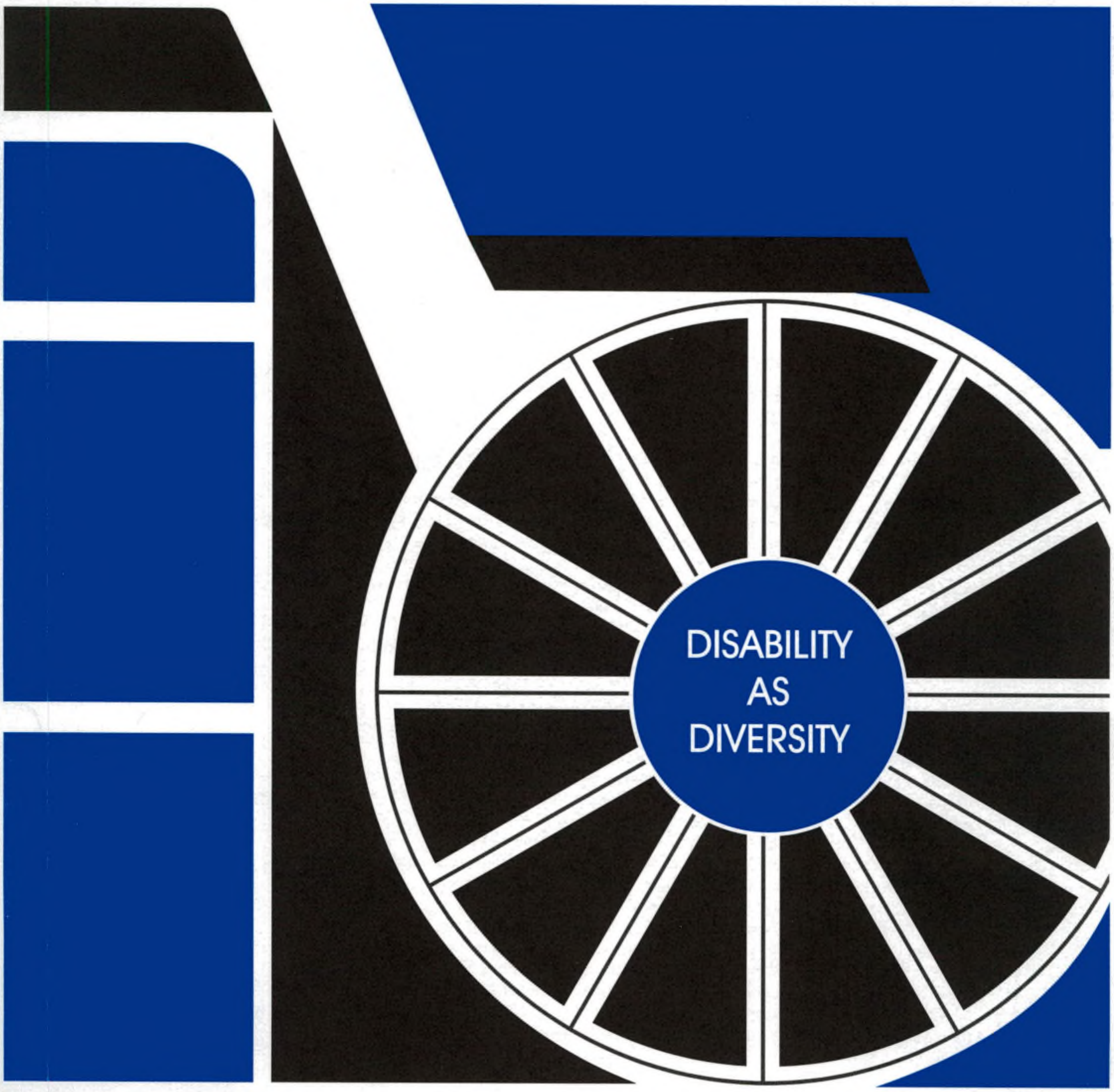
REFLECTIONS:

NARRATIVES of PROFESSIONAL HELPING



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A Journal for the Helping Professions

REFLECTIONS:
NARRATIVES OF PROFESSIONAL HELPING

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REFLECTIONS:

NARRATIVES OF PROFESSIONAL HELPING

VOLUME 5 **Fall 1999** **NUMBER 4**

Special Issue: Disability as Diversity

Special Editor Tom Bucaro

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PRINTED QUARTERLY BY **THE CSULB UNIVERSITY PRESS**

Letter from the Editor

Mary Ann Jimenez, Ph.D.

As I read the narratives in this issue on Disability as Diversity, I came to a deeper understanding of the meaning of this phrase. The articles point to a distinct reality experienced by those who cannot pretend to speak with disembodied voices, whose bodies must be acknowledged constantly in everyday life. This reminder of the tenuous nature of life may be threatening to those of us who have not come to terms with our own mortality. The view through the woods of the socially constructed everydayness of life offered by the differently abled may impel some of us to turn away with a shudder. One repeated theme of these articles that I found compelling was the way we have been schooled not to look directly at the disabled. This is not out of politeness, as we have convinced ourselves, but out of fear of being reminded of our human frailty. To live in such a shadowed reality, as a differently abled person, is to experience the oppression of the invisible. It is to experience the marginalization of being the feared other. In this way the disabled share with all oppressed groups the outcast status.

The concept of disability itself comes from the perspective of the outsider looking at persons who may have less in common than it might appear, aside from their treatment by the rest of us. I am thinking of how differently people who are hearing impaired, visually impaired, or moving through space in wheelchairs, for example, experience the world and solve the everyday problems of reality. Yet we place all those who seem different from us in a bodily way into a single group, speaking of them, reacting to them, and considering them as one. These articles made me see again the invidious nature of this social construction embraced, however inchoately, by many of us--that the disabled are less capable and less whole than we are.

The privileges of the ableist culture have shadowed the reality of the barriers we construct for the disabled. These barriers include physical ones, and it is here that progress is being made and measured, as accessible buildings, academic, and workplace accommodations are growing through legislative initiatives. These physical barriers have become economic barriers, excluding the disabled from the benefits of productivity in a market economy and it is important that they be overturned. But the psychological and social barriers of living in a world little understood by others, and of feeling minimized and dehumanized in silent but powerful ways have a profound impact that the culture of disability is forced to confront.

These articles remind us that the full range of human experiences, including support and betrayal, belongs to those whom we have called disabled. Like our hold on life, our hold on our body wholeness is time limited. The change can be sudden or gradual, but it will come. We will become the "other", sooner or later. These articles may make us wonder whether, when it is our time; we will have the strength of these authors.

Reflections welcomes letters to the Editor. Letters should be sent with the writer's name, address and daytime phone number to Editor, Reflections, Department of Social Work, CSULB, 1250 Bellflower, Long Beach, CA 90840. They can also be faxed (562-985-5514) or sent via E-mail to mjimenez@csulb.edu. Letters may be edited for length and clarity and may be published in the journal.

SPECIAL ISSUE

CALL FOR NARRATIVES

Fall 2000

American Indian Narratives

Many American Indians have experiences that can teach us about helping. Some of these stories are recent; many are not. This special issue of *Reflections* is designed to share these stories with helping professionals. Please consider sharing with us narratives:

- That help others understand American Indians and the helping processes.
- That explore the ways in which children and others are taught about helping.
- That are used in daily living and involve helping.
- That tell us about dealing with problems in living.
- That are stories about family members helping each other.
- That share experiences of being helped and helping others.

This special issue is being edited by the faculty of American Indian Studies, California State University, Long Beach. We encourage you to send in narratives that will inform others about American Indians and the helping process. Written manuscripts are preferred, but we will accept audio-taped stories for review.

Manuscripts due by March 30,2000

Mail Manuscripts to:

Lester B. Brown, PhD
American Indian Studies
California State University, Long Beach
1250 Bellflower Boulevard
Long Beach, CA 90840

Editorial: The Disability Experience: New Voices, New Images

by Tom Bucaro

Tom Bucaro, D.S.W., is the special editor of this issue on Disability as Diversity. Professor Bucaro is Associate Professor and Director of the Social Work program at the College of Staten Island, City University of New York, and a leader in the field of disability. He has developed programs in Developmental Disabilities and Social Work at C.U.N.Y. and served as the chair of the C.U.N.Y. Caucus of Employees with Disabilities. He is one of the founders and Chair of the Commission on Disability and Persons with Disabilitites, Council of Social Work Education. He has published on issues related to disability and has delivered many professional papers on this topic.

This special issue of *Reflections* focuses on the experience of "disability" and its recognition as an area of human differences along the axis of ability. Its focus is not on disability as impairment but on recognition of disability as a social distinction. The earliest cultural representations of disability are with sin and evil. Later, the representation of disability is associated with illness and deficit in functions. The latter association, based on a medical model, continues to dominate the representation of disability in the education and training of academics and practitioners. Over recent decades, the cultural shift initiated by people with disabilities has been toward a social construction of disability: a minority group model that has in common with other minority collectives themes of oppression and discrimination. This conceptualization of disability presents new visions for positive identification and opportunities for human actions. Yet, disability as diversity is a cultural transformation and an identification process not fully understood or accepted by the helping professions.

The narratives in this issue are compelling. They are the voices and images of people with disabilities and not the voices and images presented by outsiders. They are the voices and images of people with disabilities who no longer choose to remain invisible. The narratives cut across a variety of disability experiences and disability-related issues: stories by people with visual, hearing, and mobility impairments; descriptions of the experiences of people with visible, hidden, and invisible disabilities; and accounts of people who became disabled either early, late, or suddenly in life. More compelling, though, than the nuances of differing among the disabilities among our writers, the reader will recognize the many commonalties of the disability experience.

The theme of passage is expressed frequently, indirectly or directly, as our writers recount their "journeys " or "transitions." They describe their transformation toward self-acceptance and the rejection of societal negative devaluation that facilitates a reintegration of positive disability identification, that ultimately leads to cultural and self-affirmation. Another commonality is that these voices have emerged in the milieu of the worldwide disability rights movement and the Independent Living Center movements that began in the 1970's and reach their highest expression in the United States with the establishment of the Americans with Disabilities Act (ADA) in 1990. It is within these socio-political movements, which opposed the culture of oppression, that people with disabilities began to collectively identify as a minority group; these movements are the linchpins of an emerging disability culture. They provide a fertile environment for the transformation of shame associated with disability to a positive disability identity and disability pride. As the narratives demonstrate, cultural self-affirmation linked to the socio- political center often give rise to advocacy conscientiousness on behalf of self and other. Subsequently, those who have been transformed serve as cultural interpreters to others with disabilities and in this way a collective identity and disability culture continues to emerge, evolve, and expand.

Once we shift our view from a deficiency model of disability, with its negative stereotypes, to a diversity model of disability, we can come to see people with disabilities as a group who share commonalties with each other, distinct from the dominant culture of the nondisabled. While some academics question whether disability is a true culture, there is little question that the community of people with disabilities has cultural dimensions. Some of these dimensions are shared with other minority groups while other dimensions are unique to people with disabilities. Nevertheless, what remains clear is that despite varying degrees of personal struggles, people and families with disabilities share with racial, ethnic, and other minorities the common experiences of social oppression and discrimination that include the underlying devaluation of the cultural experiences related to their differences and the oppression by the dominant culture.

While the whole case for the existence of disability culture cannot be made here, we can briefly discuss its current stage of development as emerging and in flux. Its cultural history, similar to other oppressed groups and perhaps even more so, has been largely hidden and must be discovered and reconstructed from the text and subtext of the literary works and historical documents produced by the dominant culture. Also, like other minority groups, people with disabilities have become increasingly assertive. They have emerged from the shadows, fresh from hard-won political and cultural victories, to produce art, language, literature, humor, and other cultural products that emanate from the disability experience and that have fortified a growing sense of community among people with disabilities. The narratives in this issue are the product of that cultural process and will become part of its cultural history. These evolving cultural elements as well as other elements, previously hidden, are examined critically under the emerging discipline of Disability Studies. However, again as with other minority groups, it is recognized that there is not cultural unanimity among the broad spectrum of people with disabilities. For example, many persons with disabilities who have successfully assimilated into mainstream society resist identification with disability and are not quick to embrace an evolving disability culture.

The question is whether the helping professions will recognize and align themselves with emerging representations of disability or maintain the status quo. The images of persons with disabilities as social participators challenge long-held assumptions of practitioners. And as the disabled have found their voice, their call for collaborative partnerships with practitioners and their demand for self-determination are just beginning to be heard. In effect, practitioners are "at risk" of exercising acts of oppression and discrimination, even if intended to follow standards of practice or acts of kindness. It is an issue of critical importance for the helping professions as the population becomes aged, as technology expands the prolongation of life, and as people with disabilities gain visibility in the cultural life of the United States and worldwide. The recognition of disability as diversity where it intersects with the helping professions brings us to some new venues on the discourse of multiculturalism.

With the increased presence of diversity in the American culture, the need for social workers and other human service professionals to develop cross-cultural competencies has received widespread attention in the literature. While the Curriculum Policy Statement of the Council on Social Work Education (CSWE) recognizes disability along the axis of ability within the curriculum content area of human diversity, the profession has been slow to recognize disability as a diversity issue and a valid minority experience. It is disheartening to find that many of the standard texts used to prepare social work professionals make little reference, if any, to the representation of persons with disabilities as a socio-political and cultural entity. Instead, texts continue to perpetuate existing stereotypes and represent people with disabilities as a population that is universally "at risk." Similarly, conferences designed to promote the understanding and practice with diverse groups rarely include people with disabilities as part of the diversity mosaic.

Therefore, as the social work profession approaches the

21st century, one of the major challenges, as well as one of major opportunities, for social work education is to advance a disability initiative that incorporates a diversity perspective of disability into the curriculum. In 1997, the CSWE Board of Directors established the Commission on Disability and Persons with Disabilities (CDPD). Among its goals are the promotion of new emerging paradigms of disability into the mainstream of social work education and the inclusion of people with disabilities within the social work professional community. It remains to be seen how successful the CDPD will be in reaching these goals, but until they are achieved, the profession will be absent the cultural competency needed to work with the largest minority group in the United States.

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Integrating My Disability: My Journey

When the author turned 23, he suffered a serious accident that left him with a permanent disability. The accident and its ensuing disability shattered his identity and forced him to put the pieces back together in new ways in order to gain self-acceptance. Gaining this self-acceptance has been an ongoing struggle, yet through the struggle he has come to view disability and himself in new ways.

by
Robert G. Blair

Robert G. Blair, Ph.D., Department of Sociology, Social Work and Criminology, Morehead State University, Morehead, Kenutcky

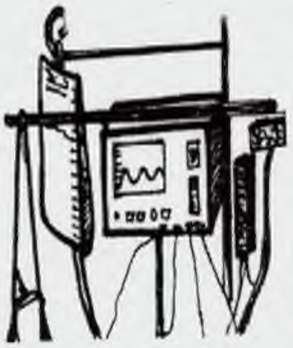
I have always loved to play and compete in a variety of sports. Born with natural athletic ability, I competed in tennis, racquetball, basketball, and swimming. Happiness was competing on a tennis court against an opponent who was my equal in the game. I would run down every ball and use lobs, drop shots, topspin shots, and any other shot that I thought would bring me some advantage. I played to win, but win or lose it was the battle on the court that I loved. I trusted my skills and my athletic ability to carry me through the fight. I was always searching for an opponent who could match my skills and push me to my limit, someone who was just slightly better than I was. This would force me to find new shots or new strategies to win, and frequently I would come up with shots that not even I knew I could hit.

School was something I did between athletic competitions. I attended class and did most of my homework, but my heart was on the tennis or the racquetball court. Even during my first years of college, sports remained my top priority. I loved to compete and felt confident in my athletic abilities. During those years I lived at home, survived on limited monies, played all that I could, and worked sporadically to earn a few extra dollars.

One part-time job I accepted was as a ticket taker for events held at the university I attended. It was a job I felt would bring me some extra cash and, I hoped, free entrance into a variety of events. On my second day of work, I was assigned to take tickets at the opening football game. The date was September 25, 1982, and it was the first game in the newly expanded stadium. Our team had a highly touted quarterback, a gifted passer and scrambler, who was always exciting to watch. Excitement filled the air as we awaited the opening kickoff. Everyone seemed to be in good spirits, so I joked and laughed with many of the patrons as they passed through my gate. I even had a chance to joke briefly with the current president of the University as he wandered around and mingled on the outskirts of the stadium.

I was 23 years old and felt "on top of the world." As the start of the game neared, the crowds swelled, but by early in the first quarter, the crowds had thinned yet were bunching up at a few of the open gates. I was asked to leave my post and ease the crowding by directing the remaining patrons to a variety of open gates, which I quickly accomplished. Next I was asked to help shut one of the iron rod gates which was about 10 feet high and 25 feet long. The gate was set on a concrete block that was about 2 feet above the ground and had rollers at the base that allowed it to be rolled open or closed. One other ticket taker was also assigned this task. We struggled to get the gate rolling, but even on rollers, it was too heavy for the two of us. Soon, several other ticket takers lined up at the gate to assist us in closing it. Since I had been regulating the crowds previously, I was on the opposite side of the gate from the other ticket takers. I thought nothing of it. With the added help, the gate quickly began to roll and then to gain momentum.

My next memory, some six hours later, was slowly gaining consciousness and recognizing that I was in a hospital bed. I had no idea what had happened, but did perceive that there was a variety of tubes and bags sticking out of my body. I recognized several of these tubes since less than a year previous I had worked as a nurse's aid on the geriatric unit at the state hospital. Several of the patients there had similar tubes, and I knew how serious their implications were. Many doctors and nurses were standing around me as I searched for a face that I knew. Recognizing my dad standing solemnly amongst the group, I asked, "What happened?" In response one of the nurses gestured with his finger over his lips to be quiet and said, "Shh, you're in extremely critical condition." I searched my memory for what could have gone wrong but found no answer. Shortly thereafter, Dad came to my side, did his best to smile, and in a subdued voice told me that the gate I had been closing had come off its tracks and fallen on me. He explained that the damage was extensive but that I was a survivor. I closed my eyes to escape and prayed to God with all my might: "Please God, let this be only a horrible dream, let me awake to an intact and whole body." Then I opened my eyes to the nightmare of reality. I began to feel physical pain beyond what I had ever experienced. My whole body shook uncontrollably as I tried to cope. The pain was unbearable and felt as if razor sharp knives were tearing me apart from the inside out. All of my body wrenched in pain. Over the next several hours and days, a variety of doctors and nurses related the details of the physical damage.



My pelvis had been crushed and pulverized in several places by the gate, which had been estimated to weigh between two and three tons. It was a miracle, some told me, that I was alive at all. It sounded good, but my situation felt anything but miraculous. My left leg was in traction and could not be moved. My colon had been brought to the surface of my stomach in what is called a colostomy and my feces would pass through it into a bag rather than through my rectum. My bladder had approximately six holes and a super-pubic catheter had been placed directly above my genitals and would serve to empty the urine from my body. Stabbing pain was ever present and the only reprieve from it was through the shots of morphine I received every few hours. Yet even their potent effects were short lived. I'd quickly return to unbearable pain racking my body. I struggled to appear optimistic but felt completely overwhelmed; both body and spirit were broken.

Various monitors were placed on my body to monitor my heart and other bodily functions. When there was a problem or, more frequently, when one of the monitors became disconnected, an alarm would sound and doctors and nurses would come running to assess the problem. It was a horribly bleak time. I knew I was holding onto life by a thread and wondered if it wouldn't be easier to just let go of that thread. I imagined how sweet it would be to slip into peaceful death, away from this inescapable pain and broken body. As I prepared to close my eyes and let life slip slowly away, I felt a renewed strength beyond my own. I wasn't quite ready to give up, but I would certainly keep it as an option. A part of me wanted to live, if my body could be fixed, but unsure if I was ready to live with this seemingly useless body.

My present circumstances were so dreary as to be unbearable. When my pain could be numbed temporarily with the morphine, I would escape to my dream world where I would play tennis, basketball, and a host of other sports. I relished running as free and fast as my powerful legs would carry me. However, my dream world would always shatter abruptly as my pain overcame the effects of the morphine. I loathed having to return to my broken body. I hated who I was now and was willing to do whatever it took to regain the ability to walk and run again. I endured numerous surgeries, always with the goal of walking and running once more. Finally, after six endless weeks, I was discharged and my parents took me home.

Mom and Dad did their best to care for me. My condition was slowly improving, but I was still incapable of dressing myself or transporting myself without the use of a wheelchair. Nonetheless, being home and around familiar faces and sounds felt wonderful. Neighbors would often visit and frequently brought dinner into our home. I still had my colostomy and super-pubic catheter. We had not figured out how to get an airtight seal on the colostomy, so there always seemed to be the smell of excrement in the air. Visitors would do their best to ignore it but Mom and Dad often left the windows open even in the dead of winter to lessen the smell.

As I gained more strength, Dad began to take me swimming once or twice a week. He still had to dress and undress me and put on my swimming suit. Then I would tuck the colostomy bag into the suit and remove the catheter bag and cap it to prevent it from leaking. It was a difficult process but worth the reward. Dad would take me in my wheelchair to the deep end of the pool and lift the wheelchair at an angle so that gravity would slide me into the water. The buoyancy of the water eased the pain in my legs and provided enough of a lift that I could propel myself under my own power. It felt great. I was at home in the water. Throughout high school I had swum competitively, been captain of our swim team, and had even become region champion in the 500 freestyle. What I could do now was a far cry from where I had been, but it was real progress to be able to move under my own power. Sometimes I would run into old friends at the swimming pool. They frequently did not recognize me at first because I had lost considerable weight and my body had become atrophied. When they did finally recognize me, they most often did not know what to say other than "I'm sorry." It was uncomfortable but this was reality. I was no longer the man I had once been.

During this time I was also attending physical therapy on a daily basis. I was weak and struggled with the pain inflicted from various exercises and stretches, yet I knew that it was the only chance I had of walking again. My primary physical therapist, Janie, was wonderful and treated me as a person of unconditional worth and value. I, on the other hand, wondered if my life was even worth keeping. Who was I and what value did I have without the use of my legs? Everything I had ever wanted had been taken from me the moment the gate had crushed me. I hated that I couldn't walk, couldn't dress myself, and couldn't even use a bathroom. I had to pee in one bag and defecate into another. I was nothing, I thought, but a pathetic cripple. I pondered what possible purpose my life could have now, and how I could possibly fit into this world where beauty and health were worshiped, and disability was shunned.

Enduring endless hours of exercises and stretches through physical therapy, I slowly began getting stronger. Yet I also experienced a variety of setbacks including a time while at physical therapy when I tried to take a step with my walker and my pants fell down to my ankles leaving me bare naked to the world. My body was still feeble so I could not bend down to pick up my pants and had to depend on my physical therapist to do it. It was humiliating. I felt completely useless, but I survived. Following this incident I remember thinking that if I could endure this, I could endure anything that life could throw at me. Progress was incredibly slow, but gradually I taught my legs to take a few steps. This was made more difficult because my legs had suffered extensive nerve damage. They seemed to no longer hear or obey the directions that my mind gave them. It was frustrating to tell them to move and to get no response. Something so simple as lifting a foot and placing it in front of another foot seemed all but impossible. Yet the nerves in my legs had not been completely severed, so I knew that it was a possibility that my legs could once again be taught to move, one step in front of the other, first with the aid of a walker, then with crutches, and finally with a cane. Each step was horribly painful but I forced myself through the pain.

Being able to take a few steps with a cane was a great breakthrough in my life. I imagined never progressing further than the cane and wondered if I could make a decent life for myself even if I was never able to discard it. Answers were not easy. I wanted more than anything to regain my former physical abilities but knew that was impossible.

As I searched for self-acceptance, it slowly dawned on me that I was prejudiced against people with disabilities. I'd never had any close friends with obvious physical disabilities. I had never seriously considered dating someone with a disability. Yet here I was now, one of them, and struggling to overcome my own prejudice. Could I accept myself in spite of my disability—broken body and all? Resolving this question was an ongoing battle within the depths of my soul for years.

As I wrestled with this question, I read a book entitled *Man's Search for Meaning* by Viktor Frankl (1992) This book had a profound effect on me. Through the first part of the book, the author relates some of his experiences in the concentration camps of Auschwitz and Dachau. He states that in the concentration camps everything was taken away: name, professional identity, clothes, hair. All that was left was an identification number. Yet after all was taken, according to Frankl, man was still free to choose his or her attitude toward his circumstances. Man was not necessarily free to choose circumstances, but always free to choose the attitude toward those circumstances. Even in the worst circumstances, according to the author, there were people who behaved like pigs and others who behaved like saints. The difference was not circumstances, but rather the attitude one took toward those circumstances. A primary key for coping well was finding or discovering a unique purpose in life. I pondered these words over and over and wondered what possible purpose my life could have now. As I searched for purpose, my focus slowly began to shift. Initially I thought only of the losses created by my accident and what I would never do again; yet gradually I began thinking of what I could do now or would be able to do in the not-too-distant future. As I struggled to find some purpose, I began making some plans and thinking about a lifestyle that might be possible. One of these plans was to return to school and complete my degree.

At the time of the accident, I had been a junior at the University and not yet sure of what I wanted to be. Now I wanted a profession that would provide me sufficient income to pay my bills. But of more importance, I wanted to work at something that would make a difference in someone's life. I thought of Janie, my physical therapist, and how our journey together had brought me from the point of being nearly hopeless to where I was beginning to believe once again in myself. She had treated me with warmth and understanding and had always believed in me. Her unwavering belief, more than anything else, had allowed me to begin forming a new belief in myself. My hope was to find a profession that would allow me to help others in the way that Janie had helped me. I thought about a variety of professions. Yet social work seemed to best embody the type of work I wanted to do. I felt it would allow me to work with individuals and perhaps have an influence on their beliefs about themselves. I also believed that social work might provide a purpose to my pain. If I could learn to cope effectively with my own pain, then I would be able to better empathize and help others who were experiencing physical and/or emotional pain.

To realize my ambition I returned to school. This was not easy. I was still weak and even with a cane could walk only a short distance. Struggling to fit in, I wanted only to be normal, yet felt so different. Walking, such a simple and effortless task for others, was nearly impossible for me. I felt my disability would forever mark me as an outsider. It was the first thing others saw. And once seen, many wanted to look no further. Nearly all students were nice to me and offered to carry my books and help me in other ways, yet I never felt like an equal. They did for me rather than with me. Even when I did not need help, they helped me. Although I was slowly becoming more self-accepting, the way most students treated me made me think that I was perceived as damaged goods. This reinforced old prejudices and made me wonder if I were, in fact, of less value because of my disability. Nonetheless, I attended my classes and did my best to appear optimistic.

Another of my plans was to date and eventually marry. Yet my ego was fragile; I had not yet been able to create a new identity for myself that reflected my current circumstances. I wanted to regain my previous physical abilities and believed that having to use a cane made me only half a man. Additionally, prior to the accident I had never seriously considered dating someone with a physical disability. Therefore, I wondered if most others felt the same way. Still, after about a year of contemplating the risk of asking someone out, I took the chance. Some of the women I met would be friendly but unwilling to date me, I assumed because of my disability. Others were condescending and unwilling even to be friendly. Yet there were a few who could see beyond my disability and judge me by what was on the inside. It took time and the risk of putting my ego on the line to find out which was which. I took the risk and casually dated a few of my female friends, ever wondering if I could be attractive to someone of the opposite sex.

