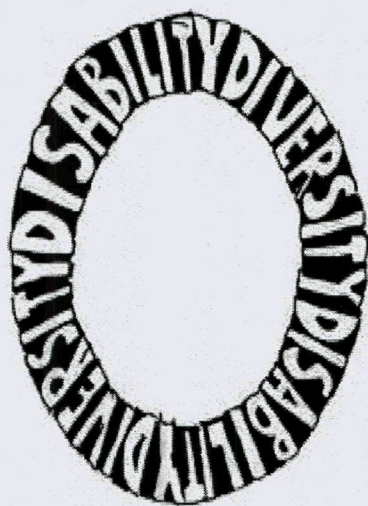# Disability As Diversity:

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.

by
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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
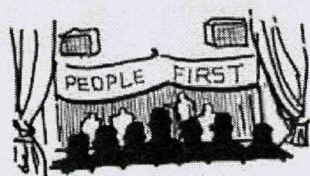
change in my linguistic focus would enhance relationships with my co-workers and friends with disabilities.

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 re-examine 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. "Diffi-

cult 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 phys-

ical 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.
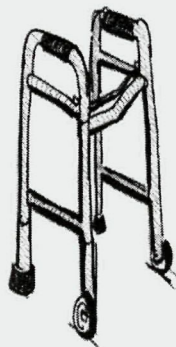
Currently, I work in an early intervention program. I have been observing the impact of a child's disability on the parents and have done quite a bit of research around the trauma these parents experience. There has been a shift in the roles parents assume in relation to their child with disabilities 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 disabili-

ties 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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