist.
3. A staff person from the IHS service unit should be assigned to oversee the project on at least a half-time basis, or 20 hours per week. It is anticipated that the staff person would spend approximately 10 hours per week in activities related to the administration and evaluation of the project, with the remaining 10 hours per week devoted to providing support to the trainees on an as-needed basis. Ideally, a person who could function both as a job coach and as a peer counselor should be selected for this position. If this is not possible, consideration should be given to hiring a peer counselor in addition to the job coach.
4. A vocational rehabilitation counselor should be assigned to the project on at least a quarter-time basis, with full administrative support from the public or tribal vocational rehabilitation program associated with the project.
5. A staff person from the IHS research unit should be assigned to the project on at least a quarter-time basis to assist with process and outcome evaluation.

Phase III: The Replication of the Job Training Model

A third phase of the AIRRTC and IHS collaboration effort, to begin Fall 1994, will involve the selection of a second IHS service unit in order to replicate the job training demonstration model on a larger scale and systematically evaluate its effectiveness in providing employment opportunities for American Indians with severe disabilities. Carbine, Schwartz, and Watson (1989) have reported that the "biggest barrier" people with disabilities face in securing employment "is not physical. . . . It is attitudinal--their own attitudes, the attitudes of employers, and the attitudes of managers, supervisors, and co-workers" (p. 3). Thus, one critical aspect of the

evaluation will be to assess whether or not the model project (a) improves or maintains employee/coworker attitudes toward persons with disabilities, and (b) improves or maintains supervisor attitudes toward persons with disabilities. Steps toward this third phase are currently underway with the development of an instrument, based on American Indian and Alaska Native standards, to measure attitudes toward people with disabilities.

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Section X

Self Definition and Self Support

The six chapters in Section X address self definition and ways in which people with disabilities may seek and find support. Patrick McDonagh examines self definition through literary self-representation in his chapter, "Aestheticizing the Disabled Body: The Writings of Christy Brown and Nancy Mairs." McDonagh shows how the writings of Brown and Mairs address disability, embodiment, and alternatives to the Cartesian mind/body dualism that has so influenced Western cultures.

Members of the Spindleworks Artists Cooperative in Brunswick, Maine, share their poetry in "Spindleworks Journey." Spindleworks is a non-profit cooperative of approximately twenty skilled weavers and other artists with developmental disabilities who have received occupational training in the expressive arts and are then free to develop those skills by designing and creating their own products. The artists are expected to produce a prescribed amount of work depending on their individual capabilities and are paid, as other artists, for the work that they sell. Their contribution to this book resonates with images of everyday life ("You, picking peas" -- Nancy Bassett), processes of self definition ("I want to get my own life" -- Terri Snape), confronting prejudice ("I don't think they'll like me" -- Terri Bonin and Diane Black), and friendship ("Don't call my friends 'retarded' they are 'extraordinary' and it lifts my heart to be with them" -- Bryce Muir).

Gerald Gold describes a relatively new form of support group in his paper, "Following the Thread: A Virtual Support Group for People with Multiple Sclerosis and their 'Significant Others.'" Accessibility to such groups through the Internet allows participants from all over the world to share their experiences and expertise, debates, laughter, and crises. The electronic "bulletin board" that Gold describes is just one example of the many that now exist. Some are disability specific; others have a broader focus. What they usually share is a combination of flexibility (topics change, members come and go) and, as Gold writes, "clearly-defined rules for interaction" (p. 273). The kinds of negotiations described (should medical professionals be members; should the "list" be limited to people with a specific type of disability, should caregivers be included) are typical for any list, especially when it is new. However, as Gold points out, such considerations are not merely academic, but reflect different and often incompatible political perspectives.

In "'Mothers Don't Get Sick': Women Living with Pain," Lynn Schlesinger, recipient of the Society for Disability Studies' 1994 Emerging Scholar Award, reviews findings from in-depth interviews she completed with women aged 20-50 who live with chronic pain. In their everyday activities (from waking up to going to sleep),

interviewees found ways to deal with their own expectations and the expectations others had of them--as women, mothers, workers, partners, friends. Schlesinger writes: "Though many women felt that others were stigmatizing them, they could and did find ways to resist such stigmatizing" (p. 283).

Mitchell Tepper, Eleanor Richards, Barry R. Komisaruk, and Beverly Whipple also discuss ways in which women with disabilities have actively sought to redefine themselves and their relationships. In "Sexuality as Experienced by Women with Complete Spinal Cord Injury," Tepper and his colleagues present results from interviews with women about their definitions and experiences of sexuality before and after their injuries. The authors found that over time the women experienced "a period of sexual rediscovery and the reincorporation of sexuality into their post-disability identities" (p. 292).

Judith Sandys, Gary Woodill, and Milana Todoroff's chapter, "The Perceptions of University Students with Disabilities: Are Women More Disadvantaged than Men?" closes this section. Sandys, Woodill, and Todoroff found that interviewees' expressions of perceived disadvantage varied, and they did not necessarily confirm previous research on gender and disability and/or the authors' expectations. Their research suggests that socialization, gender, disability, and self definition should be further studied in order to better understand both women's and men's experiences.

Aestheticizing the Disabled Body: The Writings of Christy Brown and Nancy Mairs

Patrick McDonagh, Ph.D. Candidate
Concordia University, Montréal

In this paper I explore some ways in which literary autobiographers who have disabilities incorporate their sense of the significance of their disabilities into what later becomes an artistic product: a life story. One of my underlying assumptions is that an autobiography is an aesthetic product modified by cultural influences. Autobiographies by people with disabilities draw upon and respond to various cultural discourses of identity and disability in their construction of a subject. I have chosen to examine the writings of Christy Brown and Nancy Mairs for several reasons: both are authors whose writings are largely autobiographical, both have physical disabilities, and both deal with the "mind/body" dichotomy so familiar in western culture. However, Brown and Mairs also diverge significantly on certain points. Their differences underline the role of discourse in forming conceptions of disability and in modifying the way people construct and represent themselves.

In his youthful autobiography My Left Foot, Brown (1954) explores the implications and parameters of cerebral palsy. My Left Foot is very much about Brown's body. With its implication of distance between foot and owner, the title also suggests a dichotomy that is further explored in Brown's later works: the author's alliance with a body that often opposes his will and mocks his desires, and his ongoing attempt to circumnavigate his body's dictates. Brown's left foot is, in one sense, the protagonist of the autobiography because it is that part of his anatomy that collapses the distance between mind and body, will and action.

Brown's body shifts further to the margins in his later works, but the issues dealt with in My Left Foot continue to resurface in the autobiographical novels Down All the Days (1970) and A Shadow on Summer (1974). In each of these works, the definition of self rests in a dramatic tension initially provoked by the apparent disjunction between body and mind.

Down All the Days (Brown, 1970) is an autobiographical novel. It opens with the young Brown upon the shoulders of one of his brothers at a carnival watching a peep-show movie while his brother cranks the handle which works the projector, juxtaposing the boy's disabled body with the active male heterosexuality of his brothers. Yet, while sexual frustration is immediately identified with the character who has the disability, it soon becomes shared with the other characters in the novel; indeed, frustrated desires of all kinds become the focus of the novel. Characters wanting companionship and understanding are denied it; those searching for freedom

and independence are likewise stymied. Ultimately, a distinctive sense of isolation defines each individual in this novel; pain, frustration, and thwarted desire become the markers of identity.

This strategy, locating individuality in one's dis-ease, is perhaps most recently associated with literary modernism and existentialism, but it gains new significance in Brown's works by having as archetype of identity a character with an overt disability. This is not to say that disabilities have never served as metaphors before--in fact, in literature they have rarely served as anything else. But Brown is doing more than just presenting disability as a metaphor for the human condition as he sees it. Rather, while rearticulating the definition of disability, he also reserves for himself a special status as authority. By presenting a version of disability which stresses the alienation common to all of his characters, Brown is able to oppose a dominant discourse which often constitutes a person with disability as being "pure disability," pure other (opposed to an undeclared, but clearly assumed, "pure normalcy") who carries no agency or authority.

A Shadow on Summer also features a protagonist with a disability, Riley McCombe, who exhibits numerous parallels to Brown. This book, like My Left Foot, displays a self-consciousness about its reproduction of life with disability. In some ways, McCombe's disability seems incidental to A Shadow on Summer, as it is rarely mentioned except when he is feeling tired of standing with crutches in his armpits. What appears prominently are the familiar themes of isolation and frustration. The solitude associated by Brown with his cerebral palsy in the earlier works is again evident here, associated not with disability, but with existence. Despite their efforts, the characters in this novel do not communicate with each other; they each live alone, transmitting messages that are always already incomplete and ultimately uninterpretable. This isolation, originally linked by Brown to his disability, is here not only shared by all characters, but is critical to a sense of self; one's private agony is also one's freedom, one's identity, and one's source of authority.

However, it would be too reductive to see Brown's aesthetic of identity as being formed wholly by his experience with cerebral palsy, and this is my point: it is equally influenced by existentialist modernism, one of the prominent literary aesthetics of this century. Brown uses his cerebral palsy to provide his own entry into this dominant literary discourse; disability becomes a tool to aid him in creating his aesthetic, as much as it is a factor in determining it. Indeed, through the literary discourse of the period, Brown gains from his disability a particular sort of agency. Cerebral palsy authorizes Brown's claims to the experiences valorized in existentialist modernism--and, in so adapting his experience of cerebral palsy, he transforms his readers' conceptions of it. In reworking "disability" to fit existentialist modernism, Brown obscures the boundaries separating "disability" from "ability."

The writings of Nancy Mairs provide a useful counterpoint to those of Brown for examining the manner in which conceptions of disability are constructed through discourse. Mairs, a contemporary American essayist, has lived with multiple sclerosis for the last twenty years. Her autobiographical essays, collected in Plaintext (1986), Remembering the Bone House: An Erotics of Space and Place (1989), Carnal Acts (1990), Ordinary Time (1993), and, most recently, Voice Lessons (1994), confront the socio-cultural forces shaping contemporary beliefs about disability, often linking them to those surrounding female subjectivity and sexuality. In the essay "On Being A Cripple," she writes, "Like many women I know, I have always had an uneasy relationship with my body" (Mairs, 1986, p. 16). This relationship forms the foundation of most of her writing, as she explores what it means to be both a woman and a woman with a disability.

In Remembering the Bone House, Mairs (1989) structures each autobiographical essay around a space, a house, or a town in which she has lived; the place becomes the center for her reflections on her psychological, social, and sexual development. All of the places--these houses, neighborhoods, and towns--are also ciphers for the "bone house": the body. "Through writing her body," Mairs notes, "woman may reclaim the deed to her dwelling" (p. 7). The body--its experiences, its sensations, its permutations--is intrinsic to both identity and communication. In order to develop a sense of self, Mairs rediscovers herself as a body: not only a mass of flesh, bone, and fluid, but also a cultural product whose significance can shift depending on what sort of body it is and in what context it is being viewed. Bodies, as Mairs makes clear, are signs.

The idea of the body as a semiotic signifier is fundamental to post-modern feminism, the influence of which Mairs (1994) describes in Voice Lessons: "the world we experience is itself an immense text that in spite of its apparent complexity has been made in Western thought to rest on a too-simple structural principle opposing reason to emotion, activity to passivity, and so on, every pair reflecting the most basic dichotomy--'male' and 'female'" (p. 74). This perception is critical to Mairs' development of her textual practices, which oppose rigid, totalizing constructions of identity and create alternative readings of self. Mairs inserts herself into postmodern feminist discourses, drawing from them and altering them for her own purposes.