In time, three years after my accident, I received my undergraduate degree and began attending a graduate school of social work in my home state. I was getting stronger and more confident, yet my newly formed identity was still fragile. During the first day of school, the Dean of our program stated that by the end of our course work she wanted us to have "no sacred cows." Her comment was unsettling. I had worked hard to put the pieces of my life back together, especially some of my new beliefs about god and religion. I feared that if these beliefs were challenged and torn from me, I would lose my entire identity. Nonetheless, I wanted to be a good social worker and decided to verbalize at least some of my beliefs. Many of them were challenged, and some of the challenges seemed valid. I did my best to listen to reasonable arguments that conflicted with my beliefs. Still, it was difficult because I had never had so many beliefs challenged before. Yet I continued to listen. Over time I found myself modifying several beliefs. In doing so I did not lose my identity as I had feared; rather I found myself thinking and acting more like the social worker I wanted to become.

Because of having to use a cane, my professors and fellow students were aware of my disability. I rarely talked about being disabled or the challenges of disability. It was a part of my identity that I was still trying to shun. When asked about it I would briefly tell my classmates or professors what physical problems I had, and then quickly change the subject. I remember one class where the professor asked all minority students to raise their hands. I obliged by raising my hand. Later a classmate asked me why I'd raised my hand. I told him I was a minority student because I was disabled. He stated, "Yes, but you don't act disabled." I wondered what he meant by his statement and began pondering how he thought those with disabilities were supposed to act. While contemplating this I became upset, thinking that such a statement stereotyped those with disabilities and discounted their other attributes.

His statement reminded me of numerous times when I felt that others had been unable to see beyond my cane and judged me solely by my disability. For example, I remember picking up a woman I had met at school for a date. Her father answered the door cordially and smiled at me. Yet as soon as he saw my cane his expression changed to what I perceived-to-be-disgust. Nothing was verbalized, but the rapid change in his demeanor and attitude indicated to me that I had no right to be going out with his daughter, who had no obvious physical flaws. Another time I remember getting my lunch at the cafeteria at school. As I was carting my tray to the cashier, I accidentally dropped my lunch on the floor. The ladies behind the counter sweetly told me to take a seat so that they could bring me my lunch. I felt completely useless, but I obliged. Days later I returned to the same cafeteria and the ladies again told me in the sweetest voices possible to take a seat so that they could bring me my lunch. I wanted to scream that I could pick up my own damn lunch but acquiesced to their desires. Afterwards I never again went to that cafeteria. Judgment by others was almost always subtle, but I would notice actions and expressions that indicated to me that my physical flaws eclipsed all of my other attributes. Perceiving that I was being judged by my disability was always painful and made me want to run away and hide from the world. It also reinforced the idea that I was truly damaged goods.

Despite the fear of being unfairly judged by others, I found most of my classmates and professors in the social work program to be supportive and helpful without being condescending. Besides attending class, I was required to complete an internship. Obtaining a clinical internship, I was assigned a small caseload of clients. I was also allowed to sit in with other counselors as they conducted their sessions. I learned much by listening to and observing the other counselors. Following one of the sessions, I talked with the counselor and asked his advice about being a good therapist. He responded that clients were individuals first and only secondarily did they have problems or a diagnosis. His advice rang true. It slowly dawned on me that labeling my clients by a diagnosis and then treating them primarily by that diagnosis was limiting to their other attributes. The clinical diagnosis, similar to my disability, was only one aspect of who they were. This advice has stuck with me and I have tried to value the many and varied attributes that my clients and others possess.

Over time and after working with a variety of clients, I began to notice that I was most comfortable and seemed to operate best with individuals who were suffering with depression. I knew what it was like to be depressed and felt that my personal experience allowed me to better empathize with my clients. Moreover, I was still suffering with chronic physical pain in my hip and pelvis and perceived that depression, although not primarily physical, was the equivalent of chronic emotional pain. Although physical and emotional pains are distinct, I believe they share many commonalities. Therefore, I perceived that learning to cope with my own pain was purposeful because it allowed me to better serve my clients who were struggling with the pain of depression. As school progressed and I learned more about the ethics and values of social workers, I felt assured that I had made the right choice of professions. I was performing well in my classes and enjoying what I was learning and doing. I had a few close friends and got along well with most of my professors and classmates. Yet despite my progress, I was still hesitant ever to talk about my own disability.

Following graduation, I sought a job in a clinical setting where I could work primarily with individuals who were depressed. After much searching and many interviews, I was able to obtain the type of employment I wanted. I still had much to learn and frequently believed that I was learning more from my clients than they were from me. Although I rarely said anything about my own disability, many of my clients seemed to perceive that it was an asset rather than a liability to my counseling. They often conveyed their perceptions in subtle ways. Most would relax quickly and indicate through a smile or a nod that they felt safe and were ready to tell their stories. Several of my colleagues indicated that their clients were frequently resistant to input, whereas my clients more often seemed open to the input I provided. This difference I credited to my disability. It appeared to make me less imposing as a person, and therefore less of a threat. My clients were less prone to view me as someone who could provide them with all of the answers to their problems and were more willing to work collaboratively with me in seeking solutions. As we worked together, they seemed also to discern that the physical challenges I faced were not easy, and, therefore, I was better able to understand their challenges and their pain. I enjoyed counseling but found that it was often emotionally draining.

To replenish my resources I tried to maintain a variety of friendships and to stay as active as possible. And although it may have been more of a drain than replenishment, I continued dating a variety of women, ever searching for the right match. Nine years after my accident, I met and, after dating for a time, married my wife, Christy. She was my best friend and could see past my numerous imperfections. Her love seemed unconditional. Nonetheless, I secretly wondered if she was somehow ashamed of my disability. During our first year of marriage I asked her what it was like to be married to someone who was disabled. She answered that she did not see me as disabled, that disability was not a relevant issue in our marriage. There were areas that needed improvement, she noted, but the way I walked was not one of them. Christy was sincere, and her comments lifted a burden off my shoulders. I felt, perhaps for the first time since the accident, that I was all right just the way I was—disability and all. I could let down my guard and no longer needed to worry about her rejection or to try to compensate for what I couldn't do. Christy's love and vision of me helped reduce some of my own long-held prejudices and to gradually become more self-accepting. Moreover, as I became more self-accepting, I found myself being less judgmental of others and more willing to listen to their stories and experiences without stereotyping.

Currently, nearly 17 years after my accident, I teach full time in the social work department at a university. I have the opportunity to address disability issues as well as issues associated with other minority populations. I still remember, and try to teach by example and through discussion, that whatever our minority or majority status, we are individuals first with unique abilities and talents. By taking the time to listen to our clients and others, without value judgments or stereotypes, we begin to get a glimpse of who they really are. To better explain this concept I often share a quote that I once heard at a conference: "Out beyond our beliefs of right and wrong (and beyond stereotypes) there is a field; I'll meet you there." This quote, in my mind, represents the cornerstone of good social work. It is the ability to unconditionally be with and listen to our clients.

In addressing minority populations, including those with disabilities, I emphasize the "strengths" perspective and believe that it better serves those of minority status than does the traditional medical model. By focusing on abilities rather than on the inabilityies of our clients, we empower them to discover and enhance the many and varied strengths already within them. This focus builds confidence. More important, I believe it allows those with disabilities to discover further the many strengths and abilities that they've already learned while living with a disability. Furthermore, searching for internal strengths frequently has the benefit of helping clients to observe that living with a disability, although often challenging, offers various silver linings that can be discovered.

I also explain that our society has traditionally discriminated against those of minority status and done a poor job of integrating them into the mainstream of our culture. Nonetheless, I note that the Americans with Disabilities Act (ADA) has removed many of the external barriers which prevented persons with disabilities from entering the labor market, allowing many to obtain employment. Yet numerous barriers, especially covert barriers, continue to exist. For example, despite a greater number of persons with disabilities entering the labor market, only rarely have I observed their promotion beyond the entry level. To promote further integration, I stress that a variety of micro-level and macro-level changes are still needed. For example, future federal and state policies should reduce duplication of disability services and centralize the service delivery system. But of more importance is the need for an increase in the interaction between those with and those without obvious disabilities. If communities, neighborhoods, and local organizations will encourage and sponsor activities, which promote the interaction on an equal basis between these groups, then, I believe, that as interactions increase, those without disabilities will more easily observe that a disability is only a small part of who a person is. And as those with disabilities are viewed primarily as individuals with unique talents and experiences, then covert discrimination will lessen significantly.

However, I note that most individuals who have had limited opportunities to interact with members of the disabled population feel uncomfortable and fear they will act wrongly when interacting with individuals with disabilities. Despite this fear, I point out that once those with and without disabilities interact on an equal basis, they become more comfortable with each other and gradually figure out mutual interests. Furthermore, they are usually able to discern which topics are and are not appropriate. Some individuals with disabilities are never comfortable discussing their disabilities whereas others are more comfortable. There is no set way to interact. Still, I encourage my students and others to seek out opportunities to interact with members of the disabled population and, while interacting, to focus primarily on personality and interests rather than on the disability.

In addition to teaching, I continue my personal journey toward unconditional self-acceptance. Although being disabled is only one aspect of my identity, it is an important part of who I am. Not too long ago I entered a convenience store and noticed a middle-aged man who was also walking with a cane. He looked at me, grinning, and said, "Hello brother of the cane." His statement made me smile. I knew we shared something that those without a cane or other disability could not fully appreciate. This experience, among others, has helped me to reframe the meaning of having to use a cane. It represents some of my battle wounds and the struggles that I've chosen to endure. It is a badge of honor rather than something to be ashamed of. The poem, "A Question of Energy," expresses my current thoughts on disability well:

> I'm not diminished by
> this loss of limb, I'm
> more than the sum of my
> parts, to deny my scars is
> to deny my power the
> core of heat in each cell.
> I've got wires humming
> juice surging detours on
> the path it takes less time
> now less resistance to
> complete the circuit.
> I'm well grounded you
> can touch me without a
> shock
> (Baird & Workman, 1986,
> p. 108)

Despite its importance, being disabled is still only one aspect of who I am. Multiple dimensions make up my being, and to judge others or myself by one or a few of these dimensions is limiting and inaccurate. As I've struggled to make meaningful sense out of my disability, I've discovered and continue to discover several silver linings. Primarily, I've been forced to try a variety of activities that challenge various aspects of me, rather than just a few physical sports. This variety has brought me a greater sense of emotional balance. It has also allowed me to become less concerned about winning and better able to enjoy the journey.

To date the most difficult part of my journey was the first years after my accident. My injuries initially shattered my identity. Beliefs about who I was and what I could do were no longer valid. I needed new beliefs that accurately reflected my circumstances. Struggling over months and years to redefine myself, I slowly put the pieces of my life back together and recreated my identity. Refitting the pieces of my life allowed me to put them back together in new and often better ways. For example, prior to my injuries I based my worth primarily on my physical prowess. Yet when many of my physical abilities were taken from me, I arduously learned that my true worth was based on the person I had become on the inside and the unique experiences I had. This paradigm shift has brought me a greater feeling of peace. It has allowed me to detach from many masculine stereotypes and given me the freedom to express myself in both masculine and feminine ways.

Learning to integrate my disability has also helped me as a parent. Since I am less influenced by masculine stereotypes, I am more willing to allow my children to pursue the interests they want rather than merely to push them into traditional roles. I am better able to value and love them for their unique personalities and abilities rather than solely by their accomplishments. My marriage, I believe, has also benefited. I have been more willing to detach from traditional roles so that my wife and I can experiment with a variety of ways of running our household. This detachment has allowed us to choose freely and negotiate the roles and responsibilities for which we are accountable.

Finally, my disability has offered me the choice of learning and growing or of resigning from the challenge and giving up. I have not always made the right choice, but lately I've more often made the choice to learn. This has allowed me to see disability not as the enemy but as a stern teacher with important lessons to be learned. It has helped me to gradually discover what I can do within the limitations of my disability. And ultimately, it has helped me realize that I can choose to see the cup of my life as "half full" rather than "half empty." My journey is still far from complete, but I am moving forward.

□

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Your Body Tells Me Stories: Living Pain, Flirting Madness, Transforming Care

Maureen, a body worker, and Tom, a person with chronic pain—life partners and academics—offer a narrative description and interpretation of their respective experiences. Together, in a "braided narrative" format, they examine how a person's relationship with chronic pain can either reproduce or transgress the social codes of an ableist culture and how an embodied practice of care can transform their relation with the particular "body we live."

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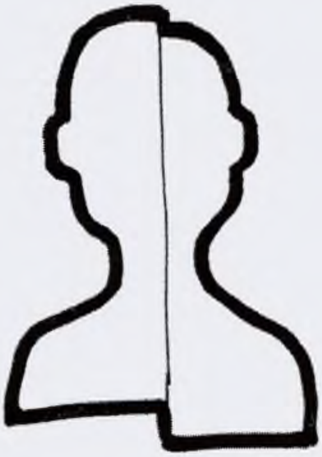

Introduction

In this narrative, by engaging and critiquing the invisible codes of the body in pain and presenting our ongoing dialogue with each other, we hope to challenge readers to enter the discussion of how we engage the insidious presumptions of a disembodied status quo.[1] This introductory section will introduce us; describe our respective locations relative to chronic pain; and present the issues and nagging questions that structure our response to living pain, flirting madness, and transforming care.

Maureen

I am a certified chronic pain therapist trained in an "alternative" (i.e., non medical) model of health care and have worked with pain clients for the past five and a half years. I blend my work as a pain therapist with my academic interests, teaching, and scholarship, and I have been working with Tom, who is in his late forties, for more than three and a half years. He has lived for the past 11 years with the adult onset disability of Myalgic Encephalomyelitis, or ME (also known as Chronic Fatigue Immune Dysfunction Syndrome or CFIDS, and Chronic Fatigue Syndrome or CFS).[2] He also lives with Meniere's Syndrome (an inner ear disorder), Chronic Sinusitis, and Obstructive Sleep Apnea, in addition to a variety of structural/skeletal issues which together contribute to intractable joint and muscle pain—one short femur, a mild scoliosis, Degenerative Disc Disease (L3/L4, L4/L5), and Osteoporosis Penne. Tom's diagnosis of ME was protracted for several months because the presentation of symptoms and characteristics did not typically "add up" to a single discrete pathology; neither did it respond to conventional medical intervention. In most cases, ME will not allow the body to return to some "fixed" pre-trauma state, nor to as "remediated" a state (Greenwood & Nunn, 1992, Craig, 1998; Toombs, 1995). ME continues to present in episodic, fluctuating bouts of pain, nausea, dizziness, weakness, neurological and cognitive confusion, environmental sensitivities, sensory overloads, and disordered sleep (among other symptoms). Persons living with this kind of intractable bodily betrayal are sooner or later challenged either to repress or to accept the unacceptable, that is, to reconcile themselves with the great mystery of their bizarre new existence—that, in most cases, will not be "cured" and to embrace the ongoing consequences that a wildly out of control body may bring.[3]

Tom

As others with ME, I live with a sleep disorder (among other bizarre symptoms) that has been described in a constant, unbearable state between being not fully awake nor fully asleep at the same time![4] As if relegated to living the terrifying cultural nightmare of non-productivity, people with ME often cannot "do" very much in the waxing and waning, sleeping and waking actualities of our existence. Yet, though the neuromuscular field of our lives has become overwhelmingly constrained in once unthinkable ways, understanding the fluctuating character of our disability is not simply an administrative problem of how to handle the "malingerer" or "complainer" who refuses to "get well."[5] No, unfortunately, the nature of our disease runs much deeper than a prickly case of patient "non-compliance." We represent, rather, disturbingly concrete exemplars of the failure of contemporary Western medicine (and the severely able-bodied ideal of Western culture in general) to face the abject horror of the wild, uncontrollable, heterogeneous side of being (Kristeva, 1995, 1984; Merleau-Ponty, 1968).

Maureen

After an agonizing first year of numerous prescription drugs that seemed to have few positive consequences and a barrage of predictable "side effects" (increased dizziness, nausea, steroid "rage," etc.), Tom gradually shifted to herbal medications, finding conventional medications to be too extreme for his highly sensitized system. He presently receives chiropractic and chronic pain therapy and is also consulting with a neurologist and a new family physician about his skeletal, structural, and chronic sinusitis issues. His family physician is able to prescribe more conventional medications for his allergies and upper respiratory infections which sometimes are not managed by the herbal medications; however, he must then deal with the heightening of responses which invariably accompanies his use of standard prescription medications. Tom's appointments with his neurologist occur once every two to three months, and usually last between 30 and 40 minutes. He sees a chiropractor once every week and a half. His original consultations (during an acute state of low back and hip pain) were 30 to 40 minutes, three times a week for six weeks. His weekly appointments initially lasted from 15 to 30 minutes but now are typically 15 minutes or less, except during bouts of acute pain or discomfort. This particular chiropractor uses spinal manipulation, trigger points, massage, touch assessment, and passive stretching. He also advocates regular exercise.

Since Tom and I are life partners, I as a chronic pain therapist am able to work with him almost daily. Our pain therapy sessions last between thirty and forty minutes and include light touch assessment of muscle tension and energy blocks, myofascial release, light and firm muscle re-patterning and pressure, and energy work.

With his treatments, Tom has manageable pain, is able to work part time, and participates in regular and even intense exercise. However, he constantly wrestles with the cultural irony of looking "healthy" while not being able to meet the productivist demands for full-time employment and financial independence. He continues to need ongoing care, modifications in his activities of daily living, and rest times during the day. Tom is also aware that his recalcitrant condition often is perceived as an affront to most practitioners (both conventional and alternative) who have committed themselves to the feel of success (Wendell, 1996; Toombs, 1995) in the face of their clients' discomfort.

Curiously, the notion of pain management (rather than cure) is still a radical notion within what Julia Kristeva (1984, 1995) calls a productivist teleology and what Wendell (1996, p.9) refers to as "the myth of control of commercial-media-soaked societies of North America." Wendell goes on to say that the idealization and objectification of the body create demands that persons control and attempt to perfect their bodies. She writes that "refusal to come to terms with the full reality of bodily life, including those aspects of it that are rejected culturally, leads people to embrace the myth of control whose essence is the belief that it is possible, by means of human actions, to have the bodies they want and to avoid illness, disability, and death" (1996, p.9). While presenting exceptional challenges in daily living, Tom's experience with disability and chronic pain over the last eleven years also has proven to be a remarkably fertile ground for ongoing scholarship based in narrative and ideology critique.

As a practicing body worker and body educator, I have come to believe that the denial of the irrational, bio-physiological (Kristeva, 1984) parts of the body-self will eventually lead to illness or chronic pain, or worsen them. Furthermore, I have seen how grappling with despair and feeling pain can lead to transformative lived relation with the body that is. My work with clients is invaluable in my research and teaching, and working with Tom has been the major inspiration for my contribution to this paper.

Living Pain, Flirting Madness, Transforming Care

Tom and Maureen

We believe that challenging the dominant discourse of disembodied "health" begins with a commitment to finding expression and giving voice to pain. Furthermore, embodied practices of care which acknowledge the textured character of pain also must provide a viable context for authentic expression while challenging normative discourse and oppressive bodily codes. Encountering chronic pain or illness face to face creates a paradoxical situation. If people are always sick or in pain, sooner or later they are challenged to confront the failed cultural ideal of a stable, healthy, and productive body they no longer can take for granted. The simplest way to avoid facing the profound failure of this paradoxical ideal is to deny the reality or permanency of one's own chronic condition. That is, though a person may be chronically ill, he or she can ignore or repress the daily signs of illness and continue to hold out for someone, somewhere, who can provide a cure. Denial is the easiest, most attractive, and most natural response to facing the overwhelming breakdown of the body.[6] It allows persons to continue to think that they have rational control of their life and to avoid the terrifying issue posed by the embodied contradiction they must now live: the horrifying awareness that they might have to continue to live with illness for the rest of their life, that there may be no cure, and that, however offensive, chronic illness now defines a large part of who they are.

In many cases, honoring the actual body we live in is the greatest risk for persons negotiating chronic pain because it may mean that, by virtue of their departure from "normal," they forfeit the rights and privileges that accompany membership in a productive community, i.e., they pose a nagging challenge to the normal pattern of lived relation with others.

Tom

When we no longer can take our actual body for granted, we are forced into a new way of being in the world that conflicts with normal, impersonal perceptions of how the body should continue to be both invisible and silent. By learning not to speak about the life-altering rupture and chaos of a radically disabling condition, I found myself giving in to the curious cultural expectation of keeping my ailing body absent and invisible by refusing to allow any transgressive experience to come to expression. As I discovered after years of repressing my own sense of chronic pain and disability, surrender to such impersonal cultural expectations led to progressive shrinking of my own space of experience, to internalized oppression of the actual body I live, and to an insidious kind of madness that comes from trying to force a non-conventional (un-stable, un-healthy, non-productive, i.e., "abnormal") body into a stable/ healthy/productive life-script.

Chronic pain/immune dysfunction disability does not work toward that kind of recovery. It does not comply with any body's demands for transition back to the cultural ideal of "normal" life. My own experience of fluctuating bodily rhythms and demands constantly subverts the invisible repressions of such culturally acceptable expectations of what counts as proper and productive comportment.

Often I have wondered about the strange silences which my unhealthy reflections have evoked in the last few years. Many times I have been puzzled and disappointed by the sudden appearance of awkward distance by those to whom I had felt close enough to share my "secret" life of chronic illness. In other more sanguine times, I could (barely) imagine the unexpected contamination of social space I must have unleashed, somehow subverting the unspoken boundaries between health and illness.

Maureen and Tom

We have found that the consequences of lived relation are often overlooked in discussions of the embodied significance of chronic illness and pain. Too often, however, the relational risk of expressing the unbearable weight of human suffering takes its toll in the breakdown of what little support may be already in place.

Tom

Shortly after experiencing the first few months of the bizarre neurological and muscular symptoms of my chronic pain disability, I recall a particular walk in front of the large, quaint, dusty old house my former wife had worked so hard to find, negotiate, and buy in the first agonizing year of my illness in 1987. I had been sick through the entire process and remember the multiple trips with our two toddlers and realtors, detailed questioning by bankers and then, ultimately, the long hours of packing and moving boxes, and the months of unpacking one at a time in our new place of residence. One sunny day, taking a short break from our two boys (ages three and a half, and two), my wife and I walked slowly up the cracked sidewalk outside our house and talked about issues of devastating illness and changes in our marriage. Then, in an unbearably intimate moment that I will never forget, she reluctantly confessed to me, "I never thought I would be a single parent." Through the next seven years of our marriage, I was reminded again and again that my own symbolic death had become the prominent theme of our relationship. Ironically, I was not physically "dying" any more than D. was (although I sometimes think that a diagnosis of "terminal" rather than "chronic" illness might have been easier). No, on that day and beyond—for at least one of us—I ceased to be a legitimate and equal partner. I could not hold up my end of the unwritten marriage contract of perceived exchange of equal goods and services. I abdicated once mutually shared household and parenting responsibilities. I became, in sum, dead weight.

In the last months of our marriage and especially after moving out of the house, I could look back and recall a disturbing pattern of unbearable disregard and repression of the illness that had so disrupted our lives. I remember the concerned conversation on the front porch and the encouragement that I consider the power of "psychosomatic" disorders. I think back to the day I reluctantly shared an abbreviated version of my first attempt to write about the experience of my own life-shattering illness and can still feel and hear the startling response, "No one can say you don't write well." Nor can I forget my frustrating attempts over the years to garner family support to keep our dogs and cats out of the house to help alleviate the severe allergies and chronic sinusitis I had developed.

One evening, not too long before the physical dissolution of the marriage, I remember standing in the kitchen after dinner and feeling a sharp, intense surge of pain at the top of my right hip and blurting out an involuntary yelp. D. was there washing dishes and stated with apparently humorous intent, "I hope that wasn't a commentary on dinner." While I had expressed pain in that way before at various times over the years, that night I felt particularly alone.

As I write now from the

unexpectedly political and subversive location of my body, I remember the days of overwhelming tension in my neck, back and hips; of the pain firing in syncopated rhythms through my connective tissue; and of the deep, unbelievably knotted muscles restricting my movements, the constraints on my thoughts, and the radical altering of my daily activities intensified by the threatening (and so damn corrosive!) cultural taboos against giving voice to such "negative" and "abnormal" body disclosure.

Curiously, my body has become a postmodern, thematic, deconstructing of the cultural ideal of disembodied minds and unperceived bodies, in short, "normal subjects" in capital-producing contexts. Paradoxically, as human beings who necessarily interact with each other in intercorporeal ways, we must return continually to the actual—but sometimes unbearable—bodies we live and face the humbling realities of wild being.[7] We must challenge the stable/healthy/productive body of contemporary consumer culture as an insidiously sedimented ideal whose unjustifiable certitude and impartial claims no longer can be tolerated.

Maureen

I do not offer my practices nor those of other somatically trained practitioners as superior or more genuinely or inherently caring. I do suggest, however, that the modalities of touch and the sensitized practice of touch have been under-explored by conventional medical practice, and that the kinds of knowledge and insight available through these modalities could have far-reaching consequences for people seeking dignified, body-honoring treatment and for health care workers committed to providing this kind of treatment.

Tom's illness and pain are highly resistant to conventional treatment, and his ongoing struggle with a chronic illness that works across several bodily systems (and the new way of being in the world that it demands) have had both personally empowering and relationally devastating effects.

As a practitioner, I use light pressure and deep pressure massage, therapeutic touch, assisted stretching, gentle manipulation, movement patterning, tension-release techniques, and energy work. Initially, there was so much congestion in Tom's muscles that I could not feel his bones, nor distinguish one muscle group from another. My hands met a wall of protective tension and firmness developed out of years of attempting to contain physical and emotional anguish. The joints and muscles were locked into tight range-of-motion patterns, taking up as little space of motion as possible. Here was a person for whom even the everyday acts of breathing, weight bearing, weight transfer, and motion could carry intense pain. Conversely, there were fluctuations in the illness when he could participate proficiently in the high-level athletic demands of activities of tournament-level tennis.

I have become acquainted with Tom's body—his joints, muscles, gestures, patterns, breathing, energy. I can tell the difference between his "old pain" (pain that has been stored from long before the onset of his disability and which has deepened during his disability) and his present pain; I can feel the muscle knots and the connective tissue textures; I can feel scar tissue, inflammation, the unpredictable traveling of pain impulses from one site of the body to another, the quivering and trembling of tissue as it feels pain or moves into relief. I can feel muscle relaxation; I can feel everyday soreness. I can feel the thick, distinctive, saturating presence of ME. I have worked with Tom as he has experienced loss of mobility, myoclonic vibration, and myofascial release. Together we have experienced his body stories and inextricably embodied insights. Some he tells me with his voice, some I feel in his tissues. I am not his psychotherapist; rather, I know his body and what it has experienced. It is knowledge forged by trust and prolonged engagement over time. We do not work on curing or healing; we work on acknowledging and caring for the body that is today, now, and all that body brings. It is this unconditional respect and regard that makes these touch modalities so powerful. Kristeva (1995) claims that love is what ought to inform psychoanalytic practice. I am inclined to agree, and in my practice I work at embodying love in such a way that every touch is a caring touch. I bring all my focus, energy, knowledge, imagination, and attunement to this moment of touching, and I make myself available for what it offers.

