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Dreams Deferred: Disability Definitions, Data, Models, and Perspectives

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When Ed Roberts, who had polio, forged new ground for people with disabilities by developing the first Center for Independent Living in 1972, the stage was set for people with disabilities and advocates to join together in a new civil rights movement. 'Invisible' no more, the disability community started what was expected to be a stratospheric leap into community inclusion. There was substantial hope held in the anticipated impact of the passage of the Americans with Disabilities Act (ADA) in 1990 (P.L. 101-336, 104 statute 327). For millions of Americans, it appeared that the ADA would provide avenues for increased economic parity and workforce participation. Unfortunately, almost 20 years later, people with disabilities have not made the much anticipated strides in employment; and attitudinal barriers continue to lock people with disabilities into a separate and unequal subpopulation.

People with disabilities are the nation's largest minority group, and the only one that any person can join at any time. If you do not currently have a disability, you have about a 20% chance of becoming disabled at some point during your work life (U.S. Department of Labor, 2009). Baby Boomers may, at last, force seismic environmental and attitudinal shifts toward inclusion as the number of people with disabilities in the United States increases to approximately 50 million (Steinmetz, 2002).

Estimating the number of people who live with a disability is difficult. The lack of one standardized definition of

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"disability" results in a variable count that ranges from 35 million (The Institute of Medicine, 2007), to 43 million (the figure used during the ADA preparation), to over 120 million, if a loose estimate of those with any chronic or disabling condition are counted (Shapiro, 1993). The 2000 U.S. Census statistic, 53 million, is widely held to be the assumed marker regarding the population estimates of disability. The United States Census reports that 53 million people live with one or more chronic conditions that adversely affect their activity level.

There are dozens of laws and statutes that contain their own interpretation of "disability." Here are five key definitions that have been used to estimate the population of people who have a disability. The text that defines disability is verbatim from the notated source.

Americans with Disability Act:

the term 'disability' means, with respect to an individual:

1. a physical or mental impairment that substantially limits one or more of the major life activities of such individual;
2. a record of such an impairment;
3. being regarded as having such an impairment.

(Americans with Disabilities Act, 2008)

The ADA also attempts to define the term "qualified individual with a disability" as: an individual with a disability who, with or without reasonable accommodation can perform the essential functions of the employment position that such individual holds or desires. The determination of what functions are essential is the employer's responsibility and is usually found in written job, or position, descriptions. The four primary titles in the ADA legislation address telecommunications, transportation, architectural barriers, and access to public community venues. (CESSI, 2003)

United States Census:

the structure of the census survey classifies disability in three domains: communication, physical, or mental.

1. People 15 and older were identified as having a disability in a *communication* domain if they met any of these criteria: (a) had difficulty seeing, hearing, or speaking; (b) were blind or deaf; or (c) identified one or more related conditions as the cause of a reported activity limitation (blindness or vision problem, deafness or hearing problem, or speech disorder).

2. People 15 and older were identified as having a disability in a *physical* domain if they met any of the following criteria: (a) used a wheelchair, cane, crutches, or walker; (b) had difficulty with one or more functional activities (i.e.—walking a quarter of a mile, climbing a flight of stairs, lifting a ten pound bag of groceries, grasping objects, getting in or out of bed); or (c) identified one or more related conditions as the cause of a reported activity limitation (arthritis or rheumatism; back or spine problems; broken bone or fracture; cancer; cerebral palsy; diabetes; epilepsy; head or spinal cord injury; heart trouble or hardening of arteries; hernia or rupture; high blood pressure; kidney problems; lung or respiratory problems; missing legs, arms, feet, hands, or fingers; paralysis; stiffness or deformity of legs, arms, feet, or hands; stomach/digestive problems; stroke; thyroid problems; or tumor, cyst, or growth).

3. People 15 and older were identified as having a disability in a *mental* domain if they met any of the following criteria: (a) had one or more specified conditions (a learning disability, mental retardation or another developmental disability, Alzheimer's disease, or some type of mental or emotional condition); (b) had any other mental or emotional condition that seriously interfered with everyday activities (frequently depressed or anxious, trouble getting along with others, trouble concentrating, or trouble coping with day-to-day stress); (c) had difficulty managing money/bills; or (d) identified one or more related conditions as the cause of a reported activity limitation (attention deficit hyperactivity disorder; autism; learning disability; mental or emotional problems; mental retardation; or senility, dementia, or Alzheimer's).

A note that follows the reported definitions of 'disability' in the three domains identified by the United States Census broadens the definition even more: "Limitations that have no clear placement in any domain were not included." (Steinmetz, 2002)

Centers for Disease Control (2002)

Disability is defined as an individual having "limitations in physical or mental function, caused by one or more health conditions, in carrying out socially defined tasks and roles that individuals generally are expected to be able to do." (Centers for Disease Control, 2009)

Social Security Administration

Social Security pays benefits only for total disability. "Disability" as defined by the Social Security Administration, uses a strict definition:

1. You cannot do work that you did before;
2. We decide that you cannot adjust to other work because of your medical conditions); and
3. Your disability has lasted or is expected to last for at least one year or to result in death. (Social Security Administration, 2009)

Individuals with Disabilities Education Act (IDEA)

This Act specifically addresses the education of infants and children with disabilities. As defined by IDEA, the term "child with a disability" means a child: "with mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and who, by reason thereof, needs special education and related services. (Knoblauch & Sorenson, 1998)

Rehabilitation Act of 1973

Considered the referent for many pieces of disability legislation, the Rehabilitation Act specifically addresses employment, training, and rights and advocacy provisions with a focus on individuals with

the most severe disabilities. (U.S. Equal Opportunity Employment Commission, 2009)

World Health Organization (International Classification of Functioning (ICF), Disability and Health)

The World Health Organization's definition and interpretation of disability is also widely used, and distinguishes body functions and body structures as markers in its definition. Impairment in bodily structure or function is defined as "...involving an anomaly, defect, loss or other significant deviation from certain generally accepted population standards, which may fluctuate over time." (World Health Organization, 2009a)

The ICF is comprised of nine general areas of functioning, in addition to a list of cognitive/mental disorders:

1. Learning and applying knowledge
2. General tasks and demands
3. Communication
4. Mobility
5. Self-care
6. Domestic life
7. Interpersonal interactions and relationships
8. Major life areas
9. Community, social and civic life

The ICF also acknowledges the multidimensionality of disability and integrates several models that offer differing conceptualizations of disability. (World Health Organization, 2009b)

The parameters of disability have continued to change, as has the types of service programs offered. A condition (such as a limb amputation) was an immediate presumption of disability. Currently, the technology behind prosthetics has restored most of the functional ability of people with amputations, thus excluding them from how 'disability' is defined. The contemporary perspective from which the definition of 'disability' has emerged balances functional, physical, and mental issues with the degree to which an individual can participate in the

community and with others without blockage from environmental restrictions (i.e. lack of curb cuts for wheelchairs, inaccessible older buildings and churches, no braille menus available in restaurants, etc.).

The measurement of 'disability' is hampered by primarily two obstacles: (1) the process of measuring a complex, multidimensional