The writings of both Mairs and Brown center on the process of self-definition. But the tensions inherent in this task, while they propel both these works, are constructed differently. For Brown, the struggle is between the inevitable necessity of isolation and the desire for communication; for Mairs, dramatic tension is instead subsumed in the reader's participation in Mairs' self dis/uncovering. In Brown's writing, the body becomes a symbol of one's isolation. For Mairs, the body is a catalyst for communication; it becomes a signifier not only of personal identity, but also of

communal interaction: "I think that my 'story,' though intensely personal, is not at all private. Beneath its idiosyncracies lie vast strata of commonality, communality" (Mairs, 1989, p. 10).

An analysis of cultural discourse is critical for an understanding of disability as a semiotic event. The body is the ultimate sign, so much so that its significance is often taken for granted. Both Brown and Mairs define and empower themselves by adapting an aesthetics of the body from a strong alternative discourse, enabling them to resist the dominant readings of disability. A recognition that identity is never a pure entity apart from its cultural environment is critical whenever we seek to articulate our own experience, to effect public policy, or to enact alternate tactics of being. One of the crucial things that literary and cultural criticism can bring to disability studies is an awareness of the various ways in which significance is generated. This is the task that texts such as those of Brown and Mairs have set for their readers.

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Spindleworks Journey

**Spindleworks Artists Cooperative
Brunswick, Maine**

Self Portrait

**I can draw very well
I can write poetry but
I can't read it aloud.**

**Somehow I can't read too good
that's a hard thing for me
I like to paint, like to draw
those are things I can really do.**

**See my nose, eyes and hair
that's me.
My mother said to me
You have an awful big nose
when I was born
I didn't put it there
God did.**

**Got a natural wave
I smile a lot
because I can work.
My eyes are very dark
Always have been
I got something like a dimple in my chin
I think a lot
I think all the time.**

Betty Pinette

My Sky

Sometimes I paint a house.
I got all kind of ideas
to make a picture.
I draw with my pencil.
I put all kind of color leaves,
sometimes dark green,
sometimes light green,
sometimes I put red leaves and orange, some-
times I put orange.
Sometimes they very stiff,
they're brown.
I saw some in that little tree.
They're all gone now,
they'll be back in the spring.
They still forever in my picture.
They fall, and on the ground,
they fall down in the fall.

I paint the sky.
I paint it blue and white.
I look outside,
how it is the sky.
But I don't have to,
I do it by my idea.
I paint it all blue.
Then I take some white
and put white lines over the blue.
Well, that what I do
for my sky.

Rita Langlois

What is Free in this Life?

Sometimes you can get an old Bible for free
from the church
sometimes they give them out.

Sometimes extra fries are free
at Newberry's they were
I had a BLT and they gave me extra fries for free.

Sometimes you can get a free ride
Louise took me to the hospital and her car broke
down
but I didn't have to pay for the ride.

And now I'm free
and I'm going down to Frosty's
and I'm going to have a hamburger
but I might change my mind....

Betty Pinette

Barking Dogs

The hot dog don't like me
its barking at me
again and again
I got it at Frosty's
today for lunch.
Those hot dogs
always barking back
but there so good.
There must be this chemical in them
that makes you burp.
Tuna fish is safer.

Betty Pinette

Extraordinary

**My friends at Spindleworks
don't like to be called "retarded"
it hurts
it means "not as good as"
no one would call an eagle "retarded"
because he doesn't act like a chicken
chickens are ordinary birds
they cluck and peck at anyone different
eagles are extraordinary birds
wild creatures
it lifts your heart to be near them
my friends at Spindleworks
are rare birds too
they don't cluck at other with hurt words
they know that everyone is different
inside
don't call my friends "retarded"
they are "extraordinary"
and it lifts my heart to be with them.**

Bryce Muir

I wanna get married someday
not right now
have to settle down first.
I can't be in that group home forever.
I want to get my own life
get out of there.
It's a skill for me,
a goal and objective.
I need to get my own life.
I'm mixed up
have to settle down
learn responsibilities
cook by myself, do laundry walk to the bank.
Don't want to be a kid all my life.
Don't like to be young all the time.
Settle down.

Terri Snape

You, in the Garden

You, picking peas,
peas like round balls,
green peas
bending down.

You, with the straw hats on,
hats like spaghetti
going round and round.

You, tipping the basket,
putting the peas in.
You've got a red shirt on.
You've got slacks on with a belt.
You, raking the grass.
That's all I see, You.

Nancy Bassett

I don't think they'll like me
I don't know
Some people laugh at me
Call me a retard
Doesn't sound nice when they say
"See that retard"
I have a lot of problems
But it's not by fault
I had a sad look on my face
I was thinking why someone would say that
They don't like me cause I'm different
I'm different a little bit
But we were all born different.

Terri Bonin
Diane Black

Life

Sometime
I feel strange
and upset
some
times I feel funny
life
life with me is
tough and wild
inside that's what life's
all about.

Minton Warren

A Handicapped Can Do Things

I know everybody knows I am handicapped.
Sometimes I don't feel like a handicap
a regular person.
I mean in the house,
I don't use my crutches.
In the shed I make things
on my own
I'd like to see the other people watch me do al-
most everything
so that way I won't get missed out.
In public I use my crutch.
Now I'm married
and have my own apartment and business.
People used to feel sorry for me
but not anymore.
I still have troubles talking but
they understand me now.

Earle Black

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Spindleworks Artists Cooperative, 7 Lincoln Street, Brunswick, ME 04011. (These poems are reprinted with permission from Spindleworks Journey, a book published by and available from the Spindleworks Artists Cooperative. A second book of poetry is scheduled for publication in late 1996 and will also be available for purchase from the Cooperative.)

Following the Thread: A Virtual Support Group for People with Multiple Sclerosis and their "Significant Others"

**Gerald Gold, Ph.D.
York University**

Research with support and self-help groups has focused on the informational, spousal, and ideological dimensions of communicating with others who live with a similar chronic illness or disability (e.g., Butler & Beltran's 1993 study of a sickle cell group). Others suggest that the illness- or disability-specific group "reaffirms the reductionism inherent in the medical model leading with a focus on the impaired body rather than the handicapping society" (Williams, 1990, p. 125). Though some of these observations apply to electronic support groups, the structure of electronic support and the content of disability-related computer communication differentiate these groups from interactional support and self-help groups in the content, inclusiveness, and frequency of communication as well as in the pervasiveness of medical metaphors and participation. Moreover, there has been little work on how computer networks sustain geographically-dispersed networks of persons with disabilities, their support persons, and medical resources.

In an effort to begin filling that gap, this paper deals with one of several electronic support groups which focus on multiple sclerosis. Though participants are geographically dispersed and may never meet each other in primary encounters, the support group is loosely structured, with clearly-defined rules for interaction in a fast-paced flow of communication in which the modes of engagement are constantly changing.

Data for this study come from several thousand screen messages or "posts" which arrive on a host computer at the rate of about twenty per day. Insights also come from my own reflexive observations as an active member of the group who both sends and receives messages. The network, or E-M.S. (a pseudonym), relies on an overseas computer to simultaneously send messages to about 220 "members" who are located primarily in the USA (about 80%), and in Canada, Holland, Italy, Israel, and England. As a "virtual community" which discusses living with multiple sclerosis, E-M.S. is characterized by an acephalous, message-focused continuity in which the inclusiveness of communication (every post is sent to the entire network) creates a community in which "members" interact as though they are in primary contact with each other on a daily, if not instantaneous, basis.

A major preoccupation of participants is creating message threads or a M.S. agenda. Significantly, threads such as "getting worse," "telling the boss," "Beta-Interferon techniques," and "pee tales," or "hang your head in shame" are never closed and, after

communication stops, they may be revived. In theory, contributing to a thread is open to anyone who sends a three-word message to the host computer in Israel, but membership has hovered around 200, and supplementary readers are accommodated by sending the messages to other lists or by persons who "lurk" without sending messages.

Shortly after joining E-M.S., the system facilitator, an Israeli professor with M.S., asks the new "member" to "post" a biographical introduction by sending it to the list. The self-identification and validating tale is immediately distributed to all members of E-M.S., many of whom will welcome the new "member" and add issues of concern to a message thread which can develop from the validating tale. For example, this introduction by a woman who had not yet been diagnosed with M.S. brought a flurry of diagnostic suggestions:

The neurologist told me I had an inflammation of the nerves in my brain stem --probably caused by a virus--and that it would eventually go away. What he wrote in my records was: "It would appear that she suffered an episode of demylelination and probable plaque formation."

Others are informed by list members that they may not find what they are looking for from a neurologist.

I'm sorry, I don't understand. If you are looking for therapies that create functional improvement . . . most current M.S. therapy is directed at symptom management . . . BTW, Welcome to E-M.S.!

Other validating tales emphasize that E-M.S. is the person's first opportunity to talk about M.S. to people who would listen:

I feel like I found some people to talk to about aspects of M.S. that I don't feel like discussing with my family or friends, and I don't have the opportunity (and appropriate "environment") to discuss with doctors. Thank you very much, all of you!

Others, about one in five and mostly men, join as caregivers. Their messages always give voice as a "significant other," though, after a few posts, these distancing explanations are dropped, and it is difficult to distinguish caregivers from persons with M.S.

In practice, E-M.S., an unmoderated group, is, like most electronic support groups, guided informally by its sponsor in Israel, who contributes opinions and narrative. Other members assume distinctive list-identities and are referred to directly, in comments, or indirectly, when their posts are absent. Some identities are captured in a name or in a signature line, such as Blue Skies, or a quote in Japanese. Another role

which draws an immediate global response is the perplexed person with M.S. or a caregiver, who broadcasts a tale of the newly-diagnosed. There is also resident expertise, such as a former medical student who responds to queries from a data base of research abstracts. As a resident source of "legitimate" medical knowledge who announced, on several occasions, that he would leave this list if his detailed, abstract-laden posts were unappreciated, his presence was constantly affirmed by list members and by the few doctors who had become subscribers. Significantly, his posts, supported by others, include a studied rejection of fringe cures for M.S., or widely-accepted but unproved theories such as the "Swank diet," or accepted medical solutions such as Beta-Interferon. But, when medical authority legitimates a solution, most list members focus, at any cost, on becoming medically-correct, though initially they may follow list expertise.

Most participants begin with a narrative of eligibility, while even the most vocal or expert of the participants add "confessional tales" which establish the legitimacy of their disability. About a third of the posts provide an update on the availability and effects of Beta Interferon and other medications. Many commentaries challenge and comment on the effectiveness and limitations of medication such as Baclofen, taken for spasticity, Cylert and Amantadine, which combat fatigue, and Solumendrol, a steroid which allays M.S. attacks.

The Beta Interferon (BI) posts--injection tales which deal with the first FDA-approved drug to arrest the pace of elapsing-remitting M.S.--are detailed and divisive. A crisis was precipitated when the medical expert reviewed the neurological publications and concluded that this high-priced wonder drug was not scientifically effective. Some members then decided not to register for a BI lottery. Nevertheless, in a few months, this opposition eroded. Posts began to include narratives of participation and advice on how to prepare the medication, including rough sketches of BI bottles. A few resisters, including an influential female correspondent, opted for the somewhat less expensive Israeli-developed COP1. (Significantly none of the Israelis opted for either drug.) Though the issue is not resolved, some of the BI-adopters have sent reports on sudden remissions and dramatic improvements (neither of which are published effects of BI).