Recently, during a bodywork session, Tom asked me how I knew he was not "making it up," i.e., how I knew his pain was real. Aside from my own lived experience of feeling the textures of his pain with my hands, I believe him. It is inconceivable for me not to believe him. I believe his pain exists and I believe it is my responsibility to honor it.[8]

I will describe several experiences which are "typical" of Tom's treatment sessions ("typical" in the sense that they are aspects of Tom's pain profile though the profound heterogeneity of Tom's pain defies generalizing or predicting). The interaction Tom and I had about whether his pain is "real" is a good starting point. As a practitioner, I have to ask myself, "how is it possible that this question can be asked at all?" or "what experiences with treatment has Tom had so that this question is a possible one for him to ask?" I also must acknowledge that ongoing responses to Tom's expressions of pain have planted a seed of doubt in his experience about the validity of his own pain. My training and practice have taught me that no matter what the source, the pain exists. As I work with pain clients, I begin with the reality of their pain and we work on developing a profile of, and relation with, their pain. In this way, we are able to explore its physical, emotional, and spiritual character.

Tom's earlier narrative reflection of living in a relationship as "dead weight" tragically illustrates particular relational consequences of living with chronic pain and disability which do not add up to a discrete, measurable pathology. When I work with Tom, I have to take into account the decade of disregard he has experienced and realize that talking about what he feels and what he needs is not a habit for him—indeed, he has been "trained" to be silent and pathetically grateful for what little care he has been able to acquire. As the pain therapist, then, I must initiate the questioning; I must provide openings and opportunities for him to ask questions and make requests, and I must respond verbally, gesturally, posturally, and in tactile ways which demonstrate that his questions and requests are welcome, necessary, "normal," i.e., I want his questions and requests to be an ongoing component of our bodywork sessions together.

Another example which illustrates connection to bodily rhythms is a recurring experience which I call "following the fish." At one of our bodywork sessions, I was working on Tom's upper arm and elbow joint—at his request. He was experiencing simultaneous pain sensations in that area—sharp jolts of pain, underlying throbbing, tremor and vibration, and reflex flicking of the hand. I was using deep pressure, soft pressure, smoothing, and myofascial release techniques in an alternating, repetitive sequence in order to keep up the skin-level and under-the-skin sensations and patterns, and in order to bring some level of relief. Tom was somewhat distressed by the heterogeneity and fluctuating intensities of the pain, but was his usual engaged and calm self. At my request, Tom was describing the shape, temperature, depth, mobility, and other features of the pain sensations he was experiencing. I am able to discern the different kinds of pain by virtue of their presentation—for example, throbbing pain actually does "throb" or pulse with a regular rhythm; spasm feels completely different, like a piece of rope, rubber, or plastic pulled taut; tremor feels like something wiggling or quivering beneath the skin ... or a fish swimming beneath my hands. We had brought the sharp pain to a manageable level with the deep pressure, and the throbbing had subsided to a dull ache. However, the tremor unexplainably began "moving" from the upper arm down into the lower arm, then back up into the shoulder, then the upper back, then suddenly, the other arm. I am "following the fish," staying with the tremor wherever it goes, and following Tom's directional cues when the tremor eludes me. We "followed the fish" for 20 minutes until we were able to achieve a stable location and stillness. At no time did I feel that this was an affront to my abilities or a challenge to be "overcome." Rather, it was how Tom's pain was presenting, and we were working together on a relief strategy. Had the movement not subsided, we would have explored other options, such as letting the fish "swim" and shifting our focus to breathing or energy while the tremor had its time and voice.

Sometimes pain is like that—it wants its time and voice—and we have to work on relief and dignity within the context of the presence of pain. In our discussion of this event, Tom revealed that he had been reluctant to say that the pain was moving and was actually surprised that I was able to follow it. His reluctance is grounded in his experiences of being dismissed; tremor is not supposed to behave this way, so saying what is happening makes the client seem unbelievable, naive, and unattuned to more "objective" observation. Even though I know that the pattern of Tom's pain is not the usual presentation of tremor, I go with what is, his pain is presenting, now—regardless of whether it is consistent with conventional descriptions of bio-physiological processes.

Finally, in a recent conversation I mentioned to Tom that I would be using our "following the fish" experience as an example of being attuned to bodily rhythms and overturning authoritative discourse of how pain is "supposed to happen." Tom's comment was that as remarkable as attunement to bodily rhythms and pain textures is, what remains most remarkable to him is the freedom to speak, to say that the pain has moved, and to feel secure in his sanity, his dignity, his own relationship with his pain and his body.

In my own training and sensibility, the person living with pain is the authority; the pain therapist is charged with creating an environment within which the client and therapist can develop a relationship with, understanding of, and respect for pain and the body in pain. Pain management allows us to work with pain in the textured context of lived relation, while at the same time honoring the complexities of ongoing bodily contingency.

Tom

Facing the phenomenal body of disability can be overwhelming—especially when it is one's own. Most of us have been so thoroughly trained to leave our body behind (by repressing any sense of deficiency or inadequacy)[9] that we simply accept the stable/healthy/productive body code regardless of its detrimental consequences to actual, personal experience. Such remarkable negation of bodily dysfunction, however, need not always take the leading role in our lives. My own experience with an aching, unpredictably functioning body, for example, leads me to believe that the overwhelming cultural refusal to embrace anything but a stable/healthy/productive ideal of living may itself be refuted and dismissed as both naive and dehumanizing. When I am tempted to commonplace thoughts of transcendence above the fray of the fluctuating rhythms of disability that I live, I can never breathe in that disembodied fantasy of "rare air" for long.[10] I am soon forced back down to the carnal, practical bedrock of daily activities, to face the once invisible challenges of walking and driving, of moving in and out of upright posture, of avoiding the piercing invasion of chemicals and nocuous perfumes, cigarette smoke and bright lights, and of negotiating the relentless onslaught of pain migrating systemically through all of my joints and connective tissue. While I often have been discouraged by the stubborn linear demands of productivity which conflict with the fluctuating rhythms of my own lived body, I am reminded that though "the abyss of uncertainty" is perhaps more visible in chronic pain disability, it is "...not necessarily broader or more dangerous" (Mairs, 1989, p.236) than that foreboding object of repression that everybody always/already lives.

Embracing the open sphere of the lived experience of bodily transgression can help to lead us to new places of self-reflection and transformation. While those of us who live within the open spaces of chronic pain disability continually breach the cultural presumptions of stable bodies and productive scripts, we offer a distinctive ontological clue to the concrete essence of wild being,[11] different bodily rhythms, practical rationalities, and the very possibility of existential freedom that breaks through the well-worn repressions of a disembodied status quo.

In a fragmented age of increasing medicalization and dismissal of the living body, we can no longer afford the flight from our own bodily existence nor can we afford the indulgent luxury of refusing to move to radical self-reflection on what it means to live with others in the world whose non-conventional bodies are different from our own. We can no longer allow ourselves to flirt with madness by living within the paradoxical rhetoric of a culture that refuses our actual bodies. Isn't it time we found some place together where we can learn to accept all the neuromuscular variations of human experience and embrace them as our own?

Closing Thoughts

Maureen and Tom

Unconditional respect and regard for the actual bodies we live make touch modalities powerful. The distinctive tactile presentations of pain—all the kinds of soreness, tension, vibration, texture, density, shape, direction we have described—are not accessible to Maureen because she is a particularly gifted body worker. They are available to her because they are there, manifesting themselves in the body. They can be felt, and their distinctive features can be learned. The different modalities of touch promote therapeutic resonances across the boundary of the skin and enable both authentic expression and perception of pain through a nonlinguistic code.

Such a focus on working authentically out of our bodies also compels questions about how medicine and other institutions of production—the health care industry, the workplace, the "academy" disregard and dismiss non-conventional/non-"productive" subjects as failures in a culture of normally absent and distant bodies.

Despite the best of intentions, might not medical, capitalistic, and even scholarly projects which address different bodies be seen as evidence of a residual colonizing mentality? The unreflective "use" of one way of being in the world to understand another (more privileged) way of being in the world demonstrates how pervasive—and seemingly innocent—colonizing practices can be. How will we respond to the largely unexamined presumptions and accompanying privileges of persons with so-called "able"(that is, productive) bodies within the implicit hierarchies that govern our lives? Instead, what would happen if we posited a continuum of inclusion that honors the absolute uniqueness of one's own body which can be known by no other way than by living it as one's own?

We no longer can allow ourselves the privilege of pretending that the "normal" codes of production, invisibility, repression, and dismissal accurately account for the tremendous spectrum of differing bodies. Those of us who know what it means to live with syncopated rhythms of pain across severely able-bodied cultural codes (which function to keep difference at bay) have learned many of the lessons that the rupture of a stable, healthy, productive ideal can teach. What would it take for others to understand and incorporate these lessons into their own habitual ways of being in the world?

We can begin to unravel the dismissive problematic of our own detached perceptions of chronic pain and disability by asking what radical new directions human practices of caring might take if we refused to accept the "natural" attitude of our "normal" conventions as the ground of our practice and interpretation of treating others. Choosing to engage in self-reflexive embodied practice means taking seriously the body we live (the body that is, here and now, at this moment) in our institutional and interpersonal lives. These choices are risky. Contingent bodies pose threats to powerful agendas and authoritative discourses, but if health care and institutional conduct are to be examined and re-imagined, we must begin to ground our expression and perception of care in honoring the actual bodies we live.

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[1] Tom has addressed more of the academic (phenomenological, semiotic, and communicological) issues of living with disability in his, "Disrupting the Disembodied Status Quo" (Craig 1997).

[2] In order to preserve the ambiguity and profound political consequences of the naming of this disease, we mention all three of its competing designations. The name, "Myalgic Encephalomyelitis" (ME) is the dominant Canadian designation, which emphasizes both the distinctive muscular and neurological symptoms of the disease. "Chronic Fatigue and Immune Dysfunction Syndrome"

(CFIDS) is the preferred designation by the leading advocacy group and many others in the U.S., who attempt to define it by its immunological differences from other diseases. "Chronic Fatigue Syndrome" (CFS) is the official U.S. designation chosen by an informal group of physicians selected by the Centers for Disease Control in order to characterize its non-discrete character. This trivializing name defines the disease curiously by its similarities with many psychological and other conditions. For further information on the intriguing political agenda of the CDC and other government organizations in naming this disease, see Holmes, et al (1988) for the original "working case definition" of the "syndrome of unknown cause that has been the subject of interest in both medical and popular literature, particularly since 1985" (p.387) and the curiously delayed follow-up report in Reyes, et al (1997), based on government sponsored "Surveillance for Chronic Fatigue Syndrome—Four U.S. cities, September 1989 through August 1993." The journalist Hillary Johnson (1996) has documented the politically volatile history of CFS/CFIDS/ME in a massive, ten-year project finally published in 1996. See also Williams (1990) for another early journalistic account on the difficulties in tracking and treating this disease.

[3] In the recent anthology, *When Pain Strikes* (Burns, et al 1999), Kecia Larkin characterizes this critical existential choice in an interview with Cathy Busby, one of the editors of the book. Larkin style: "I think a lot about pain. In respect to this disease [AIDS], that's where all this comes from. I had to decide at some point if I was just going to lie down and die spiritually and emotionally and just walk around like a shell, or if I was going to try and change, to try and live. It's a constant, never-ending thing, learning how to live. This disease woke me up in lots of ways" (Burns, et al, 1999, p. 69-70).

[4] Harvey Mudolfsky (1992) has proposed that persons with CFIDS demonstrate an "arousal disturbance within sleep" that causes them to live in a twilight world where they are "never fully asleep or entirely awake."

[5] Unfortunately, such dismissive portrayals of persons with ME have been typical since it was first addressed by the Centers for Disease Control in 1988 (Johnson, 1996).

[6] The psychologically trained phenomenologist, Maurice Merleau-Ponty (1962, pp.80-82), asserts that for "normal subjects" who do not have to think about disruptions in their engagement with the world, the full-scale refusal of any kind of deficiency leads to the ongoing repression of illness or disability whereby persons can replay the myth of a fully functional body as a more "natural" way of being in the world.

[7] Merleau-Ponty, developed the notion of "wild being" later in his career (see Merleau-Ponty, 1962, 1968; Craig, 1997), in part, to offer a contrast with the assumptions of the largely "concordant" world of the mathematically and philosophically trained founder of modern phenomenology, Edmund Husserl (see Husserl, 1962). In my own work (Craig, 1997, 1998) and in our ongoing collaborations together (Craig & Connolly, 1997, Connolly & Craig, 1999), Maureen and I attempt to demonstrate that such able-bodied presumptions of posture, ongoing sensory integration, stability across bodily systems, and production of capital are always complicated by our actual bodies .

[8] Postmodern theorists (Foucault, 1972; Bakhtin, 1981) critique medical science and capitalist modes of production as forms of discourse with great power to sanction how we talk and what we know and believe about the body, self, illness, and pain. These forms of discourse have the colonizing effect of internalized oppression, as well as the larger effects of colonization: invisibility, erasure, denial and tokenism. Bakhtin suggests that discourse may be characterized in terms of the authoritative and the internally persuasive. The authoritative discourses in our lives determine/govern our beliefs and behaviors. In contrast, internally persuasive discourse engages us from within rather than imposes itself from without. Individuals who experience internally persuasive discourses discover awakened consciousness. In my own bodywork practice, I recognize this as connecting with a primordial bodily rhythm, or knowing the shape/texture of a pain experience, or what Levin (1985) calls "a mytho-poetic truth."

[9] Merleau-Ponty (1962, p.81)

writes about "the refusal of deficiency" as a problem with the individual and her or his own body. As we have attempted to demonstrate in our narrative reflections here, we can see that the sense of "deficiency" presented in chronic illness and disability has both profound personal and social consequences. It affects the very fabric of our most intimate encounters.

[10] *Rare Air* is the title of a popular autobiography of the now retired basketball superstar, Michael Jordan, which includes the famous picture of Jordan "flying" in mid-air from the free-throw line on his way to his famous monster dunk. Such cultural icons of athletic prowess represent (in typical mythic hyperbole) the glorified ideal of the incomparable heights that are possible for the severely abled body.

[11] While able-bodied subjects can maneuver through the world with the presumption of being on automatic pilot, it is the person with disabilities who can teach us about the freedom to choose to be authentic subjects in the living present. Unfortunately, those of us who can still pretend to rise above the fray of bodily existence never seem to get this message until we are confronted with our life-altering rupture face to face(see Merleau-Ponty, 1962, pp. 126-128).

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Bridging Personal and Professional Perspectives: A Continous Process

The author introduces her narrative:

I hope that I am getting smarter personally and professionally as a result of adding to my academic preparation in gerontology the experience of aging-related crises within my own family, role modeling by disabled and older colleagues, and lessons learned from the progressive deterioration caused by my own late onset disability. No longer can I expect to accomplish "business as usual" in quite the same way, but in this narrative I describe how I have become a more goal--directed person and professor as a result of these painful experiences.

by
Jeanne E. Bader

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I had hoped my disability could remain invisible. Indeed, I was able to hide obvious symptoms for a decade. Now, at age 56, my disability has advanced to the point of forcing me to "disclose" my situation by using a "handicapped" parking placard, changing to a more accessible office, and using a cane. Eleven years ago, after driving with too few stretch breaks from Oregon to Philadelphia, my joints were aching from osteoarthritis. The following year, I was diagnosed as having Multiple Sclerosis (MS). Multiple Sclerosis is a disease of the central nervous system that results in compromised motor and, at times, cognitive function. While my arthritis is merely annoying and painful--that is, a socially acceptable disease--the MS is a "real disease"--that is, a stigmatized disease--one that I quickly discovered could become visibly apparent at any time. Then, a year ago, I was grazed by a cab that tried to beat a yellow light in the intersection where I was walking. It is not the MS that now compels me to walk with a cane, but rather the mobility impairment resulting from that injury.

For the first decade, I told only a few people about having MS. I was so relieved just to have a diagnosis--any diagnosis. I did not want anyone to feel sorry for me because I have a central nervous system disease or to think "MS" before remembering my name and other characteristics. Professionally, I did not want anyone to expect less of me or to assume that I could not manage the responsibilities of my job. Most of all, I didn't want my mother to add my name to those on her "Worry List."

Now, I manage quite well, thank you, except when I get overheated. The only two commonalities among persons with MS are the high likelihood of optic neuritis (sudden and profound vision loss) and the inevitably debilitating effects of heat. Everyone with MS needs to remain as cool as possible at all times. Each summer when the heat begins, people with MS find out how much ground they have lost during the preceding winter. In my own case, my levels of muscle fatigue increase year round, but become visible determinants of my movement patterns and balance control only after it gets warm indoors or outdoors. It's tough to keep up appearances during the summer months. At times, I stagger and pitch, occasionally even falling, for no particular reason. Summers are scary for me and cause others concern.

Three processes have helped me to bridge my personal and professional perspectives of aging and disability. First, I will relate the cumulative and interacting effects of disability on my professional life; second, the contrast between teaching about the caregiver role and my experiences as a caregiver; and third, my ongoing pursuit of better data and role models.

Adjusting Professional Activities To Accommodate Disability

As an academic program administrator and professor, I teach gerontology and spend a lot of time with older persons. I have lectured for many years about the interacting and cumulative effects of a wide range of sensory changes and chronic conditions. Now that I am experiencing MS and arthritis first hand, I have a clearer concept of sensations resulting from vision impairment, muscle fatigue, pain mixed with numbness, and imbalance. Although I am unable to articulate adequately the subjective sensations that result from these conditions, my efforts to do so are more successful each year. Being increasingly able to describe what it feels like to have muscle fatigue, in particular, is a positive outcome of coping with a negative personal experience. Of course, I was trained to identify and to analyze pertinent journal articles and other academic resources, but now I also can speak from personal experience on those rare occasions when it is appropriate to "disclose." While I find myself better able to conceptualize and describe the complex dynamics of fatigue, pain, numbness, imbalance, and other consequences of various chronic diseases, a related symptom of MS is gradually emerging: Difficulty finding the right word at a particular time. Teaching at night is increasingly difficult, especially when I am hot, tired, or stressed. Fortunately for me, graduate students have welcomed the opportunity to schedule courses on Saturday mornings as well as weekday evenings. One benefit of my changing capabilities was that I had no choice but to give away all my shoes with heels and thereafter limited myself to flat, rubber soled, wide box shoes. How wonderful it was to have an excuse to do just that! To complement my heavy-looking walking shoes, I switched over to slacks with colorful shirts and jewelry more often than dresses or skirted suits. As a result of adapting my wardrobe to fit my needs, I now assume that certain avenues of professional advancement are closed off forever because I no longer can wear high heels with my dresses and skirted suits. I make this assumption because from time to time I overhear criticisms of my relatively informal and, at times, nontraditional attire. Another consequence of having MS is that I have had to adjust my body image and mobility patterns to accommodate my changing abilities, my need for remaining cool, and my growing levels of pain and numbness, especially in my legs and feet.

Shortly after my diagnosis, as a preventive strategy, I started working out faithfully, twice a week. In addition, I signed up for a swimming class offered by the local MS Society. Once there, I was able to observe a wide array of body shapes and movements that characterize persons experiencing more advanced stages of MS. Only recently have I had to begin driving the short distances that I walked with relative ease a couple years ago. Another result of having MS is that during bouts of long-term vision loss in one eye and extreme glare sensitivity in the other, I have to limit my outdoor movements to daylight hours. On one occasion, participating in a professional conference took on humorous aspects. During one of my four bouts to date of optic neuritis, I was forced to try to identify colleagues by their walks rather than by their other physical features or by the sound of their voices. Fortunately, I discovered that people's walks are as unique as their signatures. So I walked around with an enigmatic smile on my face for the duration of the five-day conference!

Studying Caregiving vs. Providing Care

As an educator, I have been conversant for some time with the research literature pertaining to various aspects of caregiving, and in 1985 (Bader), a paper I wrote on the topic of respite care for caregivers was published. More memorable, however, are the lessons learned from being a caregiver when my own family members were in crisis. My stepfather, Jack, was paralyzed from the waist down for the last several months of his life. As my mother's only daughter, single, and a gerontologist who was supposed to know how to be helpful and to promote home safety, I rushed to the other side of the country to "help" my mother. My goals were to ensure that their home was safely and efficiently managed; that his medications were the correct ones, compatible and well organized; and that both Jack and Mom were receiving as much medical attention and social support as they needed. While I was in Philadelphia, my mother, who was Jack's primary care giver, suffered a broken hip when a chair leg came unglued under her slight weight. She decided to have her hip pinned so that she could return to caring for Jack sooner than a complete hip replacement would have permitted. Then, to speed her recovery process, she exercised even more than usual. Unknown to us at the time, one of the surgical pins had become dislodged within a week of her surgery. Weeks later, during the routine post-surgery visit, her surgeon blanched when he examined the x-ray that had been taken at another hospital within two weeks of mother's surgery. Her intensifying pain and the x-ray clearly showed that one of the pins had become dislodged early on. Of course, Mom had to return to the hospital immediately for a full hip replacement and another several weeks of in-patient rehabilitation, followed by prolonged recovery at home. During most of this process, I stayed on the east coast. Everyone was amazed when my boss at the time suggested that I needed to be with my family for as long as it took, so long as I met my previously scheduled professional responsibilities. I did just that--and remain grateful for the privilege and the lessons learned by spending time with my older family members during a prolonged period of crisis. Routinely, I would spend a fourth of the day with Mom, voluntarily staff one of the otherwise expensive "home care" shifts for a third of the day, and run errands for Mom and Jack when not fitfully sleeping. Neither Jack nor Mom had any energy to spare for any purpose beyond coping with the physical and emotional pain in their own lives. For four months, their life space was bound by the walls of the adjacent dining room and breakfast nook, which we had converted into hospital rooms for them. But they conversed with one another. The birds just outside, a resident chipmunk, and a neighbor's amazingly attentive cat gave them no end of pleasure. In addition, condominium owners in their community arranged a rotating schedule of food preparation for Mom and Jack. Casseroles, milk, and fruit just appeared in the refrigerator, one after another. The community was remarkable in another way too. Usually twice a day, a neighbor would make a welcome five--minute visit. Those short visits cheered my whole family. Then Jack died. My mother continues to grieve deeply for him and, at least at first, she was angry that her own body had betrayed her when she wanted to devote all of her strength and caring to him. From the moment the chair broke and she fell to the floor to the moment he died, she remained unable to bend down to kiss him--a fact that causes her tears today.

After Jack's death, I returned to my job at the University of Minnesota. In keeping with my academic commitments and interests, within three days of returning to Minneapolis, I accepted an invitation to review a book of which I previously had been unaware: Sankar's (1991) *Dying at Home: A Family Guide for Caregiving*. I wished I had known about "Dying at Home" three months earlier! Then, within a year of Jack's death, I relocated to a new job in Long Beach and a year later, my mother moved into a continuing care retirement community located within a mile of her previous home. Gradually, she began to regain her physical stamina and emotional independence. For at least three years, however, she cared too much about my opinions regarding every little thing. Her emotional dependence was apparent to everyone and burdensome to me. Then one day, with no prior warning, her speech pattern while talking with me on the telephone 3500 miles away clearly showed that she was re-energized, goal directed, and once again in charge of decisions affecting her life. During the time that Jack was ill, I did not want my mother to worry about anything except Jack's and her own well-being and then, after his death, her own recovery. Therefore, I told no one in mother's community that I had MS, lest the word get back to her. But I did feel compelled to tell a handful of friends in various parts of the country what was going on with me. Just opening that escape valve and letting out some of the pent-up thoughts about my diagnosis and about my caregiving experiences were therapeutic. Although I cannot imagine how the responsibilities of being a caregiver could have been more physically and emotionally demanding during my mother's and Jack's crises, it probably would have been even rougher if I had not known that a few friends cared about me, too, independent of my being a caregiver, and that they also knew about my MS. Nevertheless, each time I told a friend about my still-novel diagnosis and caregiving experiences, I asserted my right to determine when and how to share that information with others, effectively denying my friends permission to do so. One of those whom I trusted with "my story" unintentionally mentioned my diagnosis to my mother in a telephone conversation. When their conversation ended, Mom immediately called me and asked four questions: "What was my official diagnosis?" "What was the disease like?" "Was she in any way responsible for my having 'it'"? "Was I receiving good medical attention?" Since that telephone conversation, without any prompting from me, the only reference she has made to my MS is to confirm that I am aware of new medications as they become available. Not bad! Each time I ask myself anew why I resisted telling her what was going on with me, I come to the same conclusion: As stated above, I did not want my name to appear on her "Worry List."

The Pursuit Of Data And Role Models

The third process that has helped me to bridge my personal and professional views of aging and disability began before I had any inkling that I, too, would develop a disabling chronic condition. This process might be described as an ongoing one in which aging and disability data and indirect experiences are the primary players. There are accepted "facts" and "demographics" about both topics; interested parties espouse conflicting value systems and investments; and there is not yet any effective integration of perspectives. My discovery process began long before I was diagnosed with MS. First, I read *Rehabilitating America: Toward Independence for Disabled and Elderly People* (Bowe, 1980). That book strongly sparked my interest in disability. Then, my boss, mentor and friend went from being an avid runner to being quadriplegic after a driver who had been cited repeatedly for the same offense ran a stop sign. She must have chosen at some level of awareness to survive, or she wouldn't have lived. It took all my mentor's intellect, energy, and finances to cope with recovery and re-entry into her roles as a senior professor, wife, mother, and soon thereafter, widow. Although it never was her style to become an advocate or even to talk much about any personal or emotionally laden topic, I acted on the lessons she taught me by example. I began to organize conferences on disability and aging and started a statewide interest group to coalesce professionals and consumers in the fields of disability and aging studies and practice. These activities provided me with avenues for meeting people with personal and professional expertise regarding disability; they afforded me opportunities to spend time discovering what pertinent disability studies and policies existed. While I continued to read about disability, more important was the fact that I met active, visible advocates, academics studying disability-related issues, and many people of all ages with disabilities. The advocates aggressively challenged my assumptions, my disability-related lexicon, and my beliefs and behaviors. Although my MS remained fairly invisible for a decade following diagnosis, I was told early on after moving to Long Beach that "coming out" was essential for me and for the good of the Independent Living Movement. By visiting diverse agencies and organizations, I continued to learn more about the Movement and about the nature and implications of several chronic conditions. Then to my surprise, I discovered that only a minority of people with disabilities were aware of the availability of Independent Living Centers or of the basic tenets of the Independent Living Movement. These tenets include the right of disabled individuals to retain decision-making power regarding all aspects of their lives, willingness to expend a great deal of scarce energy to ensure enforcement of existing legal mandates, and demands for accessible environments and "reasonable accommodation" in housing and employment. It became my goal to continue to learn more about disability and about aging with a disability. But research data and other information on these subjects were and remain scarce. Nonetheless, I "put myself out there" by collaborating with two faculty colleagues to write and later to completely revise a chapter for a second edition of an edited volume on the continuum of long-term care. In both versions, we summarized the histories, assumptions, issues, and contexts of aging and disability policies. It never occurred to any of us to mention our own disabilities. Our personal experiences did not qualify as "data" for that kind of publication (Bader & Torres-Gil, in preparation; Bader & De Jong, 1996).