Another lively thread is the effect of cannabis (marijuana) in substantially reducing spasticity. One poster began buying marijuana, and another reported regularly on two plants (Mary and Jane) growing by his bedroom window. This led to a concerned post from Germany about the legality of discussing cannabis on the net. Meanwhile, Mary and Jane matured, and marijuana-growing gave way to the prospect of E-M.S. summer camp, an imaginary place where things happen as they did before M.S. While other topics such as "telling the boss," "getting a diagnosis," catheters, retention, and toileting elicit threads of graphically-vivid discussion, list members resisted attempts to introduce the topic of sexuality.

With extensive collaboration, some list members set up a F.A.Q. (a bank of "frequently asked questions") on a computer in England. Some resisted the F.A.Q. by insisting that an electronic support group should discuss M.S.-related issues and avoid lending Internet-permanency to a rapidly-changing topic. The topics chosen for the F.A.Q. emphasize medical and nutritional issues and avoid the discussions of social and political and humorous dimensions of M.S., which are the themes of most posts. However, the F.A.Q. provides a history and a "medicalized" charter and institutionalizes the spontaneous exchanges of the virtual support group.

Table 1
Topics Included on the E-M.S. F.A.Q.

M.S. fatigue	Bladder problems
Swank diet for M.S.	I always wanted to play the violin
Clothing	Exercise
What's a kurtzke?	What harm can it do?
Impairment of cognitive function	If it quacks like a duck

Though it is difficult to measure, much of the communication between list members takes place back-stage, in private posts which reply to specific concerns or to autobiographical accounts. Even the medical student, the two doctors, and the most prolific posters will use back-stage messages if they are concerned about a post or a question and wish to avoid the front-stage scrutiny of the entire list. Moreover, some back-stage messages are personal and potential sources of embarrassment or shame. Most back-stage communication arrives unexpectedly, as this response to my suggestion that people read Robert Murphy's (1987) The Body Silent: "I still don't know whether it's a good idea to be a 'super cripp' or not. There are so few role models in general, though probably a good number on the net."

In eight months in the life of E-M.S., three crises demanded responses from the net. In the first crisis, the medical student threatened to leave E-M.S. in reaction to some critical comments or "flames." The response was a dramatic mobilization and a flurry of reassuring messages, one of which came from a doctor of rehabilitation medicine. As all dilemmas on the "net," the crisis ended when the student continued to post messages. In a second crisis, a private message regarding the sexual effects of M.S. was mistakenly posted to the entire list. A thread emerged on "hanging your head in shame," and the embarrassed poster resumed her frequent presence on E-M.S. A third crisis was less successfully resolved after a literary disability activist, who is a visually-impaired, wheelchair user, was ejected physically from her New York apartment and hospitalized. Nevertheless, despite an appeal from a New York university, the virtual support group was less effective in mobilizing support; the victimized woman did return to post to the list.

There are several dozen virtual support groups which operate globally through the Internet, yet there are likely to be significant similarities and differences in the way in which their participants communicate and between electronic and interaction-based support groups. Many of these differences stem from the comparative involvement of the state in disability and health care policy, and some of the internal contrasts are the result of other cross-national variations. As the organizer of E-M.S. commented, Israel, which has a form of state medicine, has little of the institutionalized accessibility and commercialization of rehabilitation found in the United States. Virtual messaging underscores these differences in disability policy. Virtual support also creates the possibility of mobilizing those with less mobility, by challenging medical authority and by placing disability issues within the control of people with disabilities and their caregivers.

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"Mothers Don't Get Sick": Women Living with Pain

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This paper is about the meanings of persistent/recurrent pain for 28 women aged 20-50 living in and around a northeastern metropolitan area of the U.S.¹ Through analyzing interviews with these women, I examine ways in which they learned to live with pain. Although this process often meant daily frustration, many women also came to experience their lives and their pain as orderly and typical, at least temporarily. Living with pain also entailed managing pain and, at the same time, managing their roles as women, whether single or with partners, whether working at home and/or outside their homes, etc. Their lives illustrate stigma and acceptance, illegitimacy and validation, ambiguity and structure.

Everyday Life Activities

Waking Up

"I mean I do wake up every morning feeling the effects of the whole thing . . and there are certainly days that are better than other days" (Mary)²

For many of the women each day began with evaluations. The above example illustrates how waking up can be a significant marker or point of decision-making. As Kathy Charmaz (1991) has noted, people who live with chronic conditions may have both good days and bad days. Another criterion used by interviewees involved looking ahead to scheduled activities and deciding, based on past experience, that more or less of some thing or activity (medication, exercise) would be needed.

¹Participants' ages ranged from 24-47, and their incomes ranged from less than \$10,000 per year to more than \$75,000. All of the interviewees were white; six were Protestant, six were Jewish, and sixteen were Catholic. All of the women had at least a high school education. Eighteen were living with partners, and thirteen had at least one child. The time since pain onset varied from more than 30 years (knee problems since childhood) to one year (mean years=11.5). Women experienced or had experienced pain in the following locations: back, neck/upper back/shoulder, knees, arms/hands, jaw, stomach/abdomen, chest. Interviewees listed the following conditions or illnesses: fibromyalgia, car accident-related injury, other injuries, back problems, no specific injury, rheumatoid arthritis/lupus, chondromalacia, TMJ, and unknown.

²Interviewees chose their own pseudonyms.

Personal Care

"I am sort of you know better off with sneakers. If I like go out dancing, I can't move the next day." (Debra)

Most of the women could do personal care activities, such as washing and dressing, without assistance. Those who did need help with bathing had concerns about falling and further injury. Washing hair could aggravate neck injuries. Pain also affected decisions about clothing. Andrea wore "disgusting ucky . . . moccasin things" at work because they were better for her back than high heels.

Paid Labor

For all of the women, daily life included managing varied kinds of work, including pain work (Corbin & Strauss, 1988). Whether they worked in the home or elsewhere, decisions had to be made, and limits accepted, challenged, and/or acquiesced to. Those who worked for pay, whether inside or outside the home, were responsible to supervisors, co-workers, or clients. Work could also also come to mean being responsible for one's self, one's symptoms. Lifting computer monitors plagued Andrea and Jacqueline. Lifting animals aggravated Amber's pain. Changing their physical workspaces helped some women.

For some women, flexible schedules allowed them to still earn an income AND pay attention to their pain management needs. Beth solved this problem by providing day care in her home for a small number of children. Three other women had flexible work schedules. It is important to note that two of the women who had such flexibility were single, did not have partners and/or children, and did not have expectations that they would return home to cook, etc. A third woman was married with no children. Working part-time or as a school teacher or nurse gave other interviewees some leeway, but sometimes at a cost to income. We know that such occupations are more likely to be filled by women, and that women face a wage gap relative to men's wages (Renzetti & Curran, 1992).

Reproductive Labor

Bonnie Thornton Dill (1992) uses the term "reproductive labor . . . to refer to all of the work of women in the home. . . . All of these activities are necessary for the growth of patriarchal capitalism because they maintain, sustain, stabilize, and reproduce (both biologically and socially) the labor force" (p. 235).

In this section I am writing specifically about labor which is unpaid. Whether working solely within the home or working outside the home with a "second shift" at home (Hochschild, 1989), whether single or partnered, with children or not, all of the women felt some sense of responsibility for housework.

Vacuuming, sweeping, and washing floors were activities often mentioned that women either modified or just did not do. All of these involve extended arm movements and lifting that could aggravate back and neck injuries. Vacuuming could be modified by obtaining a lighter vacuum, cleaning the house in stages (Nan, Christina) or evaluating whether today would be a good day or a bad day to vacuum (Beth). Those who felt they could not or should not vacuum might receive help from partners, parents, and/or children. Washing the floor could be adapted by sliding the bucket around rather than lifting. At least five people hired someone to clean the house. Other tactics were to wait as long as possible and to do it only occasionally or minimally.

Laundry-associated tasks presented problems for some women. Ten women specifically mentioned activities such as lifting, folding, hanging, and ironing that aggravated their pain. Two women modified ironing by rearranging their working space. Pacing such work, doing it in stages, and using a dryer instead of hanging clothes out on a line were all modified ways by which women continued to do laundry. Others received help from children or partners. Bending down to load or empty a dishwasher, or standing over a kitchen sink, was difficult for six women. Stretching into a cabinet to find food or dishes could also make pain worse.

Cooking also presented challenges. Some women could not predict ahead of time whether or not they would have the energy to cook at the end of the day, or what they would be able to prepare: "I have carrots on days when I'm not in a lot of pain" (Nan). Some turned to partners, take-out food, and just eating yogurt as ways of dealing with their pain and fatigue

Several women mentioned shoveling, mowing, and raking as activities that they limited, modified, or did not do at all.³ Like vacuuming and sweeping, these activities involve body movements that especially affected women with neck and back pain. Yard work was a responsibility, particularly for some of the single women who owned their own homes. As Hannah put it:

You have to mow the lawn, I have to mow. I'm single so I mow the lawn . . and after I mow the lawn I think you know why did I do that but, it's, I think it aggravates it. It makes you really wonder [laughs], you know, what, what you could have done differently.

Hannah had a gross annual income of \$20,000-\$30,000. She made choices about how to allocate her resources. She hired someone to shovel, every fall tried to rake and

³I wish I had asked more specifically about outdoor work. That I did not do so, I think, reflects a gender bias on my part, and, in future interviews, I would ask explicitly about yard work and other outside activities.

then hired someone to finish, and mowed her own lawn. Other women described their frustrations with carrying trash or wood and with gardening. Another way for women to deal with yard work who did not have partners or children to help them was to rent an apartment with outside maintenance provided.

Shopping was another regular, if not daily, activity that many women either did not do or modified. Hannah asked for a few items to be placed in many bags. Jacqueline had found recently that opening a pickle jar was difficult, and she was going to think twice before buying such an item again. Some women received help unloading groceries once they got home. Others had partners or children who always or sometimes did the shopping. Heather saved her shopping for weekends. Eight women said that they chose to stop at stores that packed groceries for you and brought them to your car. Six of these went to branches of a small suburban chain, here called Easybuy. Andrea used to shop at Easybuy, too, but, because she and her partner were saving for a new house, she had switched to a less expensive store where she had to do lifting.

Socializing and Leisure

At least 15 women felt that their socializing and friendships had been changed by their experiences with pain. Activities that they used to do with others might no longer be enjoyable. Uncertainty and not wanting others to observe pain were also reasons for changes in socializing. As Laura, Nan, and Tabitha pointed out, other factors had to be considered, such as children, having moved, and work schedules. There is no doubt that, for some people, their experiences gave them a new or clearer sense of who their friends were. What constituted friendship became redefined. Understanding and validation were particularly salient needs.

Pain affected women's leisure activities. Elizabeth sewed less and did not ice skate at all for fear of falling. Such fears also affected Sloane's willingness to be in crowds and Jenny's skiing. For some, the attempt to find new hobbies and activities resulted in pleasant surprises. Jacqueline tried "windjamming." And Hannah felt that, from her experiences, she had found something wonderful in a new hobby.

Sex and Intimacy

Pain and fatigue also affected sexual activity and women's current or potential relationships with partners. At the time of the first interview nine women explained that pain had affected their sex lives, but that they had adjusted. Several women mentioned how the length of time they had known their partners, and the ways in which they had established cues and rules for behavior, were important factors in how they had learned together to live with pain. Two women even felt that their experiences had brought them closer to their partners.

For two single women, not currently seeing anyone, their experiences with pain had affected their relationships in the past by precipitating break ups, and one of these women was particularly concerned about the difficulties she faced in the future. Three women were experiencing personal problems in their relationships at the time of the first interview. Lack of time, stress, difficulties in communication, other family problems, and financial worries were some of the issues affecting these women. However, for two of the women, their partner's fears of hurting them added to an already-strained relationship. On the other hand, Christina's pain management activities (e.g., swimming) had had a very positive affect on her body image and her sense of attractiveness.