Again in accord with my role as an academic, I capitalized on information, programs and role models available in Southern California to develop a course, "Independent Living for Disabled and Elderly Persons," a course title I inherited when I moved to California State University, Long Beach. Although the course does require a few readings, it relies less on published materials than it does on experiential learning opportunities that include site visits, the examination of a wide array of assistive devices, intense discussions with guest lecturers, completing safety checks of private homes and local businesses, redesigning forms for legibility and readability, and other experiential exercises. As always, I learned as much or more from teaching this course than did the students. In this instance, all of us learned more about "the facts" regarding aging and disability, about the interactions of aging and disability, and about the challenges and benefits of "independent living." Among the many issues explored in the course, one issue is of particular interest to me: While many younger adults with disabilities demand simultaneous recognition of the social dimensions as well as the medical aspects of disability, their legal rights and their personal potentials, they seem unwilling to be identified with aging, or as having anything in common with older people. In fact, they do not want to talk about aging. At the same time, many older individuals with functional limitations do not want to be thought of as having a "real" disability or as condoning the more assertive methods of younger disabled individuals and groups, even though their needs often are identical. In this era of scarce resources, it seems to me that these two "communities" could do a much better job of working together on resource and coalition building, when appropriate. (For further discussion of some pertinent theoretical and policy issues, I recommend Kennedy & Minkler, 1999.) I understand that there is much more to learn and do about personal and societal aging than to solve disability-related issues. I also understand that there is much more to learn and do about the individual and societal consequences of disability than to solve aging-related issues. But needless competitions between the two communities, insufficient data on both topics, and unnecessarily complex support systems could be remedied to everyone's advantage. As Bowe (1980) advocated two decades ago, the results of collaboration between the aging and disability communities could be beneficial for the aged in general and for people of all ages with and without disabilities. On the other hand, failure to collaborate would continue to be costly to individuals, families, and taxpayers. In my view, scholarship regarding human aging and disability studies needs to grow at an accelerated rate in order to provide adequate data for effective planning in anticipation of the aging of the vast number of Americans born between 1946 and 1964: the "baby boomers." Many from this group will age with early- or late-onset physical or mental impairments and with aging-related chronic conditions such as arthritis and vision impairment. For others, delaying the onset or slowing the progression of disease, disability, mental illness, and chronic conditions could amount to huge family and financial cost savings. My professional contribution is research, now in progress, to identify practical suggestions, products, and policies that will accommodate their needs, those with and without disabilities, who will survive longer than their forebears dreamed possible.

I have taken the first steps in squaring my personal and professional perspectives on the issues . Even overcoming my initial reluctance to write this paper reflects emerging readiness to accept the facts that my personal and professional perspectives on aging and disability are valid, hopefully worthwhile, and interactive. In truth, however, it was not until I wrote this paper that I became conscious of the interrelationships of the various personal and professional events that I have described. Also, through the writing of this narrative, I have strengthened my commitment to bridging personal and professional perspectives on aging and disability. As a person with MS and a professor of gerontology, I ponder how I can encourage my younger colleagues, with and without disability, to ask questions and, hopefully, help answer questions essential to societal understanding of aging, disability, and their confluence. At the same time, I reflect on ways that I can encourage disabled people of all ages to help those of us in the academy to "get it right" and not just smilingly share in-jokes and criticize our lack of understanding.

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Bringing The Darkness Into Light: A Disability Rights Struggle

In this victim-blaming social and political climate, it is difficult for workers with disabilities or injuries to keep their jobs or to rehabilitate for future employment. Since disabling conditions often consume vital energy and evoke vulnerability to further injury, both self-advocacy and advocacy for or by others are risky. As a person with a mobility impairment, the author came to realize that she would have to fight to be employed again, and that this must begin at the university whose School of Social Work so intrigued her with its strengths perspective. In her quest, she assumed many different, and at times, contradictory roles.

by
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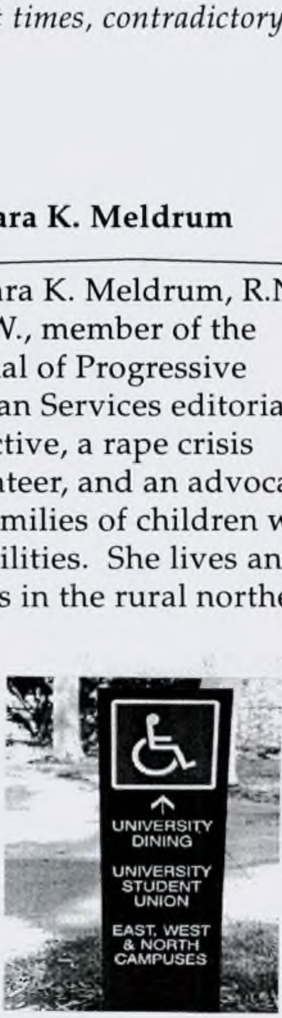


Introduction

Tilting Windmills--Don Quixote
A deluded knight-errant, seeking impossible dreams.

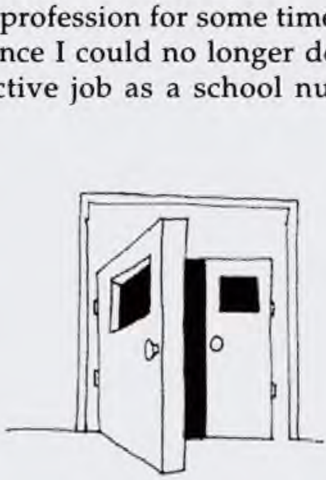
Congress passed the Americans with Disabilities Act (ADA) in 1990 but failed to fund its enforcement, so the struggle for the civil rights of 43 million citizens is not over. Some businesses, like Wal-Mart and Shop and Save, are constructing accessible renovations to attract a new market, while others are fighting compliance tooth and nail. Public universities have been under pressure to make their architecture and academic programs accessible since the passage of Section 504 of the Rehabilitation Act of 1973. Although Congress amended this Act in 1978 to include all institutions with students receiving federal financial aid, I believe that some private colleges have used litigation to fight the mandate to accommodate as a matter of principle: the principle of the free market and the freedom to maximize profits. The authors of the ADA intended to clarify the confusing body of case law regarding Section 504 by stating that any place of public accommodation, including places of education, built since January 26, 1992 (EEOC, 1991) must meet the ADA Architectural Guidelines (ADAAG), and also must make "readily achievable" accommodations for students with disabilities. Older institutions must have an access plan with a time line to describe changes that they will make to bring their spaces into compliance with the ADAAG. In the meantime, they must accommodate individuals to the extent that changes are not too costly (relative to the size of the institution) and will not substantially alter program functioning.

I believe that, on some level, many legislative supporters of the Act wished to convey the message to the public that the ADA has solved workplace and public access issues for people like me who have disabilities. Many people have told me that they thought the ADA had solved all of our problems.

A Personal Quest--The Lone Ranger: A solitary, self-appointed law officer in the Wild West

Although I've always cared because I have a sister with a developmental disability, I never imagined that I would find myself active in a disability rights movement. I have lived with degenerative joint disease since I was 11. However, I have built a post and beam house and have led an extremely active life, so I did not believe that I had a disability. Yet I have lost two professional positions because my employers would not accommodate me, and my disability would not allow me to accommodate them. Then at age 41, after my last employer, a school district, refused to make simple adjustments in my working conditions, I began to lose my ability to walk unassisted. I had requested schedule changes to prevent unproductive travel in and between buildings, and a quiet place to conduct vision and hearing screenings to avoid carrying equipment unnecessarily to repeat inaccurate testing.

During a Pupil Evaluation Team meeting, I expressed concerns for a child with profound mental retardation. The Special Education Director wanted to send her to class without the aide who knew how to treat her when she experienced respiratory failure on a daily basis. The Director, who wanted to cut costs, clenched his teeth and turned red with anger when I brought this up. After this, the Director, who was also the ADA Compliance Officer, would regularly pull me into an office and rage at me, accusing me of doing things that I knew nothing about. I stood up to him and refused to speak to him without a witness, but he used his authority against me by refusing me those accommodations I had requested. My knees failed from overuse. The only remedy that the ADA provides is my original job with back pay. I had considered social work as a profession for some time, and since I could no longer do that active job as a school nurse, I spent the month of January 1995 meeting the deadlines to apply to graduate school in social work.



The small School of Social Work I chose had an intriguing strengths and empowerment orientation. It was a private university with a strong emphasis on the health sciences, and I believed the Director of the Office for Students with Disabilities (OSD) when he said that the physical access on campus was "pretty good." The School of Social Work (SSW) was undergoing its reaccreditation, and no one was available when I visited campus prior to my acceptance to give me a scheduled tour. On that spring day I was having a "bad joint day" and my ability to walk with crutches was limited, so I took the OSD Director at his word and trusted his advice about campus access. Instead that fall, as I proceeded to my first class, I found he had not warned me that I would need to go down a flight of stairs in a building without accessible parking for drivers with disabilities.

As a result of the numerous barriers I encountered during the first two days of classes, including inaccessible parking, stairs, locked elevators and lifts, unmarked classrooms, and rigorous, archaic registration procedures, I became almost entirely dependent on my wheelchair. At that point, I encountered another layer of barriers: doors that require greater than 36 lbf. (pounds of force) to open them (the ADA allows no more than 8.5 lbf), nearly impassable one-inch marble doorsills, and steep inclines. Because maneuvering a manual wheelchair through a door demands an extremely sound and robust upper body, I soon lost the use of my arthritic shoulders and the ability to use my wheelchair independently. Since I have degenerative joint disease, I cannot prove that the doors caused the injury.

My digestive system will not tolerate anti-inflammatory medications. To be able to continue my studies, I had to take small doses regularly. When my intestines ruptured as a result of this, I had $22,000 worth of lifesaving abdominal surgery. Several weeks later I had an $11,000 shoulder operation to preserve the ability to write and use a keyboard. I am under-insured, and $5,000 came out of my disability checks. Meanwhile, I provide the sole income for a family of five. People with disabilities can experience trauma in their attempts to accommodate their bodies to their environments. Such indescribable pain caused by willful neglect has profound ramifications on a person's self- image. The effects of this trauma are similar to those experienced by survivors of war and of sexual abuse. The OSD Director, instead of seeking alternate accommodations, like finding out if the doors could be adjusted, kept insisting that the ADA does not require automatic door openers and that he did not have the authority to remove the illegal doorsills. However, he did arrange for a parking space in a loading zone.

During my second week on campus, when the Director of the OSD asked me to register with his office for the accommodations that I had received, I responded with a letter that included the following: "I feel that any accommodations that have been made were to compensate for inadequacies on the part of the University rather than unusual requirements on my part. I do believe that the University has a responsibility to be forthright in its difficulties in complying with the law, and that students should be informed about places for which access is still a problem. I am quite willing to offer my time and my own limited perspective in an effort to accomplish this. I am also willing to lend my wheelchair to anyone who would like to gain some experiential understanding of the problems caused by inadequate access. I value my continued relationship with you, and hope that we can work together to spare others some of the problems I have experienced." (Letter to OSD Director, September 1995).

In retrospect, this letter outlined all the dilemmas that entrapped me: my perspective, contrary to University practice, that the source of the problem was outside of myself; my belief that a University has an obligation to be honest about its access limitations; my willingness to advocate for others as well as for myself; and my desire to accomplish these things through relationships, rather than through conflict.

Building Alliances--Pippi Longstocking:

A quirky and persistent character in the works of the Swedish novelist, Astrid Lindgren. No one knows where Pippi is going, but she gets there just the same.

That fall semester, I called the State Human Rights Commission. They told me that it took six months to assign an investigator for a formal complaint, my only legal avenue to find a remedy. I knew my body could not wait that long and that I had to spare others what I had gone through. I also felt, as do many surviviors, that it was imperative to find some meaning in an experience that caused me so much harm. Since I am inclined more in the direction of forming coalitions and working face-to-face with people, I decided to work with the OSD Director to make broader changes. The Director was a gentle man, who has a child with multiple physical disabilities. He perceived himself as an understanding person and tried to convey that to others. Yet he took a firm, paternalistic "try harder" position with all students and withheld services until they proved that they would fail without them. He appeared to be always "under the gun," said whatever anyone wanted to hear, and was like a will o' the wisp in political situations. This stance ultimately brought the university to Federal Court over the issue of providing a note-taker to a student with learning disabilities. The university won, but with the warning that the suit was not frivolous when the University had tried to sue the student to recover costs!

Nevertheless, I remained set on forming alliances and met with the OSD Director to form an Accessibility Task Force (ATF) in the fall of 1995 to promote the removal of architectural, attitudinal, and programmatic barriers that prohibit full participation in the academic, social, recreational, and residential programs. The ATF was composed of department representatives and administrators and was to advise the new university president. I guess I was very naive to think that this Task Force might be effective; its members were willing, but the group met only eight hours in a good year and administrators came only on rare occasions to tell us how much they appreciated what we were doing. The ATF decided to do a needs assessment of students with disabilities in order to develop priorities for retrofitting and for program modification. However, because the Dean of Students did not want to include students with mental impairments among those who should receive accommodations, she blocked our efforts. The Task Force also attempted a facilities audit, but used an evaluation checklist designed to retrofit old buildings rather than to identify errors and omissions in questionable new structures (Adaptive Environments Center 1992). I believe that the two or three people who attended the Task Force faithfully were sincere. They expressed amazement at my experiences, saw the campus with new lenses, and made what changes they could in their isolated departments. Other members came and went. It seemed that each new replacement started at the beginning and required numerous one-hour-a-month sessions to begin to understand how little they knew about the experience of having a disability. The OSD Director, a part-time employee, was the only representative of the administration. His opinions changed from day to day, apparently influenced by his contacts with the Dean of Students and with the university vice president. I always sensed that he was very fearful of losing his job. The Task Force had no solid membership base and no direct link to any key decision makers at the university.

At this University the powers of the Vice President and Chief Financial Officer are vested in one person. He informed members that any ADA compliance problems identified by the Task Force in new buildings, including a state-of-the-art medical building completed after 1992, would be delegated to the current list of retrofitting projects. Some of the compliance problems identified included inaccessible bathrooms, impassable marble sills, absence of accessible safety showers and lecture halls, and doors that exceed 30 pounds of force to open them. It was obvious that students with disabilities would continue to experience bodily punishment as a result of the University facilities over the next two decades. By the fall of 1996, it became clear to me that the latent purpose of this Task Force was to direct our energies in ineffective directions and to give the illusion that the University was in compliance with the law. Within the year the other members would come to the same understanding of the Vice President's stalling tactics.

The University refused to correct its non-complying doors with automatic door openers or make other accommodations. In the spring of 1996, I had one shoulder surgery behind me and other medical interventions ahead of me. I did not receive my campus mail because the mail room was inaccessible to me and I had another grueling registration coming up in the fall. I decided to register with the OSD. The Director granted me registration by mail on an "Accommodations Sought and Granted Form," and he agreed to send my mail to me at my home and to permit me to register by mail. In addition, he stated that some means would be found to get me entrance to the one classroom building that was accessible to me. A week after shoulder surgery, I discovered that I still did not receive campus mail (including vital financial aid information) at home, and the Registrar's office informed me that it was not possible to register by mail despite a letter from the Comptroller to the contrary. By this time, it became evident to me that I should keep accurate documentation of every request, memo, and phone call. I regret that I had not done this at the outset.

After another painful registration marathon in the fall of 1996, the Chair of the School of Social Work, wrote an appeal to the President, a professed advocate of liberal causes: ..."For more than a year, Ms. Meldrum has tried to work within our systems to make learning possible.... Numerous problems remain unresolved...."

A copy was sent to the Director of the OSD, who countered it with his own letter to the President: "I do not know which student form you're referring to. The student appeal process can be found in the Policy and Procedures for Access of Students with Disabilities." The student form that on several occasions the director denied existed was the"Accommodations Sought and Granted Form" that I completed for him, and I had made a copy. Yet he went on to say in this letter that I had made no efforts to use the standard channels to gain accommodations. In any case, the "Policy and Procedures..." was an appeals policy, not a procedure to gain access. I had communicated openly and forthrightly with this Director throughout this process and his dishonesty shocked me.

I consented to a meeting with the Director, the ATF Chair, and SW faculty member, a disability rights advocate. When confronted, the Director admitted that his memo to the President was dishonest; there was no official access policy and I had used all channels available to me. He trembled and appeared highly agitated at being "caught." All the participants at the meeting agreed, as a political tactic, to proceed as if we had a fair access policy in place. The OSD Director was to make requests to the mail room, for example, as if he had the authority to do so, and I was to appeal to the ATF as if it had the power to advocate for me. We believed that this strategy would force changes and give the Director and the ATF an active role in the process. After this meeting nothing happened. The Director did not follow through or change his stance, most likely in response to pressure from the administration to ignore our efforts. As the SW Department Chair changed the focus to structural issues, my personal needs were set aside. Then he did not follow through to make further contact with the University President as he had promised, so even structural issues were lost.

After struggling over more than a year, I felt like a powerless pawn in a bureaucratic contest and that my strategy of building mutual alliances was ineffectual at best. I decided to file a formal complaint with the Human Rights Commission and received legal support from the State's Advocacy Services only after I had filed my complaint.

I had not given up completely on building alliances. The Task Force had been advocating to the President, the Vice President, and the Dean for automatic door openers to prevent further injuries to me and to others since the spring of 1996. In November, the Dean of Students came to the ATF meeting. She had been listed as a member but had attended only one other meeting. She stated that the administration had been too busy to consider the door openers because they had recently enrolled two new students with mobility impairments and their "safety needs" had to come first. Though the members of the ATF knew that I was no more able to open safely the heavy doors than the new students, no one spoke up to challenge the Dean's rationale. I guess that they felt intimidated or that they feared reprisal or loss of their jobs. Abandoned by people I considered my allies, I felt that I had been surgically excised from humanity. I waited until I was able to speak. Then I informed the Dean that the illegal doors injured me already and that, in a climate with sub-zero temperatures in the winter, the doors were a health and safety issue for me also. In addition, I reported that the door openers were not a convenience, but a matter of safety for all women with disabilities, who experience twice as many sexual assaults (Mudrick, 1983).

Later, I arranged to meet privately with the Dean after I realized that the OSD had not informed her of my injuries. She listened actively and seemed to begin to grasp my situation. She said that I was only the second person with a mobility impairment to attend the University. She offered to be of assistance at any time and said that she did have the authority to grant accommodations. However, I was disappointed when I wrote to her requesting access to one of the bathrooms in my classroom building, and she told me to make an appointment with an

Occupational Therapist (the current ATF Chair), who would teach me to use the room as it was. I was to be toilet trained to accommodate a new bathroom that failed to meet ADA standards! In any case, who could know better than I how to maneuver my chair? I refused, and chose to limit my fluid consumption during the two days each week that I was confined to this building. Bathroom access limits our mobility as much or more so than any other barrier.

A Legal Process--Portia:
A character from Shakespeare's "Merchant of Venice," who delivers the famous speech, "The quality of mercy is not strained..."

I persisted with the Task Force and my personal efforts to have barriers removed, while I pursued a formal Human Rights Commission (HRC) complaint. As a result of funding cutbacks, I learned that the HRC staff had been reduced from 12 investigators to two investigators. My HRC investigator was new to her job and was not familiar with state law. The first complaint hearing in January 1997 was a surprise to both me and the legal advocate assigned to me because the focus was on architectural barriers, rather than the procedural issues underlying all my requests for accommodations. The investigator reported numerous instances of violation of the ADA guidelines in new construction but gave me very limited opportunities about speaking to other violations known to me.

What I gained was the opportunity to hear the responses of the University's administrators as they tried to explain away these lapses. The administration had charged the OSD Director to make accommodations but had not given him the power to put many changes into effect. He was silent and deferential. The Dean of Students, who claimed to have authority and to be my advocate, was also silent because the University Vice President/Chief Financial Officer dominated the stage. He was cold and distant and seemed offended by my presence. He turned his head away abruptly whenever he caught sight of me, and he would not answer when I addressed him. He explained that the University had made a substantial financial outlay since 1992, when the ADA went into effect, and that he would not put in door openers for the "convenience" of people in wheelchairs. The investigator noted that included in the report of expenses that the University had incurred in order to come into compliance with the ADAAG were routine maintenance items, such as the repair and replacement of sidewalks. Ironically, the entire cost of the decorative marble that was installed on the campus walls and that formed the impassable marble doorsills was included.

As we toured the campus, the Vice President was visibly angered when the investigator identified each barrier. The investigator found that the emergency phones installed the week before were too high and that one was up a step. Ironically, the OSD Director had told me that these phones were installed so that people with disabilities could call for help to get into buildings!

Afterward, the investigator told me that she assumed I would be seeking redress under tort law for the physical damages that I sustained, so she would not hold a second hearing on the absence of policy and procedures for accommodations. I told her not to assume that I would sue; since I had a pre-existing degenerative joint disease, it would be difficult to prove that the doors had damaged me. Indeed, I found that was the case when I consulted a lawyer specializing in injuries.

The Advocacy Services gave me a new advocate, a lawyer who was also relatively new to the agency. However, he was willing to educate himself. I gave him copies of recent ADA case law and other articles. He was pleased to use my situation as a test case for our state's private schools. He agreed with me that the most important part of my quest was to bring about structural changes in the University. It was refreshing to work with him as equals in a mutual relationship: both teachers, both learners, and both advocates in the same cause.

A Political Process--Winged Victory:
A Greek statue in honor of Nike, the goddess of victory.

The SSW had not abandoned me. I was thrilled when its Social Action Committee decided during the fall of 1996 to take up access for people with disabilities as its current yearly project. However, I was disappointed to find how little time faculty members had to contribute to it. Under the current system, the tenure and promotion committee evaluates classroom teaching, community voluntarism, publishing, and participation in University committees when tenure or promotion is considered. Political rabble rousing in opposition to the University practices does not seem to count at this conservative University. However, social work faculty members of the Finance Committee and the Faculty Senate used their roles in support of the Social Action Committee.

The Social Action Committee came on board in November, but it was not until February that a motion that we wrote was submitted to the Faculty Senate for approval: "The Faculty Senate requests President to appoint a committee to draft an Accessibility Policy and Procedures for the University, with the first draft of this policy to be completed by September 1997. We request that this committee have representation from all three Colleges, including representation from students with disabilities, academic/student support services, and external ADA Consultant, and that a specific staff person be appointed to coordinate this effort."

The Faculty Senate Chair allowed 15 minutes total for three students to testify. We left after testifying, but I learned from faculty members that the OSD Director reported that the University had in place a workable, campus-wide policy, which was developed and endorsed by the Accessibility Task Force. In fact, the policy had not been endorsed by anyone; it was merely an appeals policy when services were denied, and the ATF had never yet discussed it. The motion went to the Steering Committee, then was passed unanimously during the Senate meeting in April.

During the spring of 1997, door openers began to appear in several of the key buildings on campus. However, the physical changes brought about by the force of law and politics did not produce a change in attitude or an understanding about providing a truly inclusive environment. For example, an undergraduate student who uses a scooter was dismayed because she had to wait for someone to let her into her dormitory each night for three months before the school issued her the remote control needed to operate the new opener herself. For me the changes came too late. My shoulder never recovered from the surgery sufficiently to wheel my chair independently. The greater issue in my mind was the inadequacy in the policy and procedures required to receive reasonable accommodations.

The atmosphere at the next HRC hearing was more foreboding. The University attorney came, along with the Dean, the OSD Director, and the Vice President. While preparing this hearing, I combed through my memos and notes and found that the University had taken six weeks to accommodate me with a key to a photocopy machine and nine months to issue me an elevator key. We went through a list of other accommodations that I had requested; they were granted on paper, but never provided. The first was mail delivery to my home, rather than to an inaccessible campus box. I distributed six mail memos from the Director to me and to various departments regarding various ineffective schemes for me to get my mail. The HRC investigator informed him that I should not have to go to such lengths to arrange my own accommodations. Then she said, "I might be missing something here, but wouldn't it be simpler to tell the mail room person to stick her mail in an envelope and send it to her?" Again the OSD Director had sent memos, but he had no authority to enforce them.

Similarly, the investigator found that other procedures to obtain accommodations, such as mail registrations, were unnecessarily complex and exhausting for students with disabilities. The Vice President asserted that it was very reasonable to request that a student with disabilities participate in the same registration procedure used by other students and that my classes would be assigned wherever the Registrar happened to put them. I would have to arrange to have them relocated later. Because of the failure to provide reasonable accommodations, each semester I found that I never recovered physically from the first hectic week of classes.

Then he reported that I would now have classes at the new medical building. (This building has no van parking and the doors require 30 pounds of force to open them.) At this point, the University attorney unmistakably signaled the Vice President to be silent, as the Dean of Students tried to explain the archaic and convoluted registration and clearance procedures. Finally, unimpressed with their explanations, the investigator said, "Haven't you people heard of computers?"

As their explanation bordered more and more on absurdity, for a moment I felt great pity for them. The Dean and the Director were pale and appeared humiliated. The Vice President looked angry and was uncharacteristically silent. I do not enjoy seeing anyone suffer, but I knew that they were not receptive to less coercive solutions. It was apparent that the authority vested in this Vice President was the greatest barrier to any attempt for students with disabilities to live a full life on campus. I am not sure that the Vice President can be swayed by anything but the law or the threat of losing his job, but in any case, most of my requests did not have a price tag and would not have required the Vice President's approval.

The University attorney asked me if I had tried to appeal. I answered by distributing copies of the letter from the Social Work Chair to the President and the OSD Director's memo subverting our effort. The room was filled with the dead silence of profound embarrassment. We discussed other procedures, and after four and a half hours, the two parties adjourned to separate rooms to address the question, "Do you want to settle (enter mediation)?" Since the mediation process is confidential, I must end my story here. I will only say that I have continued on a very clear-sighted path with no major compromises on my part. For the sake of others, I can do nothing less.

Bringing the Darkness Into Light--A Political Priestess

As a rural person, I felt out of my element in urban politics, and I did not readily trust my political instincts. I very soon learned to assess the motivations of the key players and to predict what each of them would do. I was rarely incorrect in these assessments, although my Task Force colleagues were slow to believe the deceit I encountered in dealing with the OSD Director. In the end, they saw it as well and were appalled. My experiences suggest that the "oppressed" have some very special insights into the motivations and actions of their "oppressors." I also developed a good sense of timing and knew when to yield, when to stand firm, and when to push forward. I learned that while trying to arrange accommodations, documentation is essential, even though I have always preferred to communicate in good faith. I would also seriously advise having a witness present at all meetings. Task Force members would have understood the situation sooner if someone else had testified to what college officials said to me. It would have saved me much frustration and the extreme isolation of being a Cassandra who foretells a future that no one wants to believe is possible. Many of us will grow old, if we do not die prematurely, and many of us will experience some degree of mobility impairment or other disability. It is a reality that most want to deny.

In this political endeavor, I discovered that the process of creation and destruction does not belong only to nature's life cycles. I found myself in a position where, to do what I considered right and just for myself and for others, I had to expose others' weaknesses and faults in a way that felt like an act of violence.