Sleep

Ironically, though rest and a good night's sleep could be very helpful, some found that it was when they lay down to rest or sleep that they felt their pain the most. To stop moving was to start feeling. Pepsi's philosophy of life was "Keep moving [laugh]. I stop moving, I'm done for."

Summary

So now we have come full circle, from waking up to going to bed. Hilbert (1984) has noted that pain management is processual, continually renegotiated. Though management may be fluid and nonlinear, my research indicates that people's attitudes towards their management activities are not necessarily or always fraught with the fragility implied by Hilbert. Interviewees in this study were not simply passive beings who viewed themselves solely in terms of the relative legitimacy of their pain. Rather, as social beings, they both were influenced by and acted on social meanings of health, illness, role expectations, and so on.⁴ They often developed a sense of structured flexibility. Though many women felt that others were stigmatizing them, they could and did find ways to resist such stigmatizing.

Finally, it is clear that acceptance by others was possible, at least to some extent (Bogdan & Taylor 1987, 1989). Living with pain involved a complex balancing act in which women's desires to be understood often conflicted with their desires to be accepted as normal. Informal and formal supports could provide a safety net, especially when the structured flexibility these women had developed became threatened by flare-ups, new symptoms, or increased social responsibilities. However, the ability (willingness?) of others to recognize signs of pain may be related not only

⁴See Martin (1987) for an excellent examination of how women interpreted and took control of situations involving menstruation, childbirth, and menopause; Frank (1988) on experiences of people with obvious physical disabilities; and Conrad (1985) concerning self-management of medical regimens.

to time but to the nature of relationships. Those who are most directly affected or who have the most investment may make more efforts to incorporate new dimensions of self into their definitions of who the other is. Yet for those who know us well, especially for those who live with us and, therefore, also live with our pain, this also may mean learning new definitions for who they are in relationship to the person in pain.

According to Abel and Nelson (1990), women's lives often involve "circles of care." The interactional challenges experienced by the women in this study may have been complicated by the expectations they held for themselves, and that others had of them concerning "caring about, taking care of, care-giving, and care-receiving" (Fisher & Tronto, 1990, p. 40). For many of the women in this study, everyday life involved elements of caring at home and/or at work. As women living with pain they were also struggling with ways to "take care of" themselves, to be care-receivers. For the teachers and nurses in this study, taking care of others was part of their job. They tried to develop strategies that would also allow them to take care of themselves. Elizabeth succeeded in conveying to co-workers when she needed to exchange lifting a "heavy" patient for another task. Others found it more difficult to create a satisfactory balance between disclosure and validation. As a result, they felt incompetent as care-givers and/or found it difficult to ask for and receive care.

As Fisher and Tronto (1990) point out, when women receive care from others, they are likely to encounter conflicts with external caregivers who may define "needs to suit dominant ideas and interests. . . . Care-receivers may have little control over how their needs are defined in the caring process" (p. 45). Especially when caregivers represent a patriarchal, medicalized society, women may find themselves receiving care that they do not want or understand, and not receiving care that truly comforts. If pain is alienating (whether because it is phenomenologically so, as Scarry, 1985, maintains, or because of the particular culture and time in which we live), then women who live with pain face a kind of double alienation or, as Marsha Saxton (1984) suggests, a "dual handicap" (p. 299). Negotiating pain and being a women entail dealing with powerful others, socialized norms, and institutionalized oppression.

In previous writing I have emphasized how invisibility and legitimacy are important dimensions of people's experience and management of pain (Schlesinger, 1993b). The issues raised here might also apply to other relatively invisible conditions. Harlan Hahn (1988) asks: "Can disability be beautiful?" I would also ask: "Can people with invisible disabilities be validated? Can they be beautiful people with legitimate disabilities?" Who has the authority to validate claims? All of these women, most of whom had some financial and emotional resources available to them, faced difficulties at some time and with some people in receiving informal and formal support. This ranged from dealings with Social Security, refusals by health insurance companies to pay for services, rejection by lovers and friends, and condemnation by family members (one woman's mother referred to her as an "angry bitch"). To face further

discrimination based on class, race, or sexual preference surely would complicate their lives further. (See Browne, Connors, and Stern, 1985, for writings by lesbians with disabilities.)

For future writings, I will examine the follow-up interviews completed with 24 of the participants. This additional data, as well as further readings in narrative studies, will facilitate an analysis of the frameworks within which the women told their stories and the ways in which both form and content changed over time. I meant this study to complement previous research, and I designed it with the following questions in mind: How do people who are not in intensive pain treatment programs live with pain, and how do they evaluate the quality of their lives? My hope is that this study will contribute to our sociological understanding of bodily experience, illness, and disability in everyday life.

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Acknowledgments

The paper that I submitted for the Emerging Scholar competition (Schlesinger, 1993b) was based on my dissertation research (Schlesinger, 1993a; see also Schlesinger, 1990, 1992, 1994a, 1994b). For this conference, I chose to outline the dissertation's conclusions and to suggest future research.

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Sexuality as Experienced by Women with Complete Spinal Cord Injury

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As a person with a disability working on a Ph.D., I accessed a National Institute of Health "Research Supplement to Promote the Recruitment of Individuals with Disabilities into Biomedical Research Careers." The research supplement provides additional money to existing NIH grants to cover the salary and related expenses of a student with a disability. Under this NIH incentive program, the Co-investigators--Drs. Whipple, Komisaruk, and Richards--were able to add me to their existing NIH grant (the parent grant).

Physiological Study

The parent grant is a physiological study investigating the effects of vaginal and cervical self-stimulation on pain, spasticity, and sexual response in women with complete spinal cord injury (SCI) at or below the level of T-7. The specific aims are to identify sensory, sensorimotor, and perceptual responses to vaginal and cervical self-stimulation that are intact and potentially functional in women with complete SCI.

The preliminary findings of the parent grant suggest the existence of a previously unidentified neurological sensory pathway to the brain for sexual responses. This pathway bypasses the spinal cord. Previous work by Drs. Whipple, Ogden, and Komisaruk (1992) demonstrates the existence of imagery-induced orgasms. These studies are challenging the existing, limiting concept of orgasm.

Qualitative Study

Thanks to the NIH Research Supplement, we are also conducting a phenomenological study of sexuality that allows these women with SCI to participate in identifying important themes for further research. By adding a qualitative component to the study, we are beginning to get a more multidimensional picture of the participants and their sexuality, including psychosocial, emotional, and relationship aspects.

The interview format was structured to chronologically sequence events with the intention of describing the trajectory of sexuality in the women with complete SCI. The information presented here is based on the first eight interviews with

heterosexual women. The average years post-injury of the participants was 11.7, with a range of two to twenty-one years. We began the interviews by asking participants their definition of the word "sexuality." We then asked them to describe their sexuality prior to injury, the impact SCI had on their sexuality at the time of injury, their relationship experiences after injury including their first sexual encounter, and their feelings about sexuality at the time of the interview.

Pre-injury

Sexual histories ranged from primarily negative, which included two specific reports of sexual abuse, to primarily positive. All of the women had experienced coitus prior to their injury, and all but one had experienced orgasms (but not necessarily from intercourse). Physical expressions of sex were viewed as an important part of their sexuality.

Time-of-injury

Seven of the women were young adults at the time of injury, and they were beginning to gain an established sense of self and entering into long-term committed relationships. One woman, in her 40's, was in an unhappy marriage. Spinal cord injury was accompanied by a general loss of identity measured by a loss of ability to do the physical activities they enjoyed and an inability to pursue their chosen vocational objectives. SCI was also accompanied by a loss of sexual identity.

Cognitive genital and sexual disassociation. At the time of injury, participants reported shutting down their sexuality. Sexuality that was reported by one participant as having been "an orchid . . . a budding orchid with unfolding leaves," was now described as closing up: "It closed up . . . I closed up . . . I shut down every response . . . I shut down being happy . . . I shut everything off." Uniformly, the participants made the assumption that sexual pleasure was no longer possible for them, based on a perceived loss of sensation in their genitals. There was a conscious decision not to deal with their sexuality. We identify this decision as a "cognitive genital disassociation" or, more simply put, no feeling = no sexuality.

I have no feeling . . . therefore, I can't experience any type of sexual pleasure or enjoyment . . . and I put up a barrier. I became I guess you'd call frigid . . . ice woman. . . I wanted no part of it. . . It was strictly a function of marriage . . . it was cut and dry . . . it was taken away from me. . . Yeah . . . when I look back that was my way of dealing with my disability.

Sex education and counseling. Participants reported the overall quality of sexuality education and counseling by health professionals to have been poor. Much of the sexuality education they received revolved around reproduction and pleasing a partner.

Loss of sexual self-esteem and sexual disenfranchisement. In the absence of sex education and counseling, and with poorly developed communication skills around relationships and sexual issues, the women suffered a loss of sexual self-esteem. They felt sexually disenfranchised. Sexual self-esteem was subject to internalized myths about sexuality and disability learned prior to their injury, and negative feedback from others. Participants felt deprived or, more graphically, "robbed" of their sexuality. They no longer felt like whole women, they no longer felt sexually desirable, and they no longer felt sexual pleasure. "Right after my injury I felt robbed . . . plain and simple . . . 23 years old . . . no feeling from the waist down. . . . It wasn't fair."

Sex as a low priority. Sex, immediately post-injury, was reportedly a low priority, although concerns about sexual desirability and maintaining closeness were expressed. Energies were focused on other aspects of rehabilitation that were perceived as more critical for personal survival.

I compensated by putting everything into my rehab . . . and put the sexuality part behind me. . . . I put a lot of energy into my 'independence' . . . how am I going to make a living . . . even though I felt horny sometimes, I suppressed it.

Post-acute to Long-term Sexual Adjustment

At the time of injury and for many years following, sexual adjustment and sexual self-esteem were highly sensitive to external influence. Partners' or prospective partners' willingness to engage in sexual activities with them was their measure of sexual worth. Negative feedback from partners played a major role in affirming a feeling of asexuality.

My husband certainly wasn't interested . . . so that led to a lot of problems, and that led to feeling unattractive and non-sexual.

For all but one participant who had a sexual experience after injury, re-entrance into sexual activity was motivated by a sense of marital duty or by a new partner with whom they wanted to get closer. Only one participant was motivated to have sex the first time because she felt "horny."

The first time. Participants vividly recalled their first sexual encounter with a partner post-injury, doing it for him or experimenting with a curiosity about their own sexual response, not necessarily a desire for sexual intimacy. The first sexual experience with a partner after injury was burdened with symbolism. The outcome of the sexual encounter was used as a barometer to predict the outcome of the entire relationship. "I thought that if (sex) wasn't going to be pleasurable for him . . . it was going to be

the beginning of the end." "I just knew that this was going downhill, and he couldn't handle this. . . . I felt abandoned."

The overriding concerns were what the sex partner's reaction would be and if and how their body would respond. The description of the first post-injury experience was one of awkwardness and disappointment. There was a sense of being different and the loss of familiar sexual response. There was a constant comparison between what was felt or not felt now and what sex had been before. Comments included the following: "I didn't orgasm like I did before." "It was awkward. . . . I had the body cast on . . . it was gymnastics." "It was mechanical. . . . We had finally gotten to the point of sexual intimacy, and it didn't work."

Out of bad relationships and into good ones. Over time--in some cases, seven, eight, and fifteen years--the women chose to leave or renegotiate bad or un-affirming relationships and move into good or affirming relationships. The old relationships around the time of injury were marked by an inability to talk about relationship issues and about sex. The newer relationships were marked by an openness in communication about mutual needs in the relationship and about specific sexual likes and dislikes.