Somehow, I needed to have an ending to this story, a point of resolution when I could say, "I have done all I can do." Such an act of healing would make it possible to recognize the profound connections I had developed with people and with a process, and to feel at peace once more. I now realize that I had not given others adequate credit for their sincere efforts. They were often at a different stage in the change process: I had come to the time when contest strategies were essential to me, while they had just begun the process of seeking alliances. This disjunction in the social change process often felt very alienating, and for me it was disabling physically, emotionally, and spiritually.

Advocating for myself as

a person experiencing trauma and oppression was monumentally difficult. I experienced further physical losses during this process and I have lost the ability to be employed for more than 40 hours each month. Adjusting to these losses as I negotiated this political arena while going to school and raising a family was overwhelming. As an advocate for others, I know now that I must embrace their anger and despair, which are so real and so human. When I work with trauma survivors I always tell them that I am glad they are angry because they have good reason to be so, and that expressing anger is very healthy and essential to the healing process. As I validate their anger, they become stronger and ready for the work ahead of them. For people with disabilities, this labor is exhausting and has the potential to compromise their physical, mental, and spiritual well being. We must all honor that. When people tell me, "You shouldn't stand for that," I wonder if they would tell a rape survivor, "You should have fought back." We must allow people with disabilities to choose their own battles. These days I more often put my energies into fighting for others rather than for myself. It is much safer. Yet finding peace in this struggle has been difficult, particularly since I must also face the daily grind of chronic pain. It is possible only because, in some inner place, I hold a deep regard and respect for all people, including those who oppress.

May Sarton (1991, p.19) invokes the Goddess Kali, the Terrible: *Help us to bring darkness into light\ To lift out the pain\ the anger\ Where it can be seen for what it is—*

The balance-wheel for our vulnerable, aching love. I would never have chosen to participate in this process because it was too painful and too damaging. I responded to an inner demand and the need to protect myself from further injury. However, if necessity draws me down this road again, I will choose mutuality and I will make mutual demands through documentation and contest, when necessary. I will do this with the knowledge that inherent in the breaking of trust is a drive for wholeness and forgiveness. The oppressed, as Paulo Freire (1971) asserted in the *Pedagogy of the Oppressed*, are the only ones who can restore humanity to their oppressors.

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Coping With The Transitions In Our Lives: From "Afflicted" Identity To Personal Empowerment and Pride

This narrative reflects the author's initial reaction to acquiring a disability as an adult and her eventual realization that she had internalized an inculcated shame and sense of less worth. Through becoming involved with professionals who had been disabled since childhood and with the independent living movement, she recounts how she developed an understanding of how medical model biases often routinely devalue people with disabilities and perpetuate systemic inequities in human service practice and cultural oppression.

by
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I know that many people gain an inner strength as they grow weaker but, though many travel this path, getting there is not easy in light of the social stigma that still surrounds disability. Perhaps writing about it will crystallize the experience.

My introduction to the world of disability was a gradual one. At age 34, after being diagnosed with MS (Multiple Sclerosis), I did not truly comprehend the realities of the disability experience for several years. I have known all along that my disability is progressive. At first, when I overdid, blurred vision, vertigo, and fatigue warned me to slow down. It wasn't too frightening in 1974. I would simply deal with it. I made sure I rested sensibly, didn't walk too far, or get overheated in order to continue doing all the things I was involved in — being a homemaker and mother who was active with her kids, being a businesswoman who successfully ran a company for her husband, and being politically involved in her suburban San Diego community.

The MS Society brochures talked about dealing with the symptoms, which vary greatly in each person "afflicted," and holding on for a cure. There was very little written about actually living with the disability unless the individual was considered heroic, inspirational, or courageous — or was someone who became almost non-disabled. I remember wanting to shun people who thought I was a tragic victim "afflicted" with MS. That seemed like a melodramatic excuse to avoid getting on with life. But I couldn't shun them all.

Some of them made me doubt myself. As president of the local board of education, I spearheaded the move not to renew the superintendent's employment contract. He and his supporters spread a malicious rumor that MS had affected my brain. Some of their children even taunted mine at school. I didn't run for reelection in 1978. I ran for cover.

In the years that followed, my self-esteem took a few nosedives as I went through a divorce, tried unsuccessfully to get another job, then trained for another career. By the time the State Department of Rehabilitation turned down my request in 1980 for law school tuition assistance because, in their opinion, a person with MS would be unable to hold down a 9-to-5-job very long, my sense of self worth was pretty low. I was being defined by my disability. So, as my rationale went at that time, if everyone else thought MS was so terrible — and I was the person with MS — I must be terrible.

When my sister suggested that I begin using a cane so I would not look tipsy when walking, then I knew the disability would no longer be invisible. The world I grew up in had devalued, excluded, and perceived disabled people as objects of pity and charity who needed to be cured. Suddenly, in 1974, that stigma had included me. I began to realize by the 1980s that non-disabled people who knew I had MS treated me differently even though I was essentially the same person. Embracing this confusing status and identity took many more years.

Because I had always worked, the rehabilitation counselor advised me to apply for Social Security Disability Insurance benefits. He said the Department of Rehabilitation's denial of services, more than my medical records, would guarantee my qualification. It wasn't until years later, when I learned how difficult it is to get disability benefits awarded, that I realized how right he was. I remember feeling apprehensive when the letter came stating that, unless I worked and earned more than $200 a month, monthly cash benefits of $494 had been approved effective February 1, 1982. I was officially disabled. Never mind that I had borrowed enough money to finish a university paralegal program with honors and was about to look for a job in Los Angeles. The government believed gainful employment and MS were incompatible. I decided not to take my cane to job interviews or to use it at work. Due to fatigue, I lasted only six months in the 9-to-5 job. If the ADA (Americans with Disabilities Act) of 1990 had been law in 1982, I wonder if the law firm would have provided reasonable accommodations, such as part-time work or longer breaks and a place to lie down? I doubt it.

Looking back on those years both saddens and angers me. It was the loneliest, most unenlightened period of my life. I did not seem to fit anywhere socially. In spite of that, I began doing freelance paralegal work. It wasn't too hard to give up the cane for a wheelchair once I realized that sitting down would really conserve my energy. It was harder on my family and friends. I still remember the look on one UCLA doctor's face as I rolled into his office using what I considered to be a smart-looking wheelchair and he quipped "When did you get THAT thing?" It helped open my eyes to the stigma that is attached even to the equipment we use. No one, not my doctor, friends, or rehabilitation counselor, could get past the MS "victim" perception to help me look at and understand the bigger picture.

How can we get society to accept us if we cannot accept ourselves when our abilities change and we are different? Why are disabled people readily disparaged and discounted instead of empowered to live with pride and dignity? Why are we not enabled to pursue all our employment options and possibilities? Why do we feel the disability experience is devalued by society instead of just being accepted as part of life's continuum? Why can't people see the "big picture" beyond the immediate image of disability?

In 1984, I was befriended by two scholars who grew up disabled and are leaders in the disability movement, Drs. Carol J. Gill and Paul K. Longmore. Through them, I learned about the negative language as well as the stereotypes and stigma that have historically been attached to people with disabilities. I realized I had internalized an inculcated shame and sense of less worth. Suddenly, pride began to replace my devalued self-worth.

At the same time, it became apparent to me that mainstream media largely ignore the real issues of disabled people and mirror society's misunderstandings. The media did not reflect new perspectives, such as the independent living and disability rights movement's way of interpreting society. To provide a forum for such issues, in 1986 I began writing a weekly newspaper column for the Long Beach *Press-Telegram*, "Living with a Disability," which was then nationally syndicated for eight years. I learned from and networked with disabled and non-disabled advocates all over the country. A major benefit of writing the column is that I learned about and researched Independent Living Centers (ILC).

Writing the column also made me aware that many of our human service systems have a medical model focus and treat disabled people as passive patients, "cases" to be managed, or charity recipients. In medically biased service agencies, the "patients" are not seen first as family and community members, workers, or entitled customers and consumers of services. Solutions to problems are most often approached through professional interventions, treatments, or systemic caretaking rather than through also exploring the most equitable socioeconomic, political, educational, and cultural possibilities.

For example, I learned from interviewing one of my readers, Bob Maes, that he had no options after becoming a quadriplegic in a diving accident in 1973. He needed help with personal hygiene, getting in and out of bed, and dressing. With the meager disability benefits he received, he could not afford home-based personal assistance, and his wife could not work and also handle his physical care. So the hospital's discharge planner recommended—and the government paid—to put this 37-year-old husband, father, and auto parts diemaker in a nursing home, even though he did not need nursing care. Bob and his wife divorced; he spent 16 years mostly doing nothing at taxpayers' expense.

However, in the early 1980s, a Michigan Rehabilitation Services counselor got him to go to college. It was there that a friend told Bob about something he never knew existed: the ILC serving Oakland/Macomb counties in Michigan. Among other things, this ILC helps consumers with disabilities stay out of —or get out of— nursing homes by helping them obtain a Medicaid waiver to pay for adequate in-home support services rather than institutionalization. The ILC held classes where Bob learned self-advocacy, how to hire and manage personal service attendants, how to seek housing, and what to expect — the good and the bad — when living on your own.

At age 54, Bob felt a new world opened up when a college friend helped him get into an apartment in a subsidized housing project where he lives today. The nursing home staff predicted he would not make it on his own, but he has proven them wrong. We constantly fight society's belief that to be disabled and to need assistance is to be useless and pitiful. The belief that people with severe disabilities can live independently, have their own homes, and run their own lives is unrealistic to a lot of people, service providers included. According to the medical and charity paradigms perpetuated in many human service professional and educational training programs, the biggest problems are located in the individual (who is broken or sick and needs to be cared for, fixed, or cured). According to the disability rights paradigm, our biggest problems lie in the inequitable socioeconomic, political, medical, and educational policies, as well as in oppressive cultural environments and practices.

Breaking free of the caretaker's mentality inherent in the system that put Bob in a nursing home was not easy. He cannot figure out why his life was put on hold for 16 years. Having the government pay for a full-time, home-based personal attendant would have been far cheaper than having a medically biased Medicaid system pay $40,000 a year to keep him in a nursing home.

But medical bias is still rampant in the 1990s. My feisty and independent 70-year-old friend, Sylvia, never dreamed she could lose the personal freedom she had worked so hard to maintain. When she was hospitalized for an injured leg, this tough lady, who also has MS and uses a wheelchair, had no idea she would be up against a system that treated her like an object instead of a person entitled to make choices about herself. She certainly did not expect to end up in a nursing home.

I am convinced a combination of circumstances worked against Sylvia initially: her unquestioning trust of the medical profession, her slurred speech caused by the MS, and her blurred thinking from the medications she was being given. As a result, she was unaware that she needed to call someone for help.

During her stay, the doctor at the hospital told her that he did not think she was capable of taking care of her affairs and that he had called a conservator. When she asked to go home, she was told a court-appointed attorney would come to talk with her about it. When he did, Sylvia told the attorney she wanted to contest the conservatorship. However, without Sylvia being present, a court found she was incompetent to provide for her personal needs, unable to manage her financial resources, and unable to resist undue influence. A temporary conservator was appointed, and she was put in a nursing home.

At the nursing home, Sylvia learned the conservator had closed her bank account. She had no money and no power, and she began to realize they were planning to keep her there a long time. The fact that Sylvia was tenacious is probably what saved her. She started asking questions about what was going on and learned her home was going to be sold to pay the conservator's fees. The conservator had spent her meager savings; all the money from Sylvia's monthly Social Security check and a small pension was being spent to keep her in the nursing home.

Desperate, she started calling all sorts of agencies. No one would get involved until she called the people who had helped her install wheelchair ramps at her home, the Westside Center for Independent Living in Los Angeles. They understood that slurred speech did not invalidate her as a capable human being, and they listened. Sylvia's call set off a team effort that put together a detailed plan to get her all the help she needed at home from a personal services attendant. When the plan was presented to the conservatorship firm, however, it was rejected as unrealistic. Next, the ILC advocates located an attorney who donated her services and contested the conservatorship. A temporary conservator was then found who would donate his services.

Ten months after she was put in the nursing home, Sylvia returned to her own home. The Attendant Registry at the ILC helped her find a live-in attendant who provides all the assistance she needs. But finances are tight. The original conservator put a $10,750 lien on Sylvia's house, as did the court-appointed attorney for $5,000. My friend was irreversibly traumatized by a series of events that never should have happened.

Could it happen to me? It is my biggest fear. At one time, I thought to be independent meant doing absolutely everything myself. Using that definition to prove I was a worthy, independent, disabled person, I would spend most of my time and energy doing daily tasks that a personal assistant does 10 times faster. People who have cooks, housekeepers, and chauffeurs are not thought of as "uselessly dependent." Living independently does not necessarily mean living alone or doing everything for yourself. It has more to do with having options and making choices, like everyone else, about how and where you live. So far, I still have options from which to choose.

Since 1990, my hands have gotten weaker, and I no longer drive. I need help with household chores, meal preparation, personal hygiene, getting in and out of bed, and dressing. But, after moving to Long Beach (as a recognized disability-issues newspaper columnist), the local Department of Rehabilitation reversed the original denial of services and provided me with a lift-equipped van so I could get around to research and do interviews using my power wheelchair! My mother left me enough money to buy a house in 1992 and make it wheelchair accessible. After using up my savings to pay for the increased personal assistance I now need, I have qualified for In-Home Support Services through the county — and life goes on.

In 1995, I was asked to use my writing experience and resources to increase awareness of disability rights, culture, and pride at the university level. As a result of becoming involved with California State University, Long Beach (CSULB) and its disability faculty interest group in an effort to establish a Disability Studies program on campus, I taught a course titled "Disabil-

ity, Culture, and Society: Issues and Intervention." It is a course that conceptualizes disability as a social construct utilizing an oppressed, minority group model. The course examines society's laws, policies, and practices to understand the experience of disability from the inside out.

I dread additional physical limitation and the unknown challenges it will bring. But, after 25 years of slow MS progression, I know it will probably come. And, though I will find a resourceful way to deal with the changes, it is sometimes scary. Still, I like the individual I have become, and disability is an essential and prideful part of my identity. Life and friendships seem more meaningful and honest, and I am involved and active in things that matter to me. No one ever said life's transitions would be easy.

Freedom of choice, self-determination, and independence are the corner-stones of American life. Choosing how we live and where are basic rights that are not yet a reality for many disabled people. ILCs are publicly and privately funded agencies designed to provide the support services, information, and referrals to resources that disabled individuals will need in order to live on their own. The basic idea is that disabled individuals who have successfully established independent/interdependent, productive, and satisfying lives know best what people with disabilities need. In my experience, effective centers have a majority of disabled people on their paid staff as well as on their volunteer board of directors. As of March 1999, there were 470 ILCs nationwide, each of which offer a variety of services. Services can include peer counseling, self-advocacy training, systems advocacy, benefits advocacy, mobility training, attendant registry, housing assistance, and workshops to help consumers with disabilities acquire independent living skills in order to establish and/or maintain lifestyles that are self-directed.

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INFORMATION RESOURCES

California Foundation of Independent Living Centers, (916) 325-1690,www.cfilc.org

Independent Living Resources Project, (713) 520-0232, www.ilru.org.

National Council on Independent Living, (703) 525-3406.

Disability As Diversity:

A Socio-Lingustic Construct for the New Millennium

The development of structural inequality in our social systems and the socio-linguistic construction of disability are explored through a narrative of the author's career serving people with disabilities within the disability civil rights movement over the past two decades. Human service professionals are asked to examine their own socio-linguistic constructs for disability to determine whether they are prepared to accept disability as diversity and the paradigm shift this indicates for the coming millennium.

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Recognizing disability as diversity requires a major paradigm shift for all of us. One aspect of this change in thinking requires that human service professionals consider how they construct their perception of disability. Granfield (1996) observed that professionals in an organization shape and define the persons receiving services by a profile that perpetuates the need for therapy. Diversity theorists have spent years defining diversity and determining which groups should be included in dialogues on diversity. During those same years, people with disabilities have been pressing for civil rights, access, and accommodations.

Twenty years ago at the beginning of my career in vocational rehabilitation, the social and linguistic constructs of disability reflected two primary frames of reference: the medical model, which assumed illness, or the rehabilitative model, which identified a problem to work around. Persons with disabilities were viewed as either patients or clients. Today, for the most part, those same constructs define people with disabilities as one of the many diverse groups that make up the socio-linguistic melting pot of America.

In 1979, fresh out of college, I was immediately faced with the contradictions of a changing worldview surrounding people with disabilities. As part of my college curriculum/practicum, I was educated in the ways of sheltered workshops, and we, as therapists, were content to keep the clients busy while we socialized nearby. After college I began my career in a different type of workshop in which we were expected to interact with our clients and to teach a positive work ethic by modeling. Thus, I was fortunate professionally, in beginning my career, to be in a setting that was supportive of the fledgling disability civil rights movement occurring around me. I learned to give my clients the respect they deserved as human beings and the credit they deserved for their abilities rather than focusing on what they could not accomplish.

Many of the persons with developmental disabilities with whom I worked in the sheltered workshop had been institutionalized at a young age and exhibited behaviors that were less the result of their disabilities than coping skills learned in response to the environment they had been raised in. One man, John, an African-American male in his late 50's, was basically non-communicative when he entered our program. Identified as having trainable mental retardation, he had been institutionalized for most of his life. In our program John remained isolated from staff and other clients, hoarding parts and materials for his assigned work. After several years of working with him, we learned that John was quite capable of clearly presenting himself verbally. Although the chart described John as having a developmental disability, this was not the cause of his early silence and distance from others. Instead his behaviors were coping skills learned in the institution.

Joan entered our program as a result of chronic mental illness. In her late twenties, Joan had been in and out of treatment facilities through much of her adolescence. She was untrusting, unmotivated, and frequently volatile in her response to others. Over time Joan learned to communicate her feelings to the staff with the expectation that she would be heard and this awareness resulted in a decrease in her violent outbursts.

Once non-disability-related behaviors were identified and worked through, the people in our program with developmental disabilities improved significantly and those with mental illness demonstrated a much greater capacity to learn and work than we initially expected to encounter. What they needed from us, more than protection, was mutual respect for them as people with individual strengths and ideas. When treated with respect and viewed as capable human beings, both John and Joan stretched to meet those expectations.

As the Disability Civil Rights Movement began to make its impact felt in the larger society, a colleague and I went through a process of linguistic construction as we reframed the language we used to model new and emerging understandings of the people with whom we worked. In 1979, I worked with "clients." Two years later, as a supervisor, I advised my staff to use the term "client workers." The descriptor shifted again to "client employee" as we realized that all paychecks, those of the staff and of the "client workers" were generated from the same business office; we needed each other to complete our packaging and assembly contracts. Over time, everyone became "co-workers," in our packaging and assembly plant. Although still sheltered, this change reflected the reality that everyone—regardless of job description—came to work on a daily basis to reach shared goals.

In 1982 or 1983, I attended a People First Conference. People First is a disability rights organization run by and for people with disabilities. The staff members who attended the conference were there primarily to provide transportation for delegates to the workshop. It was unsettling to realize that the delegates I had taken did not need me, the professional, and that my "co-workers" were more than capable of running their own conference. Before the conference, I had evolved only to the point where I saw my co-workers as capable of completing basic packaging and assembly tasks. I had worked with them in a setting in which the work was ready when they arrived. My staff met weekly to plan what work would be done, who would complete which aspects of a specific contract, and which individuals would work together at what times. Little was left to the discretion of our co-workers with developmental disabilities. The people at this conference, like those I worked with daily, had developmental disabilities. Some participants were difficult to understand as a result of speech and language impairments. Others communicated through the use of sign language although they could hear. A few had mobility impairments, making it difficult for them to get around in some environments, or had visual impairments, which limited their ability to benefit from written materials.

However, as I sat in the back of the room, I realized how much these individuals were able to self-organize. The speakers had specific concerns to raise and the audience, including some of my "client/co-workers," whose opinion on many things I had never thought to seek, responded appropriately to those concerns. It was during the opening sessions that the linguistic shift from "patients/clients" to "individuals/people" struck me as an appropriate match for my new construct of disability. I began to acknowledge not only their ability to work but also their ability to think, something I had not previously considered. I began to understand how much the language of my thoughts limited my expectations and therefore, limited the ability of persons with disabilities to express themselves fully in my presence. According to Lemke (1999): "Language in use always creates three interdependent kinds of social and cultural meaning. It constructs social relationships among participants and points-of-view; it creates verbal presentations of events, activities, and relationships other than itself; it construes relations of parts to wholes within its own text and between itself and its contexts" (p.11). Language, in a very real way, constructs our social, evaluative, and affective stances, producing role relationships with degrees of authority and power, normality and desirability, and rights and obligations. As a result of my experiences at the People First Conference, I became aware that a change in the linguistic constructs used in our helping organizations would hasten the movement toward civil rights for the entire disability community. And on a personal level, a change in my linguistic focus would enhance relationships with my co-workers and friends with disabilities.

By 1988, the need to apply a behavior modification model decreased as communication increased. Behavior management techniques fell to the wayside as our co-workers learned that the managing staff would listen and hear their concerns without the threat of violence. Productivity increased as skills were developed and the quality of our contracts improved as we demonstrated our ability as a team. Over the next nine-year period, the picture of disability continued to shift in our program and across the nation. And as the disability civil rights movement continues to progress, we, as human service professionals, are faced with the need to reconsider our role, our complicity in shaping, both socially and linguistically, the perception of disability. If we cannot shift from a paradigm that stresses dependency and denies competency, and we are threatened by a loss of status and self-worth, how can we be part of the expanding disability rights movement?

In 1994, disability and diversity inescapably crossed paths for me as I became the co-chair of a community college Cultural Diversity Task Force and a staff member of a statewide Technology for Persons with Disabilities (Tech Act) Project. By this time, my social circle included friends, co-workers, and students with disabilities, and I viewed the inclusion of disability and people with disabilities as part of my systems change activities. As a black female, I saw clearly that the discrimination faced by people with disabilities was very much like that faced by blacks, women, and other minorities in the United States. Educational opportunities for people with disabilities had been withheld until the mid-seventies, segregated classes were still common in the lower grades, and there was limited access at the college level. The physical and social barriers were not always consciously placed but were systemic in nature. Often, faculty members erroneously interpreted requests for classroom accommodations as requests to lower educational standards. They did not understand that access to the class material provides students with disabilities with the same opportunity as other students to reach the standard.

Once again I began to reexamine critically my own assumptions about people with disabilities for the socio-linguistic constructs that serve to maintain the status quo. I could not help the faculty without exploring and understanding structural inequality in this context. Within my vocabulary, terms like "non-compliant" and "uncooperative" revealed my sense that I should determine a path and the person with a disability should willingly oblige. "Difficult to deal with" highlighted a feeling that persons with disabilities should be agreeable. As old ideas and standards began to crumble, I realized people with disabilities could be as agreeable or as disagreeable as anyone else with whom I developed a relationship. My new goal became to listen more carefully to the concerns of individuals with disabilities and their families rather than to react to the rejection of my solutions.

Recently I visited the web site of the Independent Living Center of Kenai Peninsula. The Independent Living Philosophy states: "Individuals with disabilities can best make their own decisions about their lives. The only handicaps they face are societal attitudes and physical barriers, not the disabilities they experience" (www.peninsulailc.org/independent_living_htm.htm). Physical barriers are systemic issues that stand as structural inequalities within our society that lead to the social neglect of people with disabilities. Keeping people with disabilities at home, or in institutions, out of the public eye has meant that as our society developed in the early part of the twentieth century, people with disabilities were not allowed to develop at the same pace and resulted in the need for access to remain unrecognized. Though barrier removal for publicly funded entities was addressed by the Rehabilitation Act in the 70's, it was not until the 90's that physical barriers for all buildings were openly addressed through the Americans with Disabilities Act (West, 1991). Physical and social barriers are so intertwined that they cannot be considered in a vacuum, and the social and linguistic constructs dominated by the majority must be reexamined. Pimentel (1993) points out that language reflects, reinforces, and shapes our perceptions of people. If we describe the people that we serve under a paradigm that constructs disability as illness or deficiency, we look at them in expectation of inadequacy rather than as a diverse group with different strengths.

Currently, I work in an early intervention program. I have been observing the impact of a child's disability on the parents and have done quite a bit of research around the trauma these parents experience. There has been a shift in the roles parents assume in relation to their child with disabilities and the professionals they meet with so frequently. Turnbull and Turnbull (1990) describe a shift from early in this century, when parents were considered the cause of the disability or the source of the problem, to the present, where parents are becoming equal partners as advocates for their child. As we near the millennium, parents are organization members, service developers (e.g., Association for Retarded Citizens of America), learners and teachers, and more. They are no longer expected to be passive recipients of decisions made by professionals. Their roles as advocates and educational decision makers have brought parents into partnership with professionals on individual education plan (IEP) and individual family service plan (IFSP) teams. These relationships have ranged from weak and ineffective to points of major confrontation to productive partnerships, depending upon team dynamics. Nevertheless, with children with disabilities no longer being hidden away, parents have become strong voices in the treatment and services offered to their child.

When I began my career in human services, I did not recognize that there was a need for empowerment of the individual until I had a supervisor who believed in respecting individuals. I was raised to avoid eye contact with people with disabilities whom I did not know. Human services were delivered through the lens of the expert who knew what was best. Now, as I approach the twenty-first anniversary of my first human service position, I look back on the changes that have occurred in our social and linguistic construct of disability. I would like to believe that being a minority in this field has prepared me to respect each person as an equal without question. The truth goes back to the moment at the People First Conference when I realized my self-importance was wrapped around being needed by my clients. It was not until I had actually worked, side by side, with people with disabilities that I learned that disability does not equal less.

As we round the millennium, the linguistic construct for people who do things differently because of an impairment are "people with disability," the People First protocol, a reminder to see the person, whatever the disability, first! New paradigms view disability as a diverse way of doing life activities, consequently one is not "wheelchair bound" but a wheelchair user. Individuals with varying disabilities want and should be granted the respect sought by other diverse groups. Just as all of us have been challenged by the civil rights movement to rethink societal ethnic and gender roles, I must also rethink my understanding of the role of human service professionals. I must recognize the collaborative relationship between the human service professional and the person with a disability. People with disabilities have been made invisible by segregation, discrimination, isolation, and marginalization on many levels during this century. In the next millennium, we must collaborate with people with disabilities who have boldly spoken for their civil rights and individuality.

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Winter 2001

PSYCHOTHERAPY PRACTICE: STORIES OF GROWTH AND CHANGE IN CLIENTS, PROFESSIONALS, AND HELPING SYSTEMS

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From My View Everything is Clear: Building on Family Strengths

As a social worker and specialist in working with children with disabilities and their families, the author always tried to see the strengths in all her clients and to empower them to fulfill their maximum capabilities. In this narrative, the author recalls the first time she worked with a client who was blind and the many lessons she taught her about the special vision of persons who are blind or partially sighted. The author learned the importance of advocating for the parents as they struggled to maintain their young sons, who were also blind, at home when other professionals had a different vision of the family and could not see beyond their limitations.

by
Lonnie R. Helton

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Blind and partially sighted persons often fail to see why the rest of us cannot see life from their perspective. Having worked with many such adults and children, I believe that I have, at least to some degree, been made aware of this paradox. I began to think much more about it upon seeing *At First Sight* (Winkler 1999), a recent Hollywood movie adapted from neurologist Oliver Sacks' case study of Shirl Jennings who was reported to be one of only 20 totally blind people ever to regain their sight. In the film, Virgil (pseudonym for Shirl), the main character, states that sighted persons do not really understand how blind individuals perceive the world and those living in it. He suggests that blind persons learn to rely on all their senses in navigating their environment and relating to other people. They trust this intuition to discern what seems comfortable and right to them.

Beginnings

These thoughts made me think of the first blind person I ever worked with as a professional social worker in a diagnostic center for children with multiple disabilities. Her name was Velma Hoffman*, the mother of one daughter and four sons. All the sons had inherited aniridia, an x-linked chromosomal condition (C.F.A. R., 1999), which causes partial blindness. Velma insisted on being called by her first name. She was always baffled by others' inability to recognize her strengths and to understand her as a parent and as a woman with disabilities. She always said to me, "From my view, everything seems clear," and she was more than happy to tell anyone who was willing to listen and try to understand. Velma could express her thoughts well.

I first became involved with Velma when I received a call from Dr. Friedman, a pediatrician at the Diagnostic Center. Velma's youngest sons, David, age 5, and Billy, age 3, had been referred by the local school district for a developmental assessment for school placement. This was to be the beginning of a five-year professional relationship as case manager and counselor for Velma and her family. Dr. Friedman had said to me on the phone that of all the social workers in the clinic, she thought that I would be best

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*All names used in this narrative are pseudonyms.

suited to work with the Hoffman family. However, Dr. Friedman forewarned me that Velma was a rather difficult and somewhat obnoxious woman, who needed much assistance in understanding the diagnostic work-up of her children. Dr. Friedman had just completed her physical examination of the boys and was standing outside her office door. She grimaced and shook her head as she prepared to open the door and whispered, "A home visit is a must in this case, but you must first meet her (with an emphasis upon her)." When we entered her office, she quickly introduced me to Velma and said, "and these two are David and Billy." She then excused herself and said she had a meeting, yet welcomed me to use her office for the interview.

Velma invited me to sit in the chair next to her so that she could see me better. She was a short, large woman with long, jet black hair pulled back into a pony tail. She was wearing large, oval-shaped glasses with thick lenses. She explained that though legally blind she could still see shadows and fuzzy images. Velma said almost immediately that I sounded "nice" and added that Dr. Friedman did not like her. When I asked what she meant, she said, "I don't know, it's in her voice, I just felt it throughout." Realizing that Dr. Friedman did tend to be direct and straightforward with parents, I said that was "just her way." I was to learn later that she truly disliked Velma and wanted to have as little as possible to do with her.

Velma told me that she did not usually trust agency people or doctors, but that she wanted her boys to get the good education they needed. I assured her that the center had many resources and that I was pleased to be able to work with her. She said, "I guess Gerald (her husband) and I are just a little funny like that, but we have reason to be." Then she told me in detail how her three older children from her former marriage had been removed from her home by child welfare and that she never thought that she would have a family again. However, she and Gerald now had David and Billy and they wanted to make sure that they did not lose the boys to the authorities. She added, "A lot of people out there do not think that I am fit to raise my sons because of my blindness, but we manage fine when people stay out of our business." I explained that the staff at the Diagnostic Center shared her concern about her sons' developmental delays as well as their need for appropriate school placement.

Velma leaned a bit closer to me and asked, "You don't sound as if you come from around here?" I said that she was right, that I grew up in the Tennessee mountains and went to college in Kentucky. She retorted, "I knew it . . . I'm originally from West Virginia, you know. I miss it, especially when people start calling me and asking me questions . . . I could just tell that you could somehow understand what I was saying." I told her that I was pleased that she could trust me and reassured her that I would be her ongoing social worker. As we set a home visit, she informed me that Gerald would be at work. She noted that he was shy anyway and he preferred that she attend to the children's doctor visits and school planning conferences. She added with a chuckle, "And he knows how much I love to talk to people . . . I'd rather talk than eat."

After the meeting I conferred with Dr. Friedman about my contact with Velma and noted her strengths. Velma was open to the evaluation process for both boys and understood her sons' medical and psychological conditions, especially their visual and behavioral challenges. Dr. Friedman listened only briefly before responding that the mother seemed curt, self-centered, and insensitive to the children's needs because she had left the room several times to smoke. I acknowledged that the mother had shared some feelings of discomfort about their interview, but I expressed confidence in my initial impressions of the mother and her willingness to work with me.

Collaboration

David and Billy Hoffman had been referred to the Diagnostic Center by the local school Evaluation Consortium which was headed by Dr. Julia Carson. At the initial school-agency conference, I suggested that I be the case coordinator for the Hoffman family. Dr. Carson agreed and further explained how much these children needed evaluation and service planning. She had met with Velma, both at school and at home, and felt that Velma wanted what was best for her children. Dr. Carson stated that David had been placed in a classroom for children with multiple handicaps and that Billy should also perhaps be placed in a similar special education class. I was impressed with Dr. Carson's empathy for the mother's efforts to rear two multi-handicapped children and with her assessment of the family's strengths.

She noted that Velma had always kept appointments with her, worked hard to stimulate the children's speech and language skills, and shared parenting responsibilities with the children's father. She elaborated upon Velma's strong bonds with her sons and was impressed with the mother's intuitive questions, her sense of humor, and her astute ability to describe David's and Billy's behavioral and interactional patterns at home. She stated, however, that other school staff, especially the principal, did not share her sentiment about the family. They believed that both boys should be removed from the home and placed in a residential blind school about 100 miles away.

In addition to their visual disabilities, the boys were described as having moderate to severe mental retardation, impulsive behavior, head banging, limited self-help skills, little communication ability, and poor gross motor skills. Dr. Carson indicated her willingness to provide directly or contract out for any special education and/or treatment services necessary in order to keep the children at home. I could sense Dr. Carson's genuine concern for this family and was impressed by her insights into the mother's positive qualities and her resilience. I sensed that this family would need strong advocacy and mediation. Moreover, I felt that I would be able to rely on Dr.Carson to support this family within the school system as well as in their community.

The Family

When I arrived at the Hoffmans' home, the bottom flat of an old, two-story building, no one answered the door. Just as I was about to walk away, I heard Velma's deep voice say from a distant room, "Come on in, it's unlocked." I identified myself and opened the door. I was surprised that the house was almost totally dark. The shades were pulled and there were no lights on, except for a dim lamp in the corner of the sitting room, from which Velma was calling to me. She said that she was glad that I could accommodate her by coming out to her home. She explained that the boys were napping in a back bedroom and began immediately to tell me her story. It was a tale of heartache, depression, and loneliness. Velma was born with aniridia, a rare genetic condition which caused her to be born without irises in her eyes. She had learned with much dismay that she had a 50/50 chance of passing the disorder on to any offspring she might have. Nevertheless, Velma had resolved to marry and have children. She hoped for the best and took a chance. She married Henry Barker, a factory worker, and they had three children, two sons and a daughter. The daughter had normal vision, but both sons were born with aniridia. Velma had been devastated, thinking that she had been punished by God.

Still, she did her best to care for all three children and the family got along well until the children entered public school. Several complaints were made to the child welfare officials by neighbors and school personnel accusing Velma and Henry of neglecting the children's personal hygiene and failing to provide close supervision. Apparently, the accusers viewed Velma's disability, legal blindness, as a major compromise to her capacity to care for three children, two of whom also had disabilities. Neighbors felt that Velma could not closely supervise the children's play in the yard, while her husband was at work. They were also concerned because she sometimes relied upon her best friend, Terri, to babysit while she volunteered one day a week at a workshop at the Association for the Blind. Velma stated, "I feel like it's my duty to help out at the workshop; I enjoy helping others and, besides, unlike the others, I do have some vision for which I am grateful."

During this time, Velma saw a psychiatrist several times for her depression. He placed her on medication, which she stopped taking shortly after the therapy ended. After about an hour of giving details about her earlier family life, Velma noted that it should have been clear to the social workers and to the judge involved in her case that she was not abusive or neglectful. She had grown up in a close family and was always taught to trust in God, treat others fairly, and rely on her own good sense of what was right for her. Velma felt that the court had ignored her strengths and viewed her only in terms of her disabilities; thus it ruled to have the children removed from her home.

She was even more disturbed that the children were placed in the home of her only sister, Wanda, who was six years younger. Wanda had no children although she had been married several years. Velma and her sister had always been close. When they were younger, along with their brother Clay, they sang in the Baptist church choir. They loved to harmonize and became so good at singing a cappella that they were often asked to sing at church picnics and dances. Velma felt betrayed by Wanda whom she said had stolen her "babies" away. She had never forgotten the way the children clung to her the day they were removed by the social workers and taken to Wanda's home, located 45 miles away. Without easy transportation, Velma and Henry saw the children only every three to four months, but were never able to contest the removal in court. Still, Velma was consistent in calling the children until they no longer seemed to respond to her as a parent figure. She regularly wrote letters, and when she did not receive a response from either her sister or her children, she assumed that Wanda had not shared the letters with them. Afterward, Velma did speak with Wanda's husband, Ray, who before he hung up the telephone on her told her not to call back. Permanent custody was eventually given to Wanda and Ray, shortly before Velma and Henry divorced.

Again, Velma felt she had been dealt a terrible lot in life. She was alone and faced each day with courage and with a prayer that somehow she would get her children back. She noted that those had been the darkest days of her life, as she struggled to find new meaning. I was astonished by her endurance and remarked how strong she had to be to get through this crisis. Though she remembered feeling that her life was fruitless, she came to draw on her own strength and steadfastness that she credited to her father, whose will had been unfailing. He always told her, "Whatever happens, never give up." Velma continued to maintain hope that she and her children would one day be reunited.

She started spending more time at the Association for the Blind doing volunteer work in the adult workshop. She enjoyed the company of other blind and partially sighted persons and through this organization was introduced to audio cassettes or "talking books" for the blind. She read the Bible again daily which she felt brightened her outlook and instilled a renewed sense of hope. She became an avid reader of novels and never failed to get the latest Stephen King horror story. Velma said she liked Stephen King's style of writing and loved to be "scared to death" by reading his stories late at night. She had added, "They seem so real and they make you feel alive, like you're right there. I can picture in my mind everything that's happening and it allows me to escape for a time all my problems and worries."

She happened to meet Gerald, age 39 at the time, quite by surprise at her girlfriend's house where they were both dinner guests. They were instantly attracted to one another although their personalities were quite opposite: Velma being the outspoken one and Gerald being the more reticent and soft-spoken one. Velma said that Gerald had been so kind to her from the outset and was a wonderful listener. Although he was sighted, she sensed that somehow he could empathize with her pain. He too had grown up in rural Appalachia, so they seemed to have many common values. He had had a difficult first marriage, though, and his wife had abandoned him for someone else. He had no children and went along with Velma's suggestion that they have children of their own. He understood the risks involved: the children possibly being born with partial blindness and the fact that they were both in their late 30's.

Assessment and Intervention

As the boys underwent multiple psychological, educational, language, and psychiatric evaluations, I helped Velma understand the reason for each examination and explained each testing procedure. During many of the tests, Velma and I were able to sit in a room with a one-way mirror so that I was able to describe what was happening at each stage of testing and answer her questions. I could sense that some of the evaluators had difficulty communicating with Velma, and she found this most frustrating. She did not fail to speak her mind. She challenged even the most implacable diagnostic professionals with her specific questions about child development and her sons' adaptation to educational stimuli. As her case manager, I encouraged her to ask questions, share her ideas, and take an active role in the evaluation process. I have no doubt that the evaluation team learned a great deal from Velma's insights and her sharing of communication strategies used with David and Billy. For instance, she had a soothing style of speaking with the boys when they had behavioral outbursts or began to self-stimulate. The boys would at times cling to their mother when more than one person was in the room and tended to sit on either side of her. David and Billy demonstrated little communication with each other, but Velma was determined and never stopped trying to get her sons to interact.

Each day of the evaluation process, I recruited a social work field student to escort Velma and her sons to the cafeteria for meals. Generally, this situation turned out to be rather chaotic as the children became increasingly more unmanageable when around a large number of people. Nevertheless, Velma remained positive. She laughed and proclaimed that even the cafeteria food was tasty when compared to her or Gerald's cooking. About this time, I remember attempting to assist Velma in locating the corridor back to the Diagnostic Center. She beckoned me to allow her to lead me; she added, "I appreciate the offer, but it is much easier for me this way." I learned a significant lesson from her about blindness. Blind and partially sighted persons have their own views and routines, which if disrupted, may create unnecessary confusion. I appreciated this new awareness and have applied it effectively many times in my interaction with other blind clients and students.

During my work with Velma, she would often bring up her blindness and the bitterness she had held for so many years toward her sister for having taken custody of her three older children. She also regretted that she had not been able to go to college, feeling that she was intelligent enough and capable enough to have been successful in a career, such as writing or journalism. Velma tended to emphasize past shortcomings and previous events over which she had no control. Therefore, the therapeutic strategies I used to work with Velma and her family were more solution-focused than problem-focused.

Solution-focused treatment seemed to be an effective modality for Velma. I saw her and the children at least every other day during their two-week stays at Ronald McDonald House when both boys were undergoing diagnostic testing. In these meetings, I emphasized present events and short-term goals for the future and helped Velma to reshape descriptions of her personal and family life (Friedman & Fanger, 1991). For example, Velma tended to say, "If only I had made the right choices, then my life would not have been so disappointing." We speculated about what her life would be like today, for example, if she had not lost custody of her children, or if her sons had only been born blind, but not autistic-like as well. We discussed how although she could not change history, she had many opportunities to revise her perceptions of her life. We focused on her strengths and discussed how she could achieve a renewed sense of purpose and well-being. Velma had been happy throughout much of her life, but confessed, "Sometimes I wallow so deep in my misery that I lose touch with what's good in life."

I would encourage Velma to recount her strengths and successes. She had grown up in a close-knit family where everyone enjoyed singing and telling stories in the evenings. I encouraged her to talk about what she had learned from the stories her parents had told in the mountains. Velma said she learned to be brave and to have faith that hardship would not last forever, and that each new experience in life adds to one's wisdom and sense of freedom. Velma laughed and said that once the family exhausted or became tired of the storybook tales, they made up stories of their own as they sat around the fireplace after long work days on the farm. They laughed and concocted stories about the farm animals, school activities, and the preacher at church, especially when he ignored the fact that ministers also are fallible. I could tell that Velma's self-confidence, fortitude, and resilience were rooted in her family values and traditions.

Once the diagnostic evaluations were completed, I convened the interdisciplinary team to integrate the test results and to develop an intervention plan. The children were both found to be autistic and to have retardation. David, the oldest, was found to be severely retarded, and his younger brother, Billy, tested as moderately slow. Both boys were severely delayed in speech and language communication and self-help skills.

At the meeting were Dr. Carson from the school district, David's classroom teacher, and the school principal. Dr. Friedman, the team pediatrician, expressed her views of the mother's seeming incompetence. I elaborated on the family's struggles and their sincere attempts to raise these boys on a limited income and with challenging circumstances. She expounded upon the placement of Velma's older children outside the home and the mother's seeming inability to care for herself and the children. I reinforced the parents' commitment to these children and redirected the discussion back to the children's needs. I emphasized the family's willingness to receive necessary services for the boys, at school and in the community.

Some team members did not seem to understand the father's "silent" role in this family and deduced that perhaps he was unsupportive of the mother.

I described the arrangement for parenting and child care from a cultural perspective. The father did most of the cooking and dressed the boys for school while the mother washed dishes and completed other household chores. From my experience, this pattern is fairly typical in Appalachian families where the mother is also disabled or incapacitated. Appalachian fathers generally leave school contacts and other outside agency meetings to the mother.

The special education teacher was bothered by the mother's seeming inability to understand the routines of the classroom and thought that David needed more structure. The principal vociferously agreed. He said if the mother did not stay up late listening to old movies on television and reading her talking books, perhaps she could be more consistent with the boys' discipline at home. I defended the mother's right to stimulate her mind and acknowledged her personal strengths and expectations for her sons and her desire for both sons to reach their maximum potential.

With Dr. Carson's support, we decided that David would remain in his present special education program, with additional speech and psychological services, and Billy would be placed in a similar class. Both boys were to receive special services from a consulting teacher who specialized in designing classroom activities for blind and visually impaired students. Dr. Friedman continued to question throughout whether this family would be able to meet their sons' needs, considering Mrs. Hoffman's "obvious parenting constraints" and her husband's seeming lack of concern by his absence during the evaluation process. She and the principal raised the possibility of whether the boys should be removed by child welfare or placed in a residential School for the Blind.

Once again, I managed to refocus the discussion around the family's strengths, rather than their perceived limitations. In the end, as the family's advocate, I was able to minimize much of the negative thinking within the meeting. I now look back and regret that at that time family-focuse early intervention was just beginning to emerge as a trend in the field of developmental disabilities. Judge (1998) has stated that family-centered early intervention should identify family strengths and capabilities so that all interventions may be built around things a particular family does well. It was unfortunate that several members of the interdisciplinary team could not identify with this philosophy of building on the family's assets as a way to enhance the lives of their children. It was in this spirit that I had worked all along with this family and would continue to do so in providing services.

Velma asked many questions during the final meeting to impart diagnostic findings and seemed pleased with the results. She seemed disillusioned by David's low evaluation scores. While she hoped that he would do better, she remained opposed to residential placement of any kind and reaffirmed her faith in getting whatever services the children needed. At Gerald's request, I shared the diagnostic findings with him over the phone and planned a visit to the home. He was concerned about his sons and asked several matter-of-fact questions about school placement and prognosis. Within a few weeks the recommended special education programs were in progress and the boys were thought to be making some minimal gains. However, the Hoffmans bought a mobile home on two acres of land in a rural area some 50 miles away. Velma said that she and Gerald had always dreamed of having their own home and that they both preferred country life. Later, she confided in me that the school officials had persisted in recommending the blind school and that she had gotten "scared." She stated that she had made some mistakes in her life, "like everybody else," yet did not feel that she could survive if these children were removed or placed outside the home for schooling.

After Velma and Gerald Hoffman moved away from the city, I did a home visit to support the family in locating school and treatment services in their new county. I was pleased to learn that Dr. Carson also served as regional coordinator for several rural counties and scheduled a meeting with her and the Hoffmans at the boys' new school. Dr. Carson had met several times with local school officials and arranged for Velma and Gerald to visit the residential blind school. Velma and Gerald persisted with their plans to keep the boys at home. I supported the family's views and felt that these children's capabilities would be maximized at home, given the parents' cooperation and willingness to work closely with Dr. Carson and the special education teachers. After a few weeks, the school decided that David's serious speech delays, and attention problems warranted placement in an intensive class for visually disabled children. Velma was excited about Billy's improved self-help and social skills and said that he and fellow pupils went into the community each week to wipe off tables at a fast food restaurant. Yet, her exuberance was inhibited by her observation that David's progress was slow and that he was getting "bad about slipping away from her and hiding." This comment would prove to be foreboding.

Some of the members of the staff in the new school district dwelled on the family's challenges in caring for the boys, but Dr. Carson and I continued to advocate for the boys to receive community-based services. We also arranged for the mother to ride the bus with David to school one morning a week so that she could observe her son's progress and participate in special classroom projects along with the other parents. Velma said that once the other parents realized that she could "see things" her own way, they accepted her and she enjoyed the visits. Although the long bus ride to another school concerned her, she felt relieved that David would not have to be placed in a residential school for the blind and could still live at home. Still, one staff member had called the child abuse hotline, but neither abuse nor neglect could be substantiated.

David got pneumonia one winter and was admitted to the convalescent hospital affiliated with the Diagnostic Center. Velma called me immediately and I visited them daily on the unit during his two-and-one-half-week stay. I was surprised to see that Velma had shorter hair, dyed blonde and stylishly coiffed. She laughed and said she knew "Gerald deserved to live with a Marilyn Monroe look-alike at least for a few years before he got too old to enjoy it." She went on to say that she was happy living outside the city, but she missed her friend Terri whom she had known for more than 12 years. She chuckled and said that after her first husband left her, she and Terri had raised Persian cats for sale. They loved working together and the business was lucrative, but they had to close it down when Terri's daughter developed allergies. Terri came by several times to visit and would stay for hours. Velma was delighted, and I was able to obtain a tape player from the center so that they could listen to Velma's talking books together.

As she described her life in the country, she seemed content. She had a husband who fully loved and supported her and their sons and never looked upon her blindness as a major hindrance to their marriage and family life. Gerald supported her in daily household responsibilities such as cooking, cleaning, and bathing and dressing the children. Velma loved telling the boys stories from the Bible and recalling favorite times from her childhood in West Virginia. She reflected on walking to school on sunny spring mornings, smelling honeysuckle vines on the garden fence, and going with her sister after the cows, listening for the cowbells and chirping crickets. Moreover, they had been able to keep a budget and save enough money to buy a small piece of land outside the city for their mobile home and took delight in putting out a garden. Gerald had even bought an old car and Velma said that they loved going for long rides to the lake on weekends.

During one of my visits on the ward, the nurse came by and informed Velma that the hospital planned to have a "balloon release." Each hospitalized child's name was to be placed in a balloon and the finder would be encouraged to call the hospital immediately so that the child would be eligible to win a cadre of prizes. Although Velma was reluctant to enter David's name, I encouraged her to do so. We were both surprised when a hunter on a mountain in New Hampshire found the balloon and called the hospital. David was a winner and Velma was ecstatic. She and David were treated to a special luncheon at a fine restaurant, with me as their special guest (Gerald stayed home with Billy, saying that he didn't like big crowds). We went to the restaurant in a huge white limousine and David sat quietly by his mother. When we arrived at the Diagnostic Center's recreation room for an afternoon party, including local radio personalities, the staff gathered to learn what celebrity might be visiting the hospital. When Velma and David emerged from the limousine, with me right behind them, Dr. Friedman, who had been on vacation and did not have a clue as to what might be happening, was visibly astounded and muttered, "This is impossible. I thought this could be the First Lady visiting us again." Everyone congratulated Velma and David, and even Dr. Friedman expressed her pleasure about David's good fortune. Velma laughed all afternoon and thanked me again for encouraging her to enter David's name in the contest. She said, "This has been the most special day of David's life . . . and you know how much I enjoyed having Dr. Friedman see me as Queen for a Day." She added, "I know she's a good doctor, but we just never hit it off." David laughed along with his mother, and Velma absorbed all the attention provided by the staff and the children from the convalescent ward.

Tragedy

I will never forget David's funeral on a warm, sunny afternoon during late springtime. David had climbed out the bathroom window, wandered away from his parents' mobile home in the country, and had fallen into a nearby pond where he drowned. Velma called me and talked at length about David, herself, and her misfortunes in life. Despite all her troubles, she had not expected to lose a child, and especially not like this. She had been up most of the night listening to her favorite author, Stephen King. Usually, while she slept in the afternoons on weekends, Gerald sat with the children, but this time he had gone to town. Unfortunately, she fell asleep, as she had many times before, and blamed herself for David's death. She sobbed endlessly when we talked and she made me promise her that I would be there for the funeral. I promised.

Only a handful of people was at the funeral home, mostly school staff and social agency staff, like me. David was dressed in new blue jeans and a T-shirt and was wearing white tennis shoes. I remember Velma smiling just a bit and saying, "He looks so peaceful and normal." I sensed her underlying pain and her words made me question why death has to come to a person with disabilities for others to view him/her as normal. At the cemetery, located about two miles away along a steep hillside, after a few prayerful words, Wanda stepped over and stood by Gerald and Velma. She was followed by Velma's older children: Marie, Jimmy, and Bobby. Billy was still standing close to me, just at the head of the grave, rocking and moaning as he peered down upon the small white casket. As I started to turn around, I heard Velma and her sister begin to sing a cappella that old mountain hymn, "What Wondrous Love Is This" (Means, 1994), and that beautiful harmony resounded across the hillside. I will never forget Velma's tears as she looked toward the grave and then gazed back at her sister as they chimed, ". . . and when from death I'm free, I'll sing on . . . and through eternity I'll sing on." At that moment in time, I sensed the renewed bond between Velma and Wanda, and their shared love for the children.

Velma had always wanted David to be normal, to talk like other children, to really understand her words and her concern and love for him. And she still wanted the same for Billy. Somewhat ironically, I thought that this reunion with her family gave her some peace at one of the most difficult times of her life. I learned later that it was Gerald who made the call to Wanda the day that David drowned, and that Wanda and the children spoke with Velma by phone before coming to visit them at the house. Velma said that she was glad that Gerald had broken the silence and called Wanda during this time of crisis. He also had been bitter about Velma's loss of the older children, because he knew how close she and her sister had once been. And he told me that because of their extreme grief, he felt this might be an appropriate time for them to reconcile their differences and come together as a family.

I met with Velma and Gerald Hoffman a few weeks after the funeral and they shared their regrets and their sadness. Velma talked a lot about how Billy missed his older brother and would sometimes call out his name at night. They had been taking turns getting up to check on Billy and were planning a trip to visit Wanda. Velma said, "Now that David is gone, I want Billy to get to know his other two brothers and his sister." And even after all that had happened, Velma and Gerald did not regret leaving the city and moving to the country. They felt freer there, and I knew that they felt more comfortable living farther away from the school staff who could not seem to understand their special family dynamics and unique ways of coping. Frankly, I was surprised that the local school officials and child welfare workers did not investigate the family for child abuse again because of the circumstances of David's death. I suppose they felt that the family had been through enough, and they were impressed with the family's compliance regarding the school placement. Velma said that she was pleased that her sister had brought the older children to the funeral and felt that now, after their long estrangement, she had a fresh start with Wanda and the children. And she seemed to be coping somewhat better with the guilt experienced earlier. I acknowledged this progress, and she said that people have to go on with life, adding "You can never give up." She had resumed her reading at night, although she and Gerald were much more vigilant about Billy's whereabouts.

During a follow-up visit, I learned that Billy had started to help his mother with the dishes, after he and other special education classmates continued their weekly visits to a fast food restaurant to wipe off tables and fill napkin holders. Velma lauded, "I'm so proud of him, and Gerald and I tell him that he has quit his head-banging and rocking and can now sit with me and listen to soap operas on television." Velma paused and then said she also was pleased that David's teacher had come out to the house and presented her with a scrapbook of his work.

Conclusion

As I look back, irrespective of her reasons, Dr. Friedman had exercised good judgment in assigning Velma and her family to me. I feel that I really got to know this family and was able to help them move beyond the prejudice and stereotyping of other professionals in the Diagnostic Clinic and the school district. Somehow, I reached this family and truly engaged them. Was it because Velma and her husband had grown up in Appalachia, and we had a common cultural bond? Or was it because I tried to understand Velma's way of viewing the world? I do know that I always tried to focus on her strengths, despite what others thought about her parenting capabilities. Velma had a special, positive way of gaining compliance from the boys by using a soothing tone of voice and by gently touching them as she redirected them. Also, her lively sense of humor emerged when she would turn Billy's baseball cap backwards and chuckle, "All little sluggers wear their hats like this." After a few attempts at trying to turn his hat back around, Billy would burst out laughing and give his mother a big hug.