Regaining sense of self. The new ability to communicate came with an increasing sense of self as a valued human being. This sense of self was often achieved after surviving through long years of feeling less than fully human and making it on their own despite setbacks in relationships. The women had regained their sense of identity as people in the world, but their sense of sexual identity lagged years behind their other sense of self.

Turning points and reawakening. For many of the women, their sexual reawakening was marked by a specific turning point (e.g., a new partner).

Rediscovery, regaining sexual self-esteem, and redefining orgasm. The turning points led to a period of sexual rediscovery and the reincorporation of sexuality into their post-disability identities. All of the women went through a process of redefining orgasm for themselves. This was accomplished with the help of a partner--in half the cases, a partner with a disability--or with the help of other women with disabilities in peer support groups. Creativity, resourcefulness, and communication were seen as central to accommodating the sexual needs of self and other. One subject related, "It kind of forces you to be inventive . . . and more experimental." Exploration and stimulation of genital and non-genital areas (primarily breasts and other hypersensitive zones) generally resulted in pleasurable sexual arousal and, in some instances, self-reported orgasm.

Conclusion

Through the use of a research method that gives voice to the participants, the picture of sexuality as experienced by women with SCI is beginning to come into clearer focus. Although there is still much that is not known about sexuality and women with SCI, positive steps are being taken to learn more about the physiological and relationship aspects of sexuality. Our team and others are compiling the information needed to develop therapeutic and educational interventions to help women with SCI to maximize their response choices in developing and maintaining intimate relationships with themselves and with others.

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The Perceptions of University Students with Disabilities: Are Women More Disadvantaged than Men?

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This paper examines some preliminary findings of a study which is exploring the experiences of university students with disabilities. The study is part of a larger research project entitled Educational Barriers to Professional Careers for People with Disabilities.

Theoretical Context

The literature on disability suggests that to have a disability and to be a woman is to be doubly disadvantaged. Oliver (1990) notes that, while there is little substantive empirical evidence comparing the experiences of men and women with disabilities, many contend that women who have disabilities fare worse than either nondisabled women or men with disabilities. Hanna and Rogovsky (1991) examine data from two large American surveys and conclude that women with disabilities, compared to men with disabilities, do appear to be disadvantaged. They are more likely to be socially isolated, to have less education, to be unemployed, and to have less income. These authors suggest that the perceived inability to fulfill the roles of wife and mother, and to meet societal standards of attractiveness for women are further sources of disadvantage for women with disabilities. Similarly, Fine and Asch (1988) contend that, while men with disabilities can still aspire to powerful male roles, the situation for women with disabilities is different: "Disabled women are perceived as inadequate for economically productive roles (traditionally considered appropriate for males) and for the nurturant, reproductive roles considered appropriate for females" (p. 6).

As we looked at some of the early interview transcripts, it seemed to us that the men and women students we were interviewing often did not fit within the pattern that the theoretical literature would suggest. The women did not appear to be experiencing more difficulties than the men. Indeed, it was our impression that, overall, the women seemed to fare somewhat better than the men. Thus, in the tradition of qualitative research, we pursued this issue more closely. We asked respondents to share with us their perceptions of how their experiences differed from those of people of the opposite sex who have disabilities. Typically the question was framed: How do you feel your experiences compare with men [or, in the case of men,

women] who are disabled? It is the responses to this question that is the focus of this presentation.

Methodology

Thirty-one students with disabilities from several universities were interviewed using an open-ended, semi-structured interview guide. Interviews lasted from about 45 minutes to 1-1/2 hours. All interviews were taped, transcribed, and analyzed to identify major themes.

It should be noted that the students who volunteered were, for the most part, highly articulate. All were dealing effectively with the university environment. Many identified themselves as activists. We do not suggest that all university students with disabilities are necessarily as successful as these. This was clearly not a representative sample, and the findings must be considered in this light.

Characteristics of Respondents

We interviewed 17 women and 14 men. Of the women, ten had disabilities since birth, four acquired them during childhood, and two during adulthood. Of the men, five had disabilities since birth, three acquired them during childhood, and six during adolescence or adulthood. The age range for the women was 20-46, with an average age of 25.9. The age range for the men was 22-44 with an average age of 30.1 (i.e., the men were somewhat older than the women). In terms of disability, nine people had visual disabilities, sixteen had mobility disabilities, four had hearing disabilities, and two had epilepsy.

Findings

There were certain issues that were expressed by many students, regardless of their sex, age, type of disability, or age of onset. While most have had predominantly positive experiences, the length of time it takes to complete school work was a common theme expressed by these students. Having a disability means that it often takes longer to get things done. This can be further exacerbated when supports and adaptations are not in place, when nearby housing is not available, and/or when transportation is not convenient. For some students, attending classes and studying occupies all their time, leaving little time for developing relationships.

Having to deal with the negative attitudes of others, including teachers who discouraged the individual from pursuing a university education, was another theme mentioned by a number of people, as was having to negotiate the various bureaucracies which affected their lives. Nevertheless, these students have persevered. While all the students who responded to our study are "succeeding" at university in that they are making progress towards graduation, our initial impression

is that, overall, the experiences of the women students are somewhat more positive. The women appear to be more active on campus, they reported having more relationships, and they seem to be more satisfied with how things are going. They seem to take pride in what they are able to accomplish. The men, more often, seem to feel disconnected and isolated, and to identify more issues and concerns. A number spoke about the things they were no longer able to do. The men are, as a group, somewhat older than the women, and some of their sense of differentness may be related to being an older student. While there are fewer older women students in our group of respondents, they did not express these same feelings.

As noted at the outset, we were particularly interested in how these women and men students perceived the differences in being a man or woman with a disability. When asked these questions, some respondents answered from a deeply personal perspective, while others dealt with the question in a more abstract or analytical way. Several themes emerged from these responses.

The first group included both women and men who, consistent with the literature, felt that women are indeed more disadvantaged. Among the comments made by women were: "It's like you're disadvantaged twice as much" and "I think they [men] would just get farther faster." Similar comments were made by some men: "I have the problem of being deaf. They [women] have the problem of being deaf and [they have] gender-related problems." Another man was more specific, commenting in terms of safety and security: "I'm am not afraid of walking through the parking lot at night. . . I guess I don't need to worry so much about a sense of security on the campus after dark. The other thing is I don't have to wait for somebody to pick me up and escort me some place . . . so I guess there is a higher degree of freedom to move around."

A second group--all men--suggested that the typical differences between men and women become inconsequential or overshadowed when a disability is present. Thus, Bruce commented: "I think there would be less of a difference than there is between a male person who is not disabled and a female who is not disabled." Another interesting perspective was provided by Tom who suggested that his experiences as man who has epilepsy were in many ways similar to the experiences of women. He spoke of being able to identify "with the vulnerability of women," and of being conscious of his body in a way he felt was not unlike women: "I can tell when a seizure is coming on--like women who can tell that their period is coming on. I have the same kind of monitoring of my body that women describe around their period."

The third and largest group, which again included both men and women, felt that it is the men, rather than the women, who are at a disadvantage. The women in this group suggested that "a man who has any type of disability is more sensitive," that a man with a strange gait might be more likely than a woman to be presumed to be drunk, that societal norms of sexual prowess for men create an additional burden for

them, and that men with disabilities tend to experience more negative behavior from other people because men are "supposed to be stronger and more able."

The men themselves echoed many of these perceptions. They felt the weight of societal expectations and were burdened by their inability to fulfill expected roles: "I feel that having to ask people to do things for me is more difficult for me because I am a guy, and I am supposed to be able to do everything on my own." "It's still the belief that the male is supposed to be the number one breadwinner and protect the poor, defenseless female. . . . I see more handicapped females having relationships than handicapped males." "There are societal expectations and also my own pride, and that restricts me. . . . I don't want to have to ask somebody to keep the door open for me because that strikes at the very heart of my ability to function and also as a guy."

Conclusion

The preliminary findings of this study suggest that, contrary to what the literature would suggest, both men and women with disabilities often perceive men with disabilities to be more disadvantaged than women. This does not speak to the issue of whether or not men are, in fact, advantaged or disadvantaged on more "objective" criteria such as access to professions, jobs, income, etc. However, it does suggest that the socialization of men may create expectations and norms which men with disabilities are often not able to meet, and that the difference between reality and expectations may be a major source of frustration and anger. While women may well be more disadvantaged than men, as the literature suggests, the gap between their expectations and their reality may not be as wide. Clearly, these findings warrant further study.

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Section XI

The Power of Community as an Agent of Social Change

In this final section, we have grouped together papers that address culture, community, and social change. The first chapter is "The Disability Subculture as a Mediating Structure: Theoretical Rationale and Public Policy Implications" by G. Thomas Behler, Jr. Drawing on both classic (Durkheim) and contemporary (Berger) sociological theory, Behler shows how disability subculture can be a "mediating structure" between private and public domains. Behler notes that recent events, such as the ADA, both reflect and reinforce a developing disability subculture.

The next two papers deal specifically with Deaf culture and community. Barbara White focuses on American Deaf culture in her chapter, "Yes, There is a Deaf Culture." White presents several features of Deaf culture, features that, in the past, were ignored or unacknowledged by the primarily hearing researchers and writers who denied legitimacy to Deaf culture. These features include language, "shared attitude and experience" (p. 311), intermarriage rate, organizational structure, and elements of material and ideal culture (e.g., objects, norms, values, symbols, beliefs).

Petra Rose and Gary Kiger also write about Deaf culture in their chapter, "Intergroup Relations: Political Action and Identity in the Deaf Community." Rose and Kiger trace the development of the Deaf Power/Deaf Pride social movement from the early 1970's to the present. Rose and Kiger write: "A minority group is a minority group precisely because it lacks power *vis-a-vis* a dominant group" (p. 316). The authors use a minority group model to examine how members of the Deaf community have acted to bring about change, how those changes reflect and affect self definition, and what challenges face the group in the early 1990's.

Harlan Hahn also addresses the use of a minority group model in his paper, "The Paradigm of Personal Misfortune: Attitudes about Persons with Disabilities." Hahn asks why there has been so much resistance to regarding people with disabilities as members of a minority group. In this chapter, he examines elements of what he calls "the paradigm of personal misfortune," a paradigm composed of attitudes that discourage seeing disability as a social and political issue. Rather, this paradigm emphasizes that one's "problem" is one's own, and that one's "fate" has already been determined. Acceptance of such a deterministic and individualistic paradigm "blames the victim," not the establishment of social policies. Hahn suggests that further research and activism could benefit from looking at the similarities and differences among all groups who are subject to systematic prejudice and discrimination.

Finally, Simi Linton describes how Disability Studies can and should confront the themes found throughout this section. Disability Studies has developed as part of the wider and increased disability rights activism of the last 20 years. Disability Studies is interdisciplinary, rejects a clinical or individual (or, following Hahn, "personal misfortune") model of disability. Disability studies shares much philosophically and otherwise with other recent curricular challenges (e.g., women's studies, minority studies, multiculturalism, inclusive curricula). Yet, as Linton points out, Disability Studies is doubly marginalized in educational institutions--first, in relationship to overall curriculum development and implementation; and, second, in relationship to programs designated as "multicultural." Advocates of Disability Studies often have to struggle to be included in discussions, panels, and the planning of curriculum transformation. Linton challenges us to become more involved in such struggles: "We need to engage students in lobbying for courses and in demanding library holdings and descriptors in the library data bases to access materials, and we need faculty to nurture graduate students and to continue to generate scholarship that explicates how disability is a significant dimension of analysis that leads to a fuller more comprehensive understanding of the world" (p. 327).

Currently we face serious challenges to social programs funded at the federal, state, and local levels. How will persons with disabilities be affected by fiscal reductions and a resurgence of calls for individual responsibility rather than shared responsibility? Will universities be willing to provide resources for disability studies when they face severe budget cuts? Will disability-related laws be enforced? That disability rights, disability culture, and disability studies have come so far demands both celebration and a commitment to further scholarship, teaching, and activism. We hope that this volume of the SDS Proceedings has provided some guidelines for future work.

The Disability Subculture as a Mediating Structure: Theoretical Rationale and Public Policy Implications

**G. Thomas Behler, Jr., Ph.D.
Ferris State University**

Introduction

This paper attempts to demonstrate how the disability subculture can aid people with disabilities by serving as an important structure that mediates between the individual's "private sphere" and contemporary American social life. Emile Durkheim's (1933) theory of intermediate institutions, and the most relevant features of the more recent theory of mediating structures proposed by Peter Berger and his colleagues (Berger, 1976; Berger & Neuhaus, 1977) are used as the theoretical basis for this analysis. In addition to describing both the individual and collective benefits that can be gained for people with disabilities via such structural mediation on the part of the disability subculture, the paper notes some potential dangers that seem to be inherent in the performance of this mediation role.

**Discussion of the Nature and Significance of "Mediating Structure,"
"Private Sphere," and "Public Sphere" as Major Sociological Concepts**

Initial Theoretical Formulations of Emile Durkheim (i.e., his theory of intermediate institutions)

Durkheim's (1933) theory outlines the need for groups, located between the individual and the socially and politically distant State, through which people can express their feelings and, thus, exert influence in decision-making and policy-making processes. The occupational or professional association is espoused as the most suitable group for performing this intermediary role. It is argued that, by performing this intermediary role, the occupational or professional association can help individual members of society in their dealings with the large-scale State or governmental institution, and can help the State function more effectively as it tries to serve its constituents. These positive functions are quite encouraging, but the possible danger of "over-mediation" and extreme separatism is also suggested as a situation that must constantly be guarded against.

More Broad-Based Contemporary Theory of Mediating Structures as Proposed by Peter Berger et al.

Even though Berger's updated theory (Berger, 1976; Berger & Neuhaus, 1977) is similar to the original Durkheim theory in a number of general respects, the scope of the

theory is expanded considerably via the incorporation of a number of more broad-based concepts such as "private sphere," "public sphere," and "mediating structures."

1. The "private sphere" involves all aspects of the individual's everyday personal life (e.g., personal relationships, inner feelings and perceptions about reality, and private experiences).
2. The "public sphere" embodies all of the large-scale institutional components of the broader society (e.g., the State or governmental system, the economic institution, the educational system, and the health-care delivery system). Thus, the "public sphere" embraces all aspects of the individual's public life and dealings with large-scale impersonal public institutions in the larger societal context.
3. The concept of "mediating structure" includes any kind of structural arrangement that somehow could mediate between the private and public spheres. Although the occupational or professional association could be one such mediating structure, many other social groupings could perform the desired intermediary role as well, such as the family, the church, the neighborhood, the voluntary association, or the subculture.

Some practical observations concerning the role
of the emerging disability subculture as a helpful mediating structure
for its members, both personally and in the broader societal context

Justification for the characterization of the disability subculture as a viable mediating structure

The disability subculture meets the following four necessary pre-conditions for successful mediation as derived from the Durkheim and Berger theories discussed above:

1. The social unit must be able to generate a cohesive group atmosphere by fostering an acute sense of intra-group identity. In the case of the disability subculture, this is clearly happening to an increasing degree, as common concerns about negative societal attitudes, discrimination, and accessibility are voiced with greater vehemence. New laws, such as the ADA, should also facilitate this process, at least somewhat, although faith in the law in this regard must not be overstated.
2. The social unit must be able to strengthen and must be positively oriented toward the private sphere of social existence. This seems quite possible, as the common concerns of the disability subculture and their clear relevance to the

individual who has a disability on the everyday level become more apparent through time. The process here should also be facilitated as the potential benefits to be gained from involvement in the growing disability subculture become clearer to the individual with a disability. These benefits include a sense of security and unique personal identity, increased meaning and depth to the individual's personal life, and an enhanced ability to develop durable primary-group relationships both with people who have disabilities and with those who do not.

3. The social unit must also be favorably oriented toward the public sphere and its large-scale institutional components, or it must be willing to come to terms with them in order to promote the well-being of its members. It must encourage its members to interact and perform meaningful roles within the context of the dominant social and cultural order. The social unit cannot be a separatist social entity; if it were, it could fall prey to the danger of "over-mediation."

Examination of recent patterns and trends pertaining to the disability rights movement suggests that, even though progress may be slow, the disability subculture ultimately should realize this pre-condition. This will occur as more and more people with disabilities enter the social, political, and economic mainstream and develop cooperative working relationships with the institutional components of the public sphere. Cooperative working relationships between people who have disabilities and the major social institutions could be beneficial both to those with disabilities and to the larger society by:

- a. Reducing individual and collective estrangement of people with disabilities from the nondisabled mainstream;
 - b. Facilitating the creation of a healthier social and political climate within which people who have disabilities can operate as they pursue their common concerns; and
 - c. Engendering an increased positive orientation on the part of individuals with disabilities toward the institutional components of the public sphere, due to a feeling that those institutions regard people who have disabilities and their interests to be worthy of serious consideration.
4. The social unit must be relatively durable and permanent, in order that the positive qualities and working relationships needed to fulfill the first three pre-conditions can be fostered. It seems that the disability subculture should have no real trouble in realizing this fourth and final pre-condition. Even though it has been slow to emerge, the disability subculture has persisted, and

it has withstood a number of crucial tests of endurance (e.g., the conservative politics of the 1980's). Events such as the passage and enactment of the ADA, and the increased public interest in disability-related concerns are additional signs that point in positive directions.

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Yes, There is a Deaf Culture

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The terms "Deaf culture" and "Deaf community" appear so frequently in the current literature that many writers assume their readers clearly understand what they mean. This paper identifies the characteristics of Deaf culture documented in the literature and supports the notion that there is, indeed, a culture of Deaf people in every part of the world, although this discussion is limited to American Deaf culture.

I must admit that I have never attended a Society for Disability Studies conference, and I have heard that not many Deaf people attend these meetings. Why is there such an obvious under-representation of Deaf people at a meeting concerned with very important issues affecting their welfare? It cannot be the result of a lack of accessibility--this is one of the best planned conferences I have attended in terms of interpreting services. Is it that the disability community and the Deaf community are two separate cultures? Deaf people often say they do not have disabilities, but prefer to be perceived as a minority culture, having more similarities with Hispanic Americans than with disabled Americans. Deaf people see themselves as a cultural and linguistic minority, not as a "disabled" group.

Although the terms "Deaf community" and "Deaf culture" are used so frequently, the existence of a "Deaf culture" has been challenged in professional literature. Erickson (1993) suggests that Deaf people who hide behind the label "Deaf culture" are promoting a segregationist attitude. He claims that, to be defined as a culture, a community must have its own ethnic foods, native dress, religious beliefs, attitudes about children and the elderly, and behavioral norms, and that having a distinct language is not enough to constitute a culture. Erickson seems to take the view that only cultures that are romantic, exotic, and primitive can claim their own culture:

Love of sports, residential school education, perception of deafness, association with other deaf people, bluntness, visual sense of human, the existence of deaf clubs and national organizations are often given as examples of deaf culture. One opinion was that since native Africans and Native Americans can have a culture, then deaf people are entitled to one, too. (p. 48)

Most of the professional literature on Deaf people has been written by hearing people. Early theories suggested that Deaf people were dysfunctional or emotionally and psychologically inadequate. Thus, for most of history, Deaf people's self-definition mirrored the definition and theories that hearing people gave them. It was not until Deaf scholars began publishing their own accounts of Deaf culture that the

idea of a cultural and linguistic minority began to gain recognition (Padden & Humphries, 1988):

A deaf community is a group of people who live in a particular location, share the common goals of its members, and in various ways, work toward achieving these goals. A deaf community may include persons who are not themselves Deaf, but who actively support the goals of the community and work with Deaf people to achieve them. (Padden, 1980, p. 92)

[Deaf culture is] a social, communal, and creative force of, by and for Deaf people based on American Sign Language (ASL). It encompasses communication, social protocol, art, entertainment, recreation (sports, travel, Deaf clubs), and (to a point) worship. (Moore & Levitan, 1993, p. 217)

Padden (1980) compared the concepts of "community" and "culture":

A culture is a set of learned behaviors of a group of people who have their own language, values, rules of behavior, and traditions. . . . The culture of Deaf people is more closed than the deaf community. Members of the Deaf culture behave as Deaf people do, use the language of Deaf people, and share the beliefs of Deaf people toward themselves and other people who are not Deaf. (pp. 92-93)

Moore and Levitan include hearing people within Deaf culture if they are fluent in ASL and actively engaged in the Deaf community's activities and goals. Many interpreters and children raised by Deaf parents fall into this definition.

Geertz (1973) defines "culture" in broad terms as whatever knowledge and beliefs one has to have in order to function in a way acceptable to the group's members. It is an evolving world view of a group of people--the shared experience, knowledge, and values--and it is transmitted from generation to generation. Susan Rutherford (1993) views "culture" as an adaptation to one's environment and sees the American Deaf community as one of the many cultures making up America. She encourages scholars to study Deaf people because Deaf people in all parts of the world have adapted to an environment based on sound, as well as having created a visual language for themselves.

The following features of Deaf culture are most prominent:

Language--The idea of a separate language is most often cited as a reason why Deaf people have their own culture. ASL has only recently been recognized as a true language worthy of linguistic study, but there are now thousands of classes offered to teach ASL as well as certificate programs for ASL instructors. There are professional journals on American Sign Language and a Department of ASL,

Linguistics and Interpreting at Gallaudet. Recently, the U.S. Postal Service recognized ASL (and, therefore, the culture of American Deaf people) by a stamp featuring the "I Love You" sign. This is a clear indication that the culture of Deaf people is becoming part of American popular culture.

A shared attitude and experience--Joining the Deaf culture is not measured by the amount of one's hearing loss, but rather one's attitude. "Attitudinal deafness" means that the person has identified with the group, and that there is mutual acceptance which is almost always based on whether or not the person uses and accepts ASL. This attitude is reflected in cultural pride, demonstrated by events such as Deaf awareness weeks, Deaf cultural events and festivals, and demonstrations of solidarity at political rallies. Culture can also be reflected negatively as cultural shame, the tendency to hide negative behaviors and events within the community from outsiders.

The shared experience of state residential schools for the Deaf is another feature of Deaf culture. This experience is a primary vehicle for the survival of Deaf culture, for it is in these schools where ASL is passed on to Deaf children, particularly those with hearing parents (approximately 90%) (Solomon, 1994). When two Deaf people meet, they usually share information on the state schools they attended as children. The closings of some state schools has jolted the Deaf community, since they are perceived as a direct attack on their culture and traditions.

Intermarriage rate--The Deaf community has perhaps the highest intermarriage rate (an estimated 85-95%) of any minority group in the U.S. Although more empirical research is needed, marriages between Deaf and hearing spouses appear to be less stable (Schein, 1989).