Velma Hoffman is a client whom I will never forget. Yes, she was at times resistant and could easily be perceived as demanding and manipulative in getting her needs met. But throughout my work with Velma, I attempted to get her to realize her capabilities and concentrate upon solutions to problems and positive changes that might enrich her life. In turn, Velma Hoffman taught me much about strengths and survival, that despite many setbacks and shortcomings and regrets, one must move on. I remember her as intelligent and intuitive, with a keen sense of self and a vision of what she wanted for herself and her family. She once told me, "When you cannot see, you have to be twice as forceful with your words." And I can see now how this attitude strengthened her view all along and enabled her to cope with so many adversities as a woman and mother. I know she has inspired me to always look for the strengths in my clients, as well as in myself. Saleebey (1997) pointed out that a "strengths approach" honors "the innate wisdom of the human spirit, the inherent capacity for transformation of even the most humbled and abused" (p.3).

Velma had a special vision that made her a survivor and through my relationship with her I became more able to encourage my clients with disabilities to move beyond their feelings of powerlessness and to acknowledge their strengths.

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Overcoming the Tyranny of Space: Experiences of Multiple Sclerosis Patients

Narratives of MS patients, obtained through authors'research on their activity space, have revealed innovative ways in which patients overcome spatial constraints. These narratives reveal MS patients not merely as passive sufferers but as people actively engaged in enabling, even ennobling, themselves to have varied and positive experiences toward leading a meaningful life. MS patients' ability to overcome many spatial barriers has, in fact, been an important factor in reevaluating the authors' own views about disability experiences.

by
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"Space is a tyrant and distances enforce his rule. He militates against us, often disposing of what we propose if our plans ignore his influence. The revolution against him is already well begun, however. Among the most disloyal subjects are geographers and regional scientists. "
William Warntz (Presidential Address for Regional Science Association 1967, p.7)

Warntz's statement holds very true for (MS)Multiple Sclerosis patients, for whom space is indeed a tyrant, posing a major barrier in performing their daily life activities. Most activities of daily living are generally performed in assigned spaces. In a capitalistic and modern society, the home space is very distinct and separate from spaces assigned for work, education, shopping, banking and recreation. To be able to perform activities successfully at these nodes, one needs the ability to overcome spatial distances and obstacles. When disability in the form of MS strikes, it severely restricts mobility and impacts directly on this ability to negotiate space. It becomes very difficult, sometimes impossible, to perform work-related and routine activities of daily living. Despite these constraints, many people with MS are able to overcome the spatial barriers and obstacles. How they are able to transcend spatial constraints is the underlying theme of our research and these narratives.

About MS

MS is an unpredictable chronic disease that frequently results in several disabilities such as restricted motor abilities, coordination, vision, strength, speech, bladder control, and other faculties governed by eyes, brain, and spinal cord, which greatly curtail the mobility of individuals (Lechtenberg, 1995). It strikes individuals in the prime of their life, between the ages of 20 to 40 years, thus devastating many a life's plans and paths. Though the disease remains a mystery in terms of its cause and cure, some facts have been established. It strikes people of white races and more women than men in the ratio of 2:1(Lynch & Rose 1996).

Context

Our study was part of a larger study on the activity space of MS patients in the Akron (PMSA) and Canton-Massillon (MSA) areas of Northeast Ohio, this being one of the high-risk areas for MS in the United States. In-depth interviews were conducted with 53 MS patients between the ages of 20 and 55 years. We selected from our research narratives of only female MS patients to illustrate how they incessantly try to overcome the "tyranny of space" (a phrase coined by William Warntz, 1967); that is, they try continually to engage in routine daily activities to maintain, even enhance, the quality of their lives. Often the invisibility of the disease and its symptoms becomes a cause of misunderstanding between the patient and the family, the caregivers, and the society, leading to increased stress for the MS patients.

Narratives of Overcoming Spatial Constraints

In performing their daily activities, the MS patients, conscious of their spatial and social limitations, give much thought to planning. This is illustrated in the narrative based on an interview with a 49-year-old Registered Nurse, who has stopped working due to her MS and related stressful job conditions. Though she has no outward signs of the illness, she is suffering intensely:

"The thing is that if I'm gonna go upstairs, I'll get everything upstairs done that I want to get done, until I have to go back up to bed at night. And if there's anything down in the basement, I get it all done when I am down there the first time. I don't want to go back down unless I have to. Like right now I am doing a wash downstairs. Now I pace myself as to how frequently I am going to go up and down the steps. And while I was down there, I cleaned up the cat litter boxes, because they needed to be done, so instead of making another trip down there, I just, you know, you stand in the middle of the floor and look around and say, OK what needs to be done here, get it done now, and the same way upstairs, you stand in the middle of the floor upstairs, in the hallway and you look around and say, OK the beds are made, the clothes are put away, you know, it's dusted up and swept, the bathrooms are clean, OK let's take my bath, let's get me cleaned up, and then the last trip up here will be for bed at night, and that's what it is. If there's things that I need during the day, if someone's here, I send them up to get it for me, if not, then I wait or do without. It's called conserving energy. You know, it's a weird disease. You know, you are very limited in what you can do. You really have to plan how to do things. You know, like if I know we have a Christmas party Saturday, I would do nothing Saturday, nothing, so that I have all my energy to be able to get ready. To get ready, I know it's going to take everything out of me, so I may get ready for this party two hours in advance, so that I am able to get myself dressed and sit down here on the couch, long enough to get my strength back up and again to get out to the car, to go to the party. You just have to do a lot of planning, you know, for somebody that has MS, to be able to get around."

The narrative illustrates how she negotiates home space and how those with MS need to plan for every activity they perform to save energy, reduce fatigue, and increase efficiency. Unfortunately, the spontaneity of performing certain tasks is taken away; each task becomes an immense project. This individual, however, uses meticulous planning, given her limitations, to perform household tasks that are spatially proximate.

The narrative also highlights the layout problems of a two-story home with a basement and two flights of stairs. Such a fragmentation of living space with upstairs bedrooms, laundry in the basement, and living room and kitchen on the first floor hinders accessibility and leads to dependency on others for small tasks like carrying laundry or fetching something from upstairs. By bundling activities together and by planning, the MS patient tries to overcome the architectural constraints of such a dwelling place. Through effective activity planning, even in a poorly designed dwelling, this innovative nurse with MS has been able to maintain a sense of independence, so highly valued in our society.

The second part of the narrative depicts how an exciting socio-religious occasion, a Christmas party, could become a great burden for someone with MS. But instead of withdrawing from her social commitments, this individual has developed a well-planned strategy to conserve her energies so that she can drive to the party and thus continue to stay socially engaged. She overcomes the tyranny of space through personal planning.

The next narrative from an interview with a 40-year-old female, earlier a Realtor and now a receptionist/secretary, is an example of a spatially "non-fungible" job activity, which the person substitutes with a different and more suitable career adjustment. Spatially non-fungible activities are those whose location cannot be changed without significant loss of their integrity. A change of location results in the loss of participation in that particular activity:

"That was the biggest thing. That was my biggest adjustment, was my employment. I tried, I hadn't felt good as a realtor, sold houses. And for the last two years, I was on that job and I felt I couldn't do it, and I was really struggling, and my income went down, and I needed to find a different job so that I could have an easier time at work. Really, I got to say, this became my biggest adjustment, because the heat you know, affects you and I would be holding an open house, and they wouldn't have air conditioning, and I would get hot and then I would have trouble walking and plus you have to carry a lot of stuff when you are showing houses, you wouldn't think so, but you do, a lot of paperwork, briefcases, and that got to be difficult. And I needed to find a desk job, something that was not physical. So now I have an office job, and the air conditioning, not real physical and a steadier pay too, cause when I was selling real estate, that's real. It fluctuates, you don't know you are going to have money coming in or not, it was very unpredictable, and I said, my disease is unpredictable. I don't need everything in my life to be unpredictable, I wanted something that was steady and I knew I could count on it, you know.....I was a realtor for eight years; it was a big change. After finding out that I had a disease that was incurable and unpredictable, I tried to hang in there for a year, I worked a year after being diagnosed and I just couldn't do it, too difficult. It's very stressful, too, to sell houses, buyers and sellers, you know, arguing and getting mad at each other and I in the middle, you know. I just didn't like that."

This MS patient illustrates how, with increasing problems with MS, she changed her career path in order to continue being employed. She accepted the reality of her disability, but did not become disabled. She opted for a job that better suited her needs, a job that would be less physically demanding yet offered job security and provided a steady income. A realtor's job is not only spatially non-fungible but also spatially spread out. The receptionist/secretary job, though also spatially non-fungible, is confined to one location and is much less physically demanding. Thus, through substitution of a new career path, this woman with MS overcame spatial and economic uncertainties.

Next we hear from a 51-year-old divorced female employed as a program coordinator in social work, a very demanding job that requires much more than regular hours of work and also some traveling. While she meets her professional obligations, she is unable to devote the same energy on the social front:

"I don't visit as frequently as I used to. It's not that I do not keep in touch with friends, because I do. But a lot of us with MS are like compulsive people. I go in for work, as long as I do my 40 hours a week, I usually end up doing 50 or more a week, there's just so much that needs to be done. I am usually so tired that my weekends are so pressured. It's my time to withdraw and be refreshed. It's more that I talk to them on the phone than visit. I do have a problem with a lot of steps in a house, leading to their houses. I'd rather have them come to my house."

This MS patient expresses a need for spatial role reversibility and for spatial negotiation of social roles. She desires that friends visit her. In this situation the activity will be performed, but the location of the activity will shift to her home, allowing her to overcome spatial constraints and barriers, such as traveling distance and negotiating steps at the doors. This decision will help her conserve energy and simultaneously better fulfill her social needs, obligations, and relationships.

In the following narrative, a 51-year-old female, now a homemaker, describes how a home visit by a health professional can save an enormous amount of anxiety, hardship, and money when a person suffers from exacerbating episodes or attacks of MS. The spatially fungible aspect of medical services is well illustrated through this brief narrative. The shifting of some medical services to the home can be very helpful, save a lot of hardship, and improve access to health care delivery. Fungibility of services related to food and medicine is recognized by MS patients but needs to be realized more by the providers:

"This time when I had an exacerbation in August, I called up my doctor and told him that I do not want to go to the hospital. It's so expensive and so unnecessary as far as I am concerned. So the doctor set up a visiting nurse to come here. I have a tremendous rapport with him. It was a Saturday afternoon, and by 5:30 p.m. that evening I had the IV going."

All the above individuals suffer greatly from MS, and though they have no visible signs of MS, their spatial access has been deeply affected. The invisibility of the disease means additional stress for MS patients since the intensity of their physical limitations, suffering, and pain is not evident from their appearance. This often leaves them with the feeling that there is a lack of understanding of their problems by the able-bodied. All of them drive, three are married, and all of them live in personal houses.

The next brief narrative is that of an intellectually inclined 44-year-old female and retired medical social worker . She lives independently in housing for the ederly. She uses a wheelchair but does drive a handicapped-equipped vehicle:

"But the library book mobile comes here twice a month so I can request them to bring videos from the library. The library downtown is kind of hard to get into considering the parking, and you have to go down in the main floor which is in the basement, the wheelchair ramp is long and kind of steep so I use the book mobile from here. That is one form of recreation, I guess."

The library mobile service has great significance for someone who is well read, informed, and highly educated. The library book mobile saves her from enormous hardships of negotiating the barriers posed by the library building located in the crowded downtown since it is an older building with a steep ramp. Thus, with this service, she fulfills her recreational needs together with intellectual needs. The library is an example of an activity which can have both the spatially non-fungible aspect in the form of the library building, which houses all the books and media, and the spatially fungible aspect in the form of the library book mobile which delivers all the requested articles. The second option, of course, does not allow one to explore the library's resources and is simply a convenient substitute. In this instance a public service helps an individual overcome the constraints of space.

The same individual provides another example of how she uses a new technology — the Internet. At the same time, in the following narrative, she ponders the utilization of another kind of activity involving technology—Internet banking:

"I have a support group on the Internet that I can e-mail through, and it happens to be for lesbians with multiple sclerosis so there's about 30 or 40 of us nationally and internationally that are in this support group. So all I have to do is put my chair right over there in front of the computer. I don't know how to do banking; I need to find out though. My problem is I am limited with my computer. It's a very old computer. I don't have a big server that a lot of people use. Since I can't do graphics or anything like that, just text, I can't use AOL. I think I'd be limited in doing things like banking. I don't think I'll be able to do that. I suppose it can be done, but I am kind of leery about doing banking over the computer."

This narrative provides an excellent example of utilization of a new technology, the Internet and e-mail, for support, social and recreation purposes, a technology that clearly helps overcome barriers of space, time, and distance to allow like-minded people to join together and form activity bundles in cyber space. This person may be fearful of social marginality in the real world, but finds the Internet an empowering technology.

On the other hand, this individual has concern about one aspect of the new technology. Internet banking is a spatially fungible activity allowing one to perform numerous, though not all, aspects of banking from a personal computer. Even though the function is fungible, the person is not comfortable with the available technology to take advantage of it by substituting cyber space with metric space, for obvious well-known security concerns. But despite that, it does provide an option for one to avoid traveling to perform banking functions.

The final narrative, quite different from the above, is of a young student, single, female, 20 years old, who was diagnosed with MS three years ago. She lives with her family, who is finding it hard to learn to cope with the disease. She attends school at a nearby university and her narrative illustrates her mature approach to resolving her spatial problems:

"Most of my activity is right here, mostly at school, because everything is right there. I can walk to anywhere. I would have liked to switch to another university, one that does not have other businesses. Most of the buildings, like social security, all the main government buildings are right downtown. So if I ever need to go there, I know I need to go to social security a couple of times of year, I can just walk a block and I am there. So that is all it takes. I don't have to try to find a ride. I know that the other is a better school but it is more convenient for me just to hop on a bus and go downtown. I walked down to main campus, and then I started getting sick and I don't know what was wrong with me. I realized that I would have to go down to the C and T college (Community and Technical College) which is a small college in a college. It's all in one building, because I'd have such a hard time walking so I went there. I think it's the best decision that I have made. I just signed there for business management and some accounting. I will work for an Associate in Accounting degree or Public Relations."

She describes the reason for making a choice of attending her present university which she feels is more compact, better connected by public transit, and more conveniently located to her home and to other facilities as opposed to the other university. Her university is located in downtown, which is about 10 miles from the other. While she thinks that the other university has a better program, the more spread out campus and less accessibility by public transit pose major spatial barriers. Thus, by choosing the present university she overcomes the spatial barriers. Also within her university she decides to attend the Community and Technical College which, housed in one building resolves even more spatial barriers. Thus, she maps out her career path and her physical daily space, freeing them from as many spatial barriers as she can and at the same time overcoming the spatial non-fungibility of the university.

Reflections

Persons with MS must make many decisions in their everyday life. They have to continually devise ways to overcome numerous social and spatial barriers and constraints. Sometimes they circumvent space altogether. One of the ways is through the substitution of metric space with cyber space. For example, Internet banking can replace actual travel to the bank, or a visiting health professional may save a trip to a medical facility. Here a selective reversal of space negotiation takes place, in which instead of the individual with MS traveling to the facility, the provider travels, either in person or through cyber space. Thus, space is substituted either with a technological or a social transaction. The need by an MS person to travel to or be present at another location is obviated. Through this process, the home space begins to take on a meaning different from that of simply domestic space.

From all the narratives, we learn that disability should not be tantamount to disengagement. More frequently than not, it means even more active interaction with the social and spatial dimensions of the world. Adaptation and innovative modifications, impelled by a drive to maintain individual dignity, lead MS patients to strive toward a full and meaningful life. As we have already noticed, one individual consciously changed her career path from a realtor to a secretary in order to gain job security and to reduce spatial activity. The use of technology to overcome spatial barriers to social interaction is clearly demonstrated by the individual who uses the Internet to associate with lesbian support groups. Active and conscious planning decisions of the choice of school to arrange tasks to carry out routine household chores are all examples of conscious planning, decision making, and societal engagement.

Through this research we have become aware of the efforts of the MS patients to tame this tyrant and that more attention needs to be focussed on how individuals with MS are constantly in the process of taming space despite the constraints and barriers they encounter. Though space may continue to exact its costs, the positive striving of people with MS does need to be highlighted. As a result of our experience with MS patients, we have more clearly begun to recognize the limitations of conceptualizing human problems within one specific disciplinary framework. Whereas spatial (geographic) issues may be of critical importance from a disciplinary angle, social, psychological, and personal problems may be paramount from the MS patients' perspective. Therefore, interdisciplinary insights are necessary to address complex human issues such as disability. We have increasingly come to recognize that illness is a dimension of disability, but disability is not an illness. It has become necessary for us to reevaluate some of our attitudes about MS research.

Instead of conceptualizing research in terms of limitations and barriers alone, we have begun to redirect ourselves toward innovations, substitutions, alternatives, and other positive coping strategies in which persons with disabilities are active participants. Our research has helped us to overcome a stereotypical image of disability as inability. In addition, patient narratives provide human insights that numbers alone cannot. Methodologically our future research will draw attention toward developing measures of ability.

These narratives inform the geographic concepts of activity bundles, paths, projects, stations, and constraints developed by Torsten Hagerstrand (1970, 1975) and other scholars (Pred, 1977). Although the fundamental idea of different types of constraints (capability, authority, and coupling) are valid, we need to bring out the participatory role of persons with MS in overcoming these constraints. Hagerstrand (1975, pp.10-11) feels that constraints can be imposed by society and interact against the will of the individual. First, the capability constraints are "imposed by physiological and physical needs and some imposed by private and common decisions." These limit the activities of an individual because of biological construction (the need to sleep, to eat, to rest, for personal care) and/or the tools one can command (own a car or the distance one can cover within a given timespan). Second, "The coupling constraints refer to activities undertaken jointly, determining where and how long the individual has to join other individuals, tools and materials to form production, consumption, social and miscellaneous activity bundles. Examples are that student and teacher, customer and salesman form activity bundles." Third, authority constraints are when an individual's "set of potentially possible actions is severely restricted by the presence of other people and maze of cultural and legal rules." Time geography "focuses on the constraints which in both obvious and subtle ways limit the individual's freedom to move from station to station and choose activity bundles" (Pred, 1977, p. 638). Our focus has been on how MS patients overcome these constraints.

The significance of spatial constraints and barriers needs to be rethought. Patients may use their time and space differently and utilize the modifications as positive changes in their life, rather than as mere substitutes. By innovative thinking and adaptation, MS patients are able to circumvent space or chalk out alternative paths to perform their activities, thereby changing meanings assigned to different spatial locations. There is a need to redefine the meaning of home-based and spatially segregated activities. The boundaries between these seem to be fluid and in a constant state of flux with the changing manifestations of disability and the adoption of enablers.

Our purpose is to show not how helpless, but how innovative, a person with disability is. With more enabling technology and more active thought, the environment/space can be reshaped and reconfigured to suit particular individual needs. The person feels a degree of empowerment and not just helplessness. By focusing on the relative spatial fungibility of activities, we found that MS patients are actively engaged in shaping and reshaping their worlds, just as, if not more vigorously than, "able bodied people" do. Acceptance of such perspectives should help reduce stigmatization of patients and project a more positive image of people with MS as capable of shaping their environments, rather than accepting the tyranny of space, metric or social. □

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Coming Out: Claiming Disability In and Out of the Classroom

In this narrative, two social work educators, one with a visible disability and another with an invisible disability, tell us about their experiences with disability and how their decision to disclose has informed their students and colleagues and helped them claim disability as part of their identity.

by
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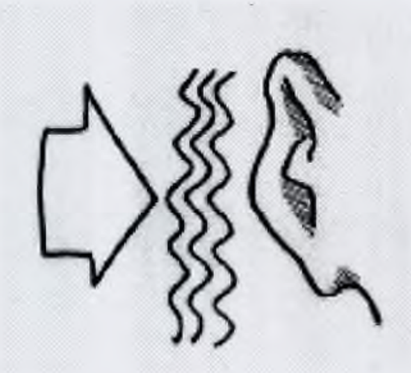


"Should I tell my supervisor that I am in Recovery?" "How should I answer clients who ask personal questions about me?"

Issues regarding how much one should disclose to clients (and colleagues) come up early in social work practice classes. Some students use self-disclosure as a means of reducing anxiety or as a means of short cutting the path to establishing rapport or building a relationship with clients. Most experienced practitioners urge the usual cautions when dealing with beginning relationships. The rule of thumb is that personal inquiries, at least for beginnings, should be deflected and one common technique is to ask the inquirers why it is important to them to know. Also, we teach that personal disclosures should be purposeful, that is, related to the nature of the contracts between the parties, and that self-involving responses are better used later than earlier in the relationship.

Yet, with the greater recognition of diversity within the profession and the larger society, some identity-related attributes, such as race, gender, ethnicity, and even disability, may be involuntarily disclosed. These factors immediately become part and parcel of the change-directed interactions and present opportunities for promoting or correcting stereotypes on both sides of the relationship. In the classroom, where the experimental norm is encouraged, the social work educator has much more latitude than the practitioner to explore these elements. In the end, though, the key to the effective use of self, including self-disclosures around identity-related issues, is achieved through the development of self-awareness of one's differences and one's relationship to the culture associated with those differences. In this narrative, you will hear the voices of two social work educators, one with a visible disability and another with an invisible disability, tell us about their experiences with disability and how their decision to disclose has informed their students and colleagues, and helped them claim disability as part of their identity.

Tom

Even though I have been a social worker educator with a visible disability for more than 25 years, it is only within the past seven or eight years that I have begun to identity myself as disabled and to share relevant disability-related feelings and experiences in the classroom. I can't say with complete honesty that I am altogether comfortable with it yet. Even this narrative was harder for me to write than I originally thought. It is a narrative about the external and internal forces that led me to this point and how I learned ways to use my experiences as a person with a disability to enhance the education of my students.

It is not that I am a stranger to presenting controversial or provocative issues. I often freely express my thinking around issues of race, gender, sexual orientation, or religion, in my classes. Included are the racist and sexist residues of my working class upbringing that I use to provoke social work students to dig more deeply and honestly into their beliefs around minorities and other human differing. Frequently, I find that because they live in a diverse and urban society, or because they have friends who are of another race or gay and even disabled, they think that they are bias free and have escaped unscathed by the subtle forces of society. It is kind of a reverse bias or snobbery. I challenge them by presenting situations for discussion that test the limits of their acceptance of others, including those of clients and communities who may not see the world in quite the way they do.

Yet, despite the fact that I have a hearing impairment, made visible by the use of hearing aids and a discernable "deaf" accent, unlike my openness in discussing other aspects of diversity, with disability issues I set up walls that were apparently well respected by students. Obviously, I had yet to learn my own lesson on the importance of taking risks to develop self- awareness around human differences. Instead, in the microcosm of the classroom, I replicated the Faustian arrangement I had structured long ago with the larger society. And the arrangement was not unlike that fabricated for people with different sexual orientation, "you don't ask and I don't tell." I had long ago accepted life's lesson that disability, like sex, was not suitable for public discussion or display. And, as in my case, if you could "pass," that is hide or minimize your disability, all the better to win the "normal" rewards of mainstream society, such as relationships and employment.

To understand how I "passed" in the world of the non-disabled, I need to tell you a little about the particulars of my impairment. First, while some disability writers use the terms interchangeably, I think it is important to make the distinction between "hidden disabilities" and "invisible disabilities." I reserve the former for those situations where people with disabilities actively seek to hide them as opposed to those who have a disability that is not readily apparent or visible, such as a heart condition.

I experienced a progressive sensori-neural hearing loss at about three or four years of age. The exact cause has never been determined. For me, it means that I can hear words but I cannot discriminate between them easily, especially if words sound alike, or if someone is speaking with an accent, or if I am in an environment where there is too much background noise, like in crowded restaurants. Since I started wearing reading glasses, I find that I can make a comparison to my hearing loss that many people understand. It is comparable to the frustration of trying to discriminate the letters and words on a page without glasses—sometimes your arms are just too short. Unlike reading glasses, though, even with hearing aids my hearing is not fully corrected. I remain highly dependent on lipreading and various adaptive strategies for day-to-day communications.

Lipreading was an adaptation I picked up on my own and, ironically, it was one of the reasons my impairment was not identified until I passed through several grades of elementary school. I was a failing student, who, at one point, common in those days, was diagnosed as mentally retarded. I never realized that my hearing abilities were so different from everyone else's. I survived marginally through lipreading and by trying to remain as socially invisible as possible, in and out of the classroom, to avoid being humiliated. Once the real problem was discovered, invisibility became impossible.

I was moved to the front of the classroom and fitted with two, large, body-type hearing aids that were held in holsters underneath my shirt. Only the ear molds with a large button and thin coiled wire were exposed. I suppose the idea was to make my "disability" less visible and to spare me any embarrassment. It did not surprise me, and I am sure you will not be surprised, to learn that it didn't work. I was routinely taunted at school and in the neighborhood by my peers. It was not the first, nor would it be the last, reminder that being disabled was not a "good thing."

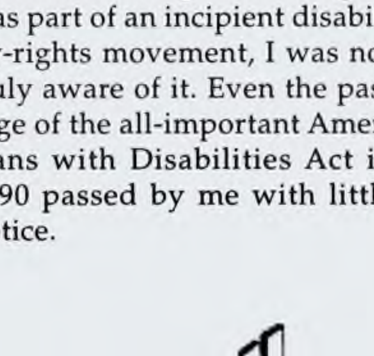
After several surgeries, my hearing was restored enough for me not to need hearing aids. However, by the second year of high school, though I resisted as long as I could for the obvious reasons associated with adolescence, I needed to wear smaller but visible hearing aids. As my hearing progressively deteriorated again, I dropped out of college. Years later, by the time I was ready to return to school, technology had advanced so that I could wear behind the ear (BTE) hearing aids, and I have worn them on both ears for most of my life. Even if they had been available at the time, I would not have been able to wear the more popular hearing aids that fit entirely or almost entirely in the ear (ITE) because they are not adequate for a person with a profound hearing loss like mine. Even if they were powerful enough, I am not sure I would buy them now. They are much more expensive that the BTE type and do not have some of the other features that I need, such as directional microphones and features that ease the use of the telephone. More to the point, I don't have the same need today to hide my disability that I did when I was younger.

Without hearing aids, for all practical purposes I am essentially deaf, but in situations where I can make good use of my hearing aids and by lipreading, I can pick up 85-95% of what is being communicated. (When using the phone, my hearing capabilities are reduced by half or more of that percentage.) The balance of what I do not hear, I adlib or make up through sheer pretense. It means smiling or nodding affirmatively or making some gesture that leaves the speaker with the impression I am hearing them when I'm not. It means laughing when I see other people laugh even though I have not heard the punch line of the joke. Saying "yes" when I mean "no"; of course, there are times when my responses are inappropriate; but once I pick up on it, it is not hard to say I misunderstood. Of course I meant "no" instead of "yes." It means attending plays or movies knowing that I will miss much of the performance as well as voices of friends who whisper comments in my ear during the performance. It is in those darkened theaters with multiple avenues of human communication that I feel the most thoroughly alone. The feeling that "I didn't know whether to laugh or cry" is a common one among people with disabilities. For example, overcoming barriers to communication through pretense meant eating seemingly odd meal combinations in restaurants and assuring friends or servers that it was exactly the meal I wanted—smiling all the way, of course. Never complaining and never demanding are ways of hiding one's disability and remaining invisible to others, and helped me "pass" in the world of the hearing.