Formal organizational structure--There is an elaborate structure of hundreds of local and international organizations of Deaf people, including the National Association of the Deaf, the World Federation of the Deaf, the National Athletic Association of the Deaf, the National Fraternal Society of the Deaf, and Telecommunications for the Deaf. There are the World Games for the Deaf every four years, and a national Miss Deaf America contest every two years (although some Deaf feminists object). Deaf clubs were once the central means of Deaf social contracts, but their popularity seems to be waning, particularly as a result of technology. Captioned TV programs, captioned videotapes, TTYs, and vast electronic mail and information highways are satisfying the leisure time and informational needs of Deaf people, particularly those in the middle class. There is research underway to make large screen movies accessible to Deaf people through various devices, none of which are completely satisfactory. Deaf people seem to prefer open captions, but the movie industry claims that hearing viewers will be distracted. Computer technology, in particular, is transforming the way Deaf people communicate not only with each other, but with the larger culture of which they are a part. Communicating in print is an easy adaptation to the barriers that voice-only communication once entailed.

Material culture--Assistive devices that allow the culture to adapt to the world of sound include TTYs, baby crier signals, vibrating alarm clocks, flashing smoke detectors, and flashing doorbell lights. (Thanks to the ADA, when I check into a hotel, I am given a suitcase full of these devices.)

Norms--Certain rules of behavior are expected in Deaf culture, including stomping on the floor or flicking light switches to get attention, raising and shaking hands in the air to applaud, standing at a greater distance when communicating, maintaining a certain level of light in the room, not standing in front of a window when communicating, and knowing what to say when first meeting. Touching the side of the shoulder is preferred to the back, and showing affection by hugging is common. In addition, lingering after a social gathering is expected, as is, at times, not starting events on schedule. Other rules relate to ASL, such as not exaggerating lip movements, and not speaking while signing.

Values--Values that Deaf people cherish include a strong positive regard for ASL and the belief in the cultural model of deafness rather than the medical or disability model. There is a high value placed on Deaf education, particularly residential school models with a bi-lingual/bi-cultural approach. There is great skepticism and often blunt disapproval of mainstreaming Deaf children, since the word "inclusion" is meaningless when Deaf children are, in fact, more isolated in a mainstreamed environment. There is a negative evaluation of cochlear implants and any efforts to "cure" deafness. Deaf children are highly valued, since it is they who will carry on the Deaf heritage. Deaf elderly people are also held in high esteem for their wisdom and their gifts of transmitting Deaf cultural heritage (Padden & Humphries, 1988; Becker, 1980), a value which has been compared to respect for elders in Chinese culture (Levy & Langer, 1994).

Not surprisingly, many Deaf parents are overjoyed when their babies are diagnosed with deafness (Dolnick, 1993); and a large percentage of Deaf persons who apply to become adoptive parents request Deaf children (White, 1993). The issue of "ownership" of Deaf children has been debated in Deaf publications and conferences, since most Deaf children are not born into their own culture. The Deaf community has pushed to have hospitals and clinics which identify deafness through early testing notify the state associations of the Deaf so that hearing parents can be given positive information about the Deaf community in addition to the medical information they receive from doctors and audiologists. The case of Corey Brown (Van Biema, 1993) and the strong advocacy of the disability community to disregard her mother's wishes not to resuscitate her can be compared to the feelings of ownership by Deaf community members.

Symbols--A few symbols represent Deaf culture, such as the "ILY" sign, which has become internationally known. Many commercial products promoting Deaf causes

use an ILY logo. Another symbol, most often seen in public places to identify the TTY location, is a picture of an ear with a slash through it.

Literature and art--Deaf culture is made richer by a legacy of literature, folklore, poetry, theater, and art. A book on Deaf cultural heritage has been published by a Deaf author (Gannon, 1981), allowing this heritage to be transmitted in print to the next generation. There is a wealth of ASL history, stories, poetry, plays, and folklore. One Deaf-owned theater company deals exclusively with Deaf culture (Barwiolek & McKinney, 1993), and the national TV program "Deaf Mosaic" has won several Emmy awards. There are also many famous Deaf artists, including some who depict the Deaf experience in their work. For example, a drawing by Betty G. Miller of two hands in chains gives the viewer a powerful image of the language oppression Deaf people have endured throughout history.

In spite of centuries of language and cultural oppression, Deaf culture has endured. As the Deaf community faces new threats to its existence, such as the closing of its residential schools and efforts to eradicate deafness by medical technologies, there most certainly will be a collective resistance against "cultural genocide." Deaf people are fiercely proud of their language and their cultural heritage. For Deaf people, the human need to leave part of oneself to the next generation, which Erik Erikson (1968) calls "generativity vs. stagnation," is met by leaving part of their Deaf self.

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Intergroup Relations: Political Action and Identity in the Deaf Community

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In 1972 Barbara Kannapell started the organization Deaf Pride to enhance the self image of deaf persons. Deaf Pride and the Deaf Power movement it fostered led persons in the Deaf community to reevaluate their characteristics, status, and self image. This reevaluation culminated in the Deaf President Now (DPN) protest at Gallaudet University during March 1988 (Gannon, 1981, 1989; Sacks, 1989). The transformation involved deaf persons (a) identifying themselves as members of a community sharing common values and traits (e.g., sign language), and (b) evaluating the group and its values and traits in a positive light. Ironically, as a group's members come to value themselves after a long period of self deprecation, the consciousness-raising can lead to anger, resentment, and political action over perceived injustices.

Groups form on the basis of differences. We have cultural categories available to us about group differences. Persons who are deaf are different from hearing persons. On the basis of categories like this, individuals identify with others; and shared values, norms, traits, and sentiments become the basis for group membership. Beyond differentiation, though, evaluation takes place. Groups are not only perceived to be different, one group is evaluated as better than another (Allport, 1954; Sherif, 1966).

Identification with a group and subsequent evaluation of that group's characteristics influence an individual's social identity. If one's group is not positively evaluated in the larger culture, and if (a) group boundaries are ill defined, (b) movement in and out of the group is possible, and (c) the social system in which the group is situated is perceived by the individual to be legitimate and stable, then the individual is likely to renounce group membership and exit from those relationships (Brown, 1986).

Alternatively, if one's group is not positively evaluated, and if just the opposite conditions exist, i.e., (a) group boundaries are sharply defined, (b) movement is impossible, and (c) the social system is perceived as illegitimate and unstable, then the individual cannot easily exit from the group. One can "pass" (see, for example, Goffman, 1963) and try to maintain a positive personal identity by having others identify him or her as a member of a valued group. If "passing" is not an option, then the individual's self image (i.e., personal and social identity) is stigmatized, spoiled,

and/or discredited (Goffman, 1963). In the past, this condition existed for most deaf Americans.

What changed in the 1970's and 1980's for deaf Americans was the Deaf Pride and Deaf Power movements, especially the Deaf President Now protest in 1988. Members of the Deaf community acquired "voice." This term was coined by Henri Tajfel (1978, 1982) to describe social action directed toward enhancing a minority group's status.

At this point, group members reevaluate their characteristics and traits, and they cast them in a positive light. What before had been deprecated is now celebrated. For members of the Deaf community, the most salient characteristic is sign language and, more specifically, the use of American Sign Language (Padden, 1980; Padden & Humphries, 1988).

Here an irony emerges. To bolster group members' self image, the group must exaggerate its members' distinctiveness and value it. As a minority group acquires "voice," it develops ethnocentrism to a heightened form as well.

As the members of a minority group develop more positive self images, their perceptions of social justice change. Their sense of injustice leads to an unwillingness to stand for discrimination. Research on intergroup relations shows that, to be successful, a minority group must demonstrate high consensus among members and consistently respond to points of perceived injustice (Brown, 1986).

When a minority group begins to reevaluate its status, members also reevaluate their notions of what the group and its members deserve. For example, deaf Americans no longer compare themselves to deaf Americans twenty years ago and note how much better off they are. Rather, members of the Deaf community begin to compare themselves to hearing people and feel cheated (Barnartt & Christiansen, 1985).

Out of perceived inequities come anger, resentment, and mobilization for group action. Positive personal and social identity is transformed into political action. However, just thinking one's group deserves more cannot overcome structural barriers to change. For deaf Americans these barriers include inaccessible environments (e.g., absence of interpreters); negative, stereotypic beliefs held by hearing persons, particularly those in powerful positions (e.g., employers, education officials); the medicalization of deafness as deviance; and the dominance by hearing persons of educational programs for deaf children (Lane, 1992).

A minority group is a minority group precisely because it lacks power *vis-a-vis* a dominant group. For politically active members of the Deaf community, the next few years will be a crucial turning point in intergroup relations with the hearing world. There are two factors that seem particularly important. First, members of the Deaf community need to control decisions made about the education of deaf children.

While efforts to mainstream deaf children create the opportunity for diverse social interactions, deaf children do not develop the *sine-qua-non* of Deaf culture, sign language. However, with residential schools, although deaf children develop sign language and acquire Deaf culture, they may be taken further and further away from the hearing culture in which they will need to participate if they are to have economic mobility and political power.

Second, the Deaf community must work simultaneously on solidarity among deaf Americans, on the one hand, and participation in the hearing world, on the other. If the Deaf community is to have political power, members must present a united, consistent front. Broad recruitment of deaf individuals into self-identification with the Deaf community poses problems. In Deaf culture, there are criteria for membership. Broad inclusion, while difficult, will enhance political power.

Participation in the hearing world is another strategy for political success. While full integration is not desirable and probably not possible, pluralism, perhaps, holds the most promise. Pluralism establishes parallel institutions for deaf and hearing persons. While no deaf person could be denied access to hearing institutions, deaf persons would be free to develop their own institutions over which they would exercise control: schools, social clubs, certain businesses, and so forth. But, ultimately, resources to effect significant social change reside in the hearing world. Consequently, pluralism cannot be isolationism. Finally, it seems that many of the negative stereotypes of deaf people are being broken down. Positive representations in the popular culture, for example, go a long way to breaking down the negative stereotypes which may serve as justification for inequities and hostilities.

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The Paradigm of Personal Misfortune: Attitudes about Persons with Disabilities

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One of the principal reasons for the prior failure to recognize persons with disabilities as a minority group deserving of equal rights has been a widespread consensus that regards this segment of the population as the victims of a personal misfortune that cannot be alleviated by public policy. This paper will seek to explore the origins and implications of "the paradigm of personal misfortune" that long prevented policy-makers from recognizing the demographic characteristics of disadvantage or oppression and from accepting the "minority group" model of disability, which focuses on attitudes and discrimination as the major problems facing citizens with disabilities.

There are two major components of the traditional attitudinal paradigm about disability. First, the problem is regarded as individual. Disability is commonly perceived to be the product of a "natural lottery" which strikes specific persons randomly, provoking anxiety and a loss of faith in a "sense of justice." The focus on the individual thus enables the nondisabled person to avoid any conscious consideration of this risk. Because most disabilities stem from health conditions, this emphasis has also reinforced the clinical orientation of medicine and psychology that tends to exclude factors outside the confines of a person's body from analysis. Moreover, the difficulties of a disability are usually ascribed to functional defects that cannot be repaired. As a result, persons with disabilities form the only minority group that has not yet successfully disproved allegations of biological inferiority. The second element of this paradigm, therefore, associates disability not only with a lack of good fortune, but also with a negative fate. But society is excused from any responsibility for dealing with this issue because collective policies are presumed to be ineffective. Implicit in this perspective is the image of an infinitely perfectible body and the belief that anyone who cannot approximate this standard is both incompetent and ineligible for equal treatment. The interaction of individualism and perceptions of misfortune yields a sentiment similar to the emotions evoked by tragedy, which combines pity and fear. The only appropriate adjustment to disability, consequently, is represented by persons who "overcome" their disabilities and who conform to the myth of "courage"; and any departure from this expectation may be viewed as a form of hubris or an excessive desire for personal pride in the quest to gain dignity.

The predominant response to perceptions of personal misfortune has been a charitable benevolence that often yields paternalism. In part, these attitudes reflect both

confusion about persons who are seen as "not quite human" and an effort to assuage feelings of guilt and vulnerability prompted by the threat of disability. In addition, charitable benevolence is the product of Judeo-Christian legacy that long interpreted disability as punishment, especially for sexual transgressions, and of the historical role of persons with disabilities as entertainers and beggars. This perspective also defines disability as an appropriate problem for private charity instead of public policy. But benevolence also precludes an equal relationship between citizens who have disabilities and those who do not. As a result, debates about disability have been permeated by an ethos of paternalism that has inhibited the development not only of public opposition to the goals of the disability rights movement, but also an indigenous perspective based on creativity and empowerment derived from personal experience with disability.

Perhaps most importantly, charitable benevolence has been employed to smother and subdue an underlying aversion to people with disabilities. Attitudes about disability may be inextricably linked to the development of a sense of self; and the source of discrimination against this minority may develop earlier than other forms of prejudice based on race or ethnicity, gender, sexual orientation, and age. Fundamentally, they seem to reflect "aesthetic" as well as "existential" anxiety. But they are cloaked by a paternalism which impedes their articulation. As a result, people with visible disabilities often must resort to an interpretation of nonverbal behavior to discern the true feelings of those without disabilities. The failure to recognize covert prejudice has resulted in major errors in judicial rulings about disability rights. And it has presented social scientists with a formidable challenge in the study of unspoken antipathy.

A significant response of persons with disabilities to this issue has been reflected by the movement to redefine personal and political identity. Increasingly, although most people who have disabilities remain oppressed by stigma, disability has been reinterpreted as a positive rather than a negative phenomenon, which permits them to see their surroundings in a different way that can promote creativity and empowerment. Avoiding the pitfalls of "essentialism," experiences with a disability can engender a distinctive perspective on social issues equivalent to viewpoints derived from the everyday lives of women, African-Americans, Latinos, gays and lesbians, and aging persons. This seems to be the most promising path to breaking the shackles of paternalism.

Prejudicial attitudes on the basis of race or ethnicity, gender, sexual orientation, age, and disability generally appear to take different forms. As a result, various policies may be required to curb discrimination. But the fact that almost all of these attitudes seem to reflect a response to identifiable physical characteristics may eventually provide a foundation for the construction of a unified framework for the study of bigotry and for the formation of political coalitions and alliances. The challenges

implied by the endeavor, however, seem to represent one of the most crucial tasks confronting research on diversity.

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The Disability Studies Project: Broadening the Parameters of Diversity

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A front page headline in the New York Times Science section reads: "Sexes Equal on South Sea Isle." The news story reviewed the results of a two-year investigation by an anthropologist of the sparsely-populated island of Vanatinai near Papua, New Guinea, where a unique social arrangement exists: men and women live and work as virtual equals. Dr. Maria Lepowsky, the anthropologist who studied the culture, reports, "It is not a place where men and women live in perfect harmony and where the privileges and burdens of both sexes are exactly equal, but it comes close" ("Sexes Equal," 1994, p. C1). She said that the findings are close enough to challenge some theorists' contention that male dominance is universal or somehow inherent in human cultures.

From what do readers draw in their experience and knowledge base to help them make sense of this? What makes this newsworthy, and how do we know it is newsworthy? As marginal as Women's Studies is in the academy, and as marginal as women's issues are in global and domestic politics, at least among many New York Times readers, there is some shared curriculum and a recognition of the ubiquitous nature of women's oppression. But if they were to read a report of a similarly integrated and equitable society with respect to disability, would the significance be as clear? If an island were found where people with disabilities were incorporated as equals in the social and economic life of the culture, who would have the epistemological/intellectual tools to delineate the unique qualities of the culture and to understand the significance of the findings?

Nora Groce's (1985) research on the island of Martha's Vineyard is such a study. In the Vineyard, for over two and a half centuries ending in 1952, there was a large concentration of people who were deaf. They participated fully in the economic and social life of the Vineyard. It is likely that their lives were more like non-deaf people than in any other community in the United States or elsewhere in the world. The Vineyard was unique for many reasons, but most significantly because the non-deaf residents accommodated to the deaf residents and were fluent in sign. This ethnohistory provides an opportunity to consider the social variants that determine the full participation and equal opportunity of all people with disabilities. The significance of the study can be understood by anyone familiar with the history of the marginalization and oppression of people who have disabilities, anyone who recognizes how important it is to disseminate evidence that helps people recognize that the social position of individuals with disabilities is not inevitable--it is not our

fate. Our destinies are constructed--through social interactions, through laws, policies, and practices. And, as they have been written, they can be rewritten. And we are writing. We have crafted laws and policies. And we are writing theory and conducting research as we build the field of Disability Studies.

To begin to understand what Disability Studies is, it is helpful to look at the way disability is traditionally represented in the academy. It would appear from a review of traditional curricula that disability is a personal problem, a deficit that resides in the individual, requiring rehabilitation and special treatment to amend what is "wrong," to make up for what is missing or dysfunctional. Disability is often discussed this way in academic departments such as medicine, rehabilitation psychology, "special" education, and other applied fields. The academic curriculum is entrenched in this medical view of disability. It is designed to prepare workers to help people with disabilities adjust, fit in, get better, and adapt to the existing social and political structure. When disability is represented in liberal arts fields, the deficit paradigms remain, and the focus is on the individual as deviant subject, rather than on the social structures that label difference as deviance and pathology.

For instance, I was speaking to a sociology professor about the availability of information about disability and gay and lesbian perspectives in courses in sociology. He told me that sociologists always discuss these things and that a required course in his department covers these phenomena in depth. "And the name of the course?" I asked. "The Sociology of Deviance," he replied.

Of course, creating the field "Disability Studies" did not create the scholarship. Instead, the name organizes and circumscribes a growing multidisciplinary knowledge base. The field examines myths and conceptualizations of disability across cultures and throughout history. The analyses embodied in Disability Studies form a prism through which one can gain a broader understanding of society, human experience, and the significance of human variation.

Traditionally, the meaning accorded to disability is that it is a personal medical condition, rather than a social issue; an individual plight, rather than a political one. This is remarkably similar to the traditional representations of women, described by Carol Tavris (1992) in The Mismeasure of Woman. Her book describes the way traditional research has often measured women against some idealized male norm, and it attempts to explain behavioral differences in terms of perceived biological or psychological differences, rather than differences in power and circumstance. Thomson (1990), discussing the position of people with disabilities in society, reminds us of the power differential between persons with and without disabilities, reinforced because "the dominant group defines itself as normative" (p. 238).

Disability Studies challenges the idea that the social and economic status and assigned roles of people with disabilities are inevitable outcomes of their condition,

an idea similar to the argument that women's roles and status are biologically determined. The designations of "disabled" and "nondisabled" are just another way that humans divide themselves up and allocate power and resources. But Disability Studies goes beyond cataloguing discrimination and arguing for social change. As with Women's Studies, Disability Studies redresses omitted histories, ideas or bodies of literature, and it analyzes the construction of the category "disability" and the impact of that construction on society and on the content and structure of knowledge--fundamental epistemological issues.

The problem for Disability Studies scholars has not been in documenting the social construction of disability, in identifying the contributions of ignored people with disabilities, nor in indicating ways that identity as a person with a disability informs a scholar's perspective. The problem has been in convincing the academy that Disability Studies has a legitimate place in the academic curriculum. Of course, the usual skeptics of curriculum reform, meaning those opposed to a more diverse or a multicultural curriculum, see Disability Studies as the ultimate proof that the diversity movement serves identity politics, that its purpose is to boost self-esteem, that it is fragmenting our knowledge base and our nation, and that it is based on parochial and narrow interests. Of greater concern is that we have been unsuccessful in gaining acceptance and support from those who are working toward making the curriculum more accurate, representative, comprehensive, and diverse. They have, for the most part, ignored us or actively opposed the incorporation of Disability Studies in their curriculum transformation efforts and have not recruited people with disabilities to sit at the table in discussions on curriculum reform.

As a result of many forces--resistance from those working within curriculum transformation and those who are opposed to it, resistance from those invested in traditional fields such as rehabilitation and special education, and resistance from those inside Liberal Arts fields who do not recognize disability as a valid area of inquiry in the non-applied fields--the perspectives of people with disabilities and the field of Disability Studies are conspicuously absent across a broad range of endeavors. Projects called multiculturalism, diversity, pluralism, and transformation, though tremendously varied in purpose and scope, focus primarily on race/ethnicity and gender. For numerous reasons, many still to be articulated, the construction of "multicultural" places those perspectives at the center of the discourse. The history and the consequences of that construction, for the most part, are invisible, giving the impression that multiculturalism as it is usually presented or understood circumscribes the logical domain of curriculum reform. For instance, Henry Louis Gates, Jr. (1993), asks:

What is this crazy thing called multiculturalism? . . . multiculturalism itself has certain imperial tendencies. Its boundaries have not been easy to establish. We are told that it is concerned with the representation of difference--but whose differences? Which differences?" (p. 6)

Despite its appearance of fluidity, egalitarianism, and openness, multiculturalism has formed its own shape and texture, and it now renders its own authority. Therefore, the knowledge that it privileges and the knowledge it marginalizes need to be critiqued, particularly from the perspectives of the margins.

The most daunting job that Disability Studies scholars face is to convince the academy that the marginalization of Disability Studies has ramifications for the curriculum as a whole as well as for the multicultural/diversity curriculum. Schuster and Van Dyne (1985) discuss this process in their work on transforming the curriculum to include the experience of women and other subordinate groups. They delineate six stages of curriculum transformation that can occur as increasing amounts of information and numbers of perspectives are incorporated. In the first stages, we merely identify the contributions of previously invisible people, challenge the adequacy of the existing knowledge base, and work to develop the "insider's perspective." In describing the fifth stage, called "women as challenge to the disciplines," they ask, "How must the organizing questions of each academic discipline change to account for the diversity of gender, race and class?" (p. 24).

To have the academic community engage that question with respect to disability, it would be necessary to convince them that Disability Studies provides a prism through which one can gain a broader understanding of society and human experience, that human variation and the cultural meaning of that variation are critical vectors of analysis in understanding the human condition. As Longmore (March 1992, personal communication) points out, Disability Studies deepens the "historical comprehension of a broad range of subjects, for instance the history of values and beliefs regarding human nature, gender and sexuality; American notions of individualism and equality, and the social and legal definitions of what constitutes a minority group." Other issues such as autonomy, wholeness, independence/dependence, health, physical appearance, aesthetics, the integrity of the body, community, and notions of progress and perfection pervade every aspect of the civic and pedagogic cultures. They appear as themes in literature, as variables in social and biological science, as dimensions of historical analysis, and as criteria for social policy and practice (Linton, Mello, & O'Neill, 1995).

However, few people outside the Disability Studies circle recognize the ways that the field can significantly alter their understanding of the world. Their recognition of its significance will be determined by social processes that include the dissemination of scholarship and support of it by administration; the presence of credible faculty who use the material in their classes and promote it to students and colleagues; the development of courses that are permanent, and not "special topics" courses that rely on specific faculty members to teach them; and voices inside and outside of the college lobbying for courses and curriculum revisions.

Ultimately, the incorporation of Disability Studies into the curriculum will rest on shifts in these forces. I believe that the diversity/multicultural initiatives and the field of Cultural Studies are the best points of entry into the curriculum. The tiny Disability Studies community within the academy will need to step up the pressure. We need to engage students in lobbying for courses and in demanding library holdings and descriptors in the library data bases to access materials, and we need faculty to nurture graduate students and to continue to generate scholarship that explicates how disability is a significant dimension of analysis that leads to a fuller more comprehensive understanding of the world.

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