Consequently, I imagined that I had learned to manage my disability but I had only learned to manage my impairment. Like many others with disabilities, based on accumulated pain, shame, guilt, and societal rejection associated with differences in abilities, I had internalized my disability as a negative part of my identity and directed much of my anger inward. And because it was possible for me, I denied my disability status in every way possible. How could it have been otherwise? I grew up and came of age when the operative community value was on assimilation and not on respecting diversity. Further, disability had been medicalized to the point that disability-based discrimination, often disguised as pity, benevolence, or treatment, was not as readily recognized by society or by people with disabilities as it was with other diverse groups.

Somewhere along the line, however, at first no doubt unconsciously and then consciously, I decided to act as "normal" as possible. This deception of self and others was not as grand as that of President Roosevelt, but it received the same overt and covert societal support. Family, friends, and the larger society prefer avoiding the subject of disability and adopt aversive behaviors toward people with disabilities. When it was first recognized that I was hard of hearing, professionals cautioned my parents against the "evils" of learning to sign and actively discouraged me from associating with people with hearing loss or other disabilities. None of the members of my family, my closest friends, and not surprisingly, colleagues or students has ever used the word "deaf" or "hard of hearing" with me or has engaged me in a discussion about it. I was socialized to the same disability-based biases and aversive behaviors as they were. I fulfilled my part of the arrangement by denying that part of my identity and, in effect, validated the negative evaluation of the mainstream culture. The reward of "passing" in the hearing world was that I was able to participate in its cultural activities, but never fully, such as never admitting that I could not catch everything at a movie or a play or missing a joke at a party. The cost of living an inauthentic life is that it supports the internalized negative devaluation of self that further erodes self-esteem and confidence. Also, the constant anxiety of being discovered and not "passing"ironically reinforces self-excluding behaviors and social isolation.

The power of denial can never be underestimated. After earning my MSW degree, I worked in the mental health field and advocated for and with people with developmental disabilities and mental illnesses for improved rights and services. However, I did not identify myself with their struggle. My denial was so deep that though I was part of an incipient disability-rights movement, I was not truly aware of it. Even the passage of the all-important Americans with Disabilities Act in 1990 passed by me with little notice.



A crack in my wall of denial occurred after teaching for several years in a college-level human services /social work program. I was asked to serve as its Section 504 (1973 Rehabilitation Act) Compliance Officer. Though I received financial benefits from the "Rehab Act" when I returned to college, I didn't know that much about it. It was not included in the curriculum when I went to social work school in the mid -70's. Disability was taught from a clinical or medical perspective and still is, for the most part, rather than from a socio-political or cultural perspective. Nevertheless, I took the job seriously. At first, still unconnected (or "clueless" as it is said), I expended much effort toward maintaining a professionally "detached" and even had a "there but for the grace of God go I" attitude toward the students with different disabilities. They were not me, and I was not them. I had asked for few, if any, "favors" or accommodations, either as a disabled student or as a teacher. Nevertheless, I found myself becoming increasingly angry when faculty or staff demonstrated stiff resistance to making even the most reasonable and easily achievable accommodations. I found myself talking with highly educated people who were insensitive to the needs of the students and who did not have a clue about disability or disability rights.

One of the psychology professors came to speak to me privately one day to tell me that she did not mind making special testing arrangements for learning-disabled students in her classes. However, she thought it would be more efficient if all disabled students were placed in one class. I was literally in shock that she couldn't see the blatant discrimination, prejudice, and inhumanity of her statement. The lines from a poem about the Holocaust immediately came to mind, "First they came for the Jews . . . [actually it was the disabled]." Another professor in the sciences had his class vote to decide if a sign interpreter should be allowed in class to accommodate a deaf student. I encountered administrators and campus planners who hid behind technicalities. One could repeat like a mantra that a ramp "was in compliance with code" (and it may have been technically) even when he could observe that students using wheelchairs could not negotiate it. I began to connect with disabled people who were treated as nonhuman or objects of pity without rights. Oddly, I could also empathize with my co-workers because I was raised in the culture of the ableist.

However, what I was learning from the students about the disability experience was more compelling: that disability and dignity could coexist and that people with disabilities were entitled to equal rights and inclusion. I began to have what might be called "flashbacks" to my own experiences. I remembered the teacher from high school who thought my hearing aids were radios and demanded that I take them off. I remembered the language professor who would not permit me to substitute a written translation in place of an oral one. She insisted that I would speak German, even though I tried to explain that I could not read lips in German.

The crack in the wall of denial broadened when I joined a few other professors with disabilities from the different branches of the large university where I was employed. They had formed a coalition to push the university to implement the unfulfilled promises of the Americans with Disabilities Act. An immediate sense of community emerged upon meeting my peers with disabilities, who, despite differences in the type and degree of impairments, expressed common aspects of oppression. Unlike myself, many of them had long-term associations with other people with similar disabilities, albeit often in institutional and segregated settings, and across disabilities as part of their active political participation in the Disability Rights Movement. I remember feeling envious and laughing to myself as I realized for the first time the "benefits" of being part of a community of disabled people. A nascent feeling of disability pride emerged —a feeling that I never associated with my hearing loss before. With the support of the group, I proudly became more public about my disability. I was even more proud when we made demands on the university to comply with the law and ultimately filed a complaint against the university with the Office of Civil Rights, U.S. Department of Education.

I continued to learn more and more about disability culture as I enlarged my community of people with disabilities by becoming a member of a local chapter of SHHH (Self Help for the Hard of Hearing, a support group for people who are hard of hearing) and by joining the Society for Disability Studies that supported the development and inclusion of disability studies in the academy. At a national conference of social work educators, I became involved with other social workers, only some of whom were disabled, who had established a task force to foster new sociopolitical and cultural representations of disability into the curriculum.

Although I was undergoing a political transformation and psychological reintegration of disability-related aspects of my personality in a positive way, it was not enough yet to eclipse years of shame and inauthenticity. I remained tentative and ambivalent about whether I should or how I could bring my disability into my classes. I thought that part of my ambivalence might have been gender related. While I considered myself a man who was gender sensitive and one who could ask for directions when lost, I had not reconciled traditional male traits—sexuality, achievement, etc.--with disability. Nevertheless, my personal transformation continued and insidiously spilled over into my role as a social work educator. First, I rationalized that since the students were aware of my activities to make the campus more accessible to students with disabilities, I could safely and appropriately use my work to illustrate a community organizing lesson on matching community change strategies and tactics to the issues and players involved. In a social policy class, during a lesson on the role of values in the shaping of societal decisions about distribution of goods and services, I asked students to identify the values underlying the allocation of special parking for people with disabilities in the environment of scarce resources—parking spaces on campus. Parking was a hot issue on campus and the immediate real life relevancy of the situation made the ensuing discussion one of the liveliest of the semester. It became a reference point for many students when we discussed issues of equity, compensation, and fairness in other policy spheres.

The integration of self and educator advanced and there was no turning back. Since humor is a strong component of my personality and central to my collaborative approach to teaching, it was a natural way to open myself more in my practice classes and to encourage the students to inquire about the disability experience. I wanted them to learn what I was learning: that Disability was diversity--it was another way of being in the world and had its own culture and subcultures; That disability was not always a negative, and it could even be a positive. After a role play of an interview with a client that was not going well for a student, I took over and, of course, performed perfectly. Since beginning students tend to get discouraged when they are first learning to conduct an interview or a group, I reminded them that I have been doing it for several decades. And if I did not know how to do it by now, I might be in the wrong profession. Then I added that they shouldn't be too hard on themselves because as hearing people they were just learning to focus and develop good attending skills, while since I have been deaf or hard of hearing most of my life, I had to learn early "how to focus and listen for the verbal and nonverbal clues." They saw the humor and the truth of my remark, and it opened the door to other questions about disability.

On another occasion, one student felt comfortable enough to ask me why it took so long for my hearing loss to be detected. I sensed from the non-verbal clues that other students were uncomfortable with the question. As most of my students come from the surrounding Italian-American community, I half-jokingly responded, at the risk of perpetuating stereotypes, that I grew up in a poor, working class Italian family that shouted a lot when they spoke, so it wasn't until I went to school that anyone noticed that I had a hearing problem. This use of humor relieved the tension and moved us into a discussion of how ethnicity added to the variations of the disability experience in the same way it shaped the gender, race, or sexual orientation experience.

One of the illuminating lessons that has emerged from my integration of self and disability occurred during a lesson on human behavior and social environment. I related a recurring experience that I have, one that is familiar to many people with visible disabilities when they interact with non-disabled people. It goes like this: I will be waiting in line in a bank or a movie theater and invariably, a parent, usually a mother, will be in front or behind me either carrying or standing with a young child. I note that the younger the child is, the more apt he or she is to notice differences among people—skin color, hair style, or the tiniest hole in clothing—and will be fearless about announcing it. This is something properly socialized adults rarely do. Much to the chagrin and deep embarrassment of the mother, the child will stare suspiciously at my hearing aids, point at them, and might even ask, "What's that in your ear? " Usually before I can even begin my already prepared explanation to the child, which includes a wonderful analogy to the volume control on a radio or television, the parent(s) without fail will admonish the child severely. Some parents even attempt to physically punish them while I attempt to reassure them that it is OKAY.

Most students remember when they were children being similarly admonished never to stare at the unfortunate person in a wheelchair, or the person who walks or talks funny, etc. They were able to relate to those early socialization experiences that generalized to avoiding contact with people with disabilities, who were to be pitied or worse. Even those students who reported having friends with disabilities and thought they were disability bias free related that it was still their first tendency to avoid eye contact with people with disabilities whom they didn't know. The retelling and exploration of this common, shared interaction between disabled and non-disabled people impressed upon them how they might be unintentional partners in a societal arrangement that excludes and segregates people with disabilities in a way that makes them invisible.

The more comfortable I have become with my disability, the more authentic I have become in and out of the classroom. But, I am still not completely comfortable. Disabled people, for many reasons, make non-disabled people anxious. I am not ready to share with them the depth of the pain and anger, at the primal level, that many people with disabilities feel toward a society that has segregated and excluded them for so long and continues to oppress them. And I still "sweat" when a student from the back of the room asks me a question while covering his mouth with his hand. Only, now I explain that I read lips and that I can't communicate well if they cover their mouths. I am not ready to share with my students how exhausted I become from the strain of a hard day of listening, how I look forward to taking off my hearing aids, like a pair of tight shoes, and reading the closed captions on the television broadcast of the evening news.

Since I have added appropriate disability content into my teaching, I know that both the students and I are enriched. And as a social worker educator with students who will face a rapidly aging population, I am concerned that our texts and our curriculum do not include complete and accurate information about the many themes and variations of the disability experience and its impact on the lives of our clients. I am distressed that my colleagues do not seem to be informed about the struggle for equal rights for people with disabilities—and that almost 10 years after the passage of the American Disabilities Act, the landscape remains cluttered with architectural and social barriers. I am upset with the mixed reaction of my colleagues, as well as the social work profession, to the demands of faculty and students with disabilities. And I am perplexed as to how the profession will make its transformation to new understandings of disability as diversity when students and faculty with disabilities remain virtually "invisible"on its campuses.

Rosalind

Disability takes many, many forms: some you can plainly see, some you can hide to pretend they do not exist, and others are hidden. You cannot see my disabilities; I look "normal" and do not need anyone's help most of the time. The world assumes that I know nothing about the world of disability since I do not appear to be disabled. As a person with a number of invisible disabilities and chronic medical conditions, I am disabled all of the time but you cannot see my physical conditions or understand what I must endure in order to survive every day. I am a long-time insulin-dependent diabetic with chronic visual difficulties along with other medical conditions that are not readily apparent. My diagnosis of diabetes came when I was 17. The doctor did not believe me and thought I was pretending to be sick so I could skip school; I was in a diabetic coma for three days following his disbelief of my symptoms. This initial disbelief of my medical problems continues to this day among friends, family, and the medical system. When I returned to high school following my initial diagnosis, some friends were afraid of hanging out with me since I was now different. My best friend in high school happened to be a person with epilepsy because disabled people seek each other out for support.

Many times, I am annoyed when others only see me as a normal, temporarily able-bodied person (TAP) and do not understand the requirements of managing my diabetes. Many people do not know how to help me when I do require physical assistance, but I have gotten wonderful assistance from people who have lived with diabetics or from those I have instructed. Since you cannot see my medical complications, no one assumes I am disabled at all. Opposing reactions are part of my life.

I attend many professional conferences. When I participate in discussions or attend conferences with people who do use assistive technology devices, I am considered an outsider and not identified as one of THEM. Instead in their eyes, because my disability is not visible, I am a TAP. When I present information about disability issues, some wonder why this healthy looking person is talking about disability. I sense that physically disabled people are throwing questionable looks at me; I know they are wondering, "Why are you here with us?" I sometimes feel like stating loudly: No, I do not have the same type or degree of disability as you but you cannot see my hidden problems. I want to say I do fit in and I am one of you—let me be part of the group. Do I have the credibility truly to understand being mobility, sight, or hearing impaired? Yes, to a limited extent, I have experienced these conditions at different times in my life. However, I have to convince others by telling my story and explaining my issues since they are invisible. Then, with a sense of realization, I am told that the others had no idea that diabetes can be so disabling.

At times, accommodations to my physical needs have been non-existent. In my current and previous roles as a social worker, doctoral student, adjunct faculty, and even now as a full-time faculty member, class and meeting times were not geared to meet my eating schedule. As a doctoral student, I was required to take a demanding class when I needed to eat lunch. The schedule did not permit a break between morning courses. I did not do well in that course, missing many of the lectures because of having to take care of my medical needs. At another academic location, I requested a revised schedule of classes and changes in meeting times. I was only given sympathetic looks. Oh, we are sorry but we really cannot change our routine just to meet your "essential must eat" times. Why not just have a snack and then you can eat later? This advice was not only patronizing but unneeded . My direct request for a change in the schedule was ignored and I did not feel comfortable demanding extra attention. When I requested large-print materials while attending an undergraduate conference for social work educators, I was given a magnifier sheet of plastic instead. These magnifier sheets do not work well and do not replace large print materials. Although this group felt they were providing an adequate substitute, they did not understand the difference between reasonable accommodations and convenience for themselves. Many other conferences have provided excellent large-print materials with ease. How hard should I fight for my needs? Demanding accommodations requires effort; Why can't others simply understand? Failure to respond appropriately contradicts their best intentions and serves to exclude me.

Living with a disability is a challenge. I do explain to students, colleagues, and clients that I occasionally need a brief break to take care of my medical needs. Many understand my medical requirements and have offered helpful assistance, while a few have formally complained. Helpful actions have been carried out by students and colleagues familiar with diabetes. Others have looked at me when I was having a severe, low blood-sugar reaction and gave me a sympathetic look. They did not offer to get me a glass of juice or a high sugar snack. They felt sorry for me—I hate that. At a professional conference on mental retardation, I joined a group of the conference organizers along with the keynote speaker for breakfast. They offered to share their abundant breakfast with me. I said yes, but I also need some protein. The keynote speaker (a psychiatrist, a minister, a man born without arms) immediately offered to share his omelet with me. He heard me say, "I need," and he knew what to do and responded graciously. When I socialize or work with other disabled people, this acute sense of tuning in is so evident and so refreshing. I can only hope that more students and faculty will learn about and be more interested in tuning into the world of disabilities.

I wear an insulin-infusion pump which requires intensive monitoring. A few years ago during the beginning of a three-hour practice class, my pump started alarming. I had to stop to take care of the problem; it was an emergency. Because I really had to take care of myself, I gave the class an early break. I was lucky that I could fix the insulin delivery problem quickly, since my blood sugar had already risen to a very high level. A few students were very worried and talked to me afterward; this group understood that disability is part of everyday life. In class, I try to generalize about my disability and about a broad range of disabilities and demonstrate that disability does not mean only negative things. Our school has a "Take a Professor to Lunch" program where I can answer more personal questions.

Social work educators need to sensitize students to the positive aspects of adapting, coping, and managing a disability without pathologizing the person. Discussing diversity concepts in my classroom always includes disability content. Students must be educated about disabilities, focusing on the coping strengths rather than on the problems of disabled persons. "See the person first" ideology or strengths perspective thinking is the critical element, not the problem-oriented perspective. For many students, this is the first time they appreciate the difference between pathology and strengths. For many faculty, hearing about a disability in a different and positive way opens their understanding of disability as just one part of a person's life. This is exciting.

Among persons with disabilities, horror stories are universal. They range from simple insensitivity, blatant discrimination, obvious ignorance, intensive curiosity, to just plain insults. One of my horror stories involves a "sympathetic" comment from a colleague. I believe she wanted to compliment me for my skills and bravery in handling my medical condition. She said: "Ros, you handle your diabetes so well, you do not make us feel uncomfortable." I did not react because I did not know what to say to her. Should I have said, "I am glad you do not cringe when I test my blood sugar or demand a rescheduling of classes"? I still vividly remember this comment because this highly respected colleague was so unaware and insensitive to its full implications. I only wish she admired my strength and skill in handling my medical problems. I still wonder what she meant or what I should have said.

When I mention to someone that I have diabetes, a typical first reaction is: "Do you have to take shots; I could never give myself shots; I hate needles." I respond politely and say "you might change, only if you wanted to stay alive." My primary reaction is why did you even say this? I then counteract by saying, "Many people in our field have significant problems in living, would you respond in a similar fashion by reflecting, I could never live in your neighborhood?" I am disappointed because I am treated as "different" from others. Cultural sensitivity is essential to social workers; we emphasize the "isms" of society. Why is disability left out of these concepts?

I attended a "Low Ropes" Retreat in the great outdoors. It's a way of bonding closer to your colleagues while engaging in outdoor exercises. I was worried about participating in the program due to potential low-blood-sugar problems; I prepared as much as I could but I did have a number of diabetes-management problems that day. I informed the others that I may need their help with snacks. To my chagrin, no one helped me during this long day. Later when discussing my experience of being abandoned by the others, the leader of the group said: "We are all responsible for ourselves—you can't expect us to take care of you." The irony of this message is that this was a group of medical educators—occupational and physical therapists, social workers, and nurses—bonding together to create a new gerontology program. Apparently these medical educators have a far road to travel to really learn about strengths, accommodations, adapting, and giving help before they can teach others how to treat people with respectful care.

I became more aware of my differences as I felt more excluded from professional and social activities such as not eating the same food at the same time as everyone else. In having to take care of my disability-management needs before participating in these activities, I realized that I was set aside and not fully part of the group socialization. I would make requests for accommodations and they were dismissed; I knew that I needed to make a stronger stand to gain credibility. I did not want to be labeled a "whiner" but simply as a person with a chronic illness who needs flexibility and consideration at times. In connecting with other social work faculty with disabilities, I felt included and connected. Meeting with those who have experienced these exclusions was illuminating and enriching. I did not have to explain why or if I needed some help; the assistance came gracefully and with care. I felt a strong connection to this group, as powerful as the diabetes support groups I attend.

Students with disabilities present many more challenges in surviving academia. I use my own story of medical diagnosis in class to explain many social work concepts such as access to medical care—I almost died before I finally got diagnosed; uneducated consumers—my parents were unable to learn how to take care of me, so at 17 I became responsible for my own care at diagnosis; and accepting and facing my own problems by seeking help—knowing when to ask for help. Knowing when you need help and knowing when you can survive without help are important wisdoms for me and how I teach social work practice. I see many students with disabilities who are afraid to request any help. One of my biggest challenges in working with these students is to have to almost plead with them to ask for help from those around them and from the formal support system. For some, asking for help represents defeat, being labeled as disabled, losing independence, and simply being treated as different and less capable than others. For others, the awkward formal system enables them to reach their academic goals. Many students seek me out because of my disabilities; they share their stories with me and I try to encourage them to ask for help. We commiserate about disability ignorance in society and the need to explain again and again so THEY finally understand. If disability were seen as a normal and expected part of life, then asking for help and receiving assistance would not brand us as different. These concepts are directly related to social work practice interventions—enabling people to ask for assistance when they need it without labeling them, providing help when asked in a supportive non-labeling manner, and creating alternative, innovative solutions to problems.

Instead of separating those with disabilities as different, social workers need to be more inclusive and better educated, and social workers with disabilities can help by claiming their disability and "coming out of the closet." Remember, hidden disabilities are just that—not obvious. Don't assume that a person you see using a handicapped parking space is illegally parking there as a TAP. You cannot see many disabilities, so we do not really know what is happening. Assumptions get us into trouble. Sympathetic looks are unnecessary; instead ask about the person's condition but don't invade anyone's privacy. I want to teach you about disability; give me the opportunity to tell you about my condition and my perspective and what I have struggled with. Acknowledge that you do not know much and want to learn more; I would like to teach you.

Social work practice focuses on diversity and oppression. When I teach about practice and oppression, I use my life experiences to illustrate feeling different, losing friends because of your diagnosis, lost opportunities, and oppression. Currently, disability is not a key component in teaching about cultural diversity. Faculty are unfamiliar with and also uncomfortable with the topic, so disability is usually a brief mention in a few courses. Instead, all of us need to learn more about disability. Disability issues also identify valuable skills for all social work practitioners. Social workers must become tuned into these concepts, soon. Disability, whether it's hiding, hidden, or visible, takes endurance, skill, commitment, and knowledge.

Tom and Rosalind

" Having come out, the disabled person no longer regards disability as a reason for self-disgust, or something to be denied or hidden, but rather as an imposed oppressive category to be challenged and broken down" (Swain & Cameron, 1999, p. 76).

Similar to gay men and lesbian women, the coming out process for disabled people is a declaration of identity outside the norm. For disabled people it is the redefinition of one's personal identity that includes a self-declaration, or claiming of that difference, rejecting its devaluation by the larger society, and integrating it into a healthy self-concept (Corker & French, 1999; Swain & Cameron, 1999). Corker (1996) identifies the coming out process as one of the "key tasks of identity formation" for people who are oppressed.

Acknowledging your disability, asking for help when needed, and then demanding accommodations can be a humbling experience for those of us with either visible or invisible disabilities. It takes courage, insight, and support from others to come out to the community.

Yet we have found disclosing disability can be a powerful tool to encourage students to explore this aspect of human diversity, in much the same way that they discuss issues of sex, gender, color, etc. The experience has been a positive learning one for both students and teachers. On the other hand, it has been our experience that students are much more receptive to disability and its accommodations than our social work colleagues—most of whom, like ourselves, have been socialized to regard disability with negative emotions of shame, guilt, and fear. And they have been resistant to embrace the emerging discourse on disability under the rubric of disability studies, a discourse that correctly distinguishes "impairment" from "disability" (Linton, 1998). While social work educators do not have to have a disability to bring the subject into the classroom, until the profession "claims" and reintegrates the new disability discourse as part of the curriculum, it will not be whole or inclusive, in or out of the classroom.

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Book Review:

Faster: The Acceleration of Just About Everything

by
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FASTER
The Acceleration of Just About Everything.
James Gleick.
New York: Pantheon Books, 1999.

So you are waiting on an elevator after two seconds, the door still hasn't closed. You are in a hurry, and push the "door close" button, the door closes, it works! Did you do it? Perhaps not, because many of those buttons are phony. Like a placebo, they make you feel better. They have been put in by the elevator company to make you less anxious and to give you the feeling that you have some control. Just look at how much time you saved, perhaps two or three seconds. Not much you might say, but those seconds add up, particularly if you are in the TV business. Remember those fade-outs, between commercials on TV? You haven't noticed them lately because they are not there anymore. The industry saves one or two seconds by melding right into the next scene. Those seconds mean money in many industries, and certainly in the TV business where a five-or-thirty second commercial can bring in big bucks.

Those are just a few of the fast facts that Gleick presents to us in his book, *Faster*, a bright work that not only reflects the push to speed but gives us some things to think about and insights into what is happening to us because of that push. James Gleick, who also wrote the book *Chaos*, and other science pieces, wonders just how much speed humanity will be able to take. Not that we are near some unknown danger point, but how will speed change the world as we know it, and have we paid attention to the changes that have already taken place? Are we jogging more and reading less? Will more people become Type A, a social invention of the last half of this century?

Technological advances, the web, and MTV programs speed up peoples' views of time and ferment the desire for "quick time" change. An article in the *New York Times* noted, "People are time starved, they're drained, their attention span is short and they're full of stress." You might wonder why, since we seem to be saving all those seconds.

Will I have time to read a book while I am busy multitasking? Maybe, Gleick noted, there is already a book out, with one-minute bedtime stories to tell your child as you put him or her to bed. While that might cut into "quality family time," it will give us more time to surf the net and learn how to be better parents. He points out, however, that certain things just can't be rushed, noting that "compost" takes time to develop. We might wonder how many managers really became better after reading the One-Minute Manager.

Psychologists, who study the impact of time on the mind, seem to be about the only ones in the helping professions who have paid much attention to speed. Their interest stems from their traditional research works, such as reaction times of mice and people. Nothing new in therapy though. Gleick does spend time discussing the contributions of Frederick Taylor and Scientific Management, pointing out his initiation of time studies in the work place. He shares responsibility for starting this speed thing in the first place.

We shouldn't ignore our contributions to things going faster, however. We have always had the 50-minute hour, and that seems like a speed up in use of time to me. We also have seen the use of "time out" as a control device. One of my students told me of a "one minute time-out" for a child who was presenting a problem. There isn't much in the book that deals with helping, so we may never get to the one-minute social worker, but there are important questions to reflect on. Will society's demand for speed lead to even shorter "short term" therapies? Is it unrealistic to think our clients might expect a fast fix? Some are already trying to find it in chat rooms and with on line "therapists" for a fee, of course. Will the miracle question and solution-oriented therapy reduce the number of sessions paid for by the insurance companies?

Both practitioners and academics say they have no time to read the professional literature. Persons on welfare are given a time by which they must get a job, or they are off welfare. We can fax or e-mail clients and students and vice versa. This can save time but also take time if we were to answer all the questions students and clients might e-mail us. Some might believe shorter staff meetings would save time.

While the book raises important questions, I slowly dragged through the discussions on the development of the exact time-piece, the "master clock" and the world- wide need for some people to have the exact second wherever they are, even if they have to purchase a multi thousand dollar watch, when a five dollar one will do. Of course not everything is speeding up. Speeds on the highways during rush hour are down to about 20 miles an hour, and try to make a phone call to get service for your computer or to question a bill. It takes more time to get through all the button pushing, but it does save the companies money. They can hire fewer people, since many callers give up after waiting to speak to a live person if they don't get what they want from the buttonniers.

There is smoothness, intelligence, and a sense of wonder in his book, and it reads fast. What isn't fun, of course, is the feeling he has that a lack of time to reflect may lead us into making poor moral judgments, something I commented on awhile back related to important political decisions made by our leaders. (Abels,1999) Unfortunately the book offers little as to what to do about the speedups. People feel overworked, and feel like they are on an assembly line. Many people are feeling sleep deprived. It takes time to change, too much time. I still push that door open button on elevators.

There are some fun parts to the book, particularly the contrasting advice given by countless books on how to save time, and not waste it. There is also a fine suggested list of articles to read about time, work, speed, etc. But who has time to read any of them? While the book suggests the world and everyone in it is in a rush, it may not give you the kind of rush you hope for.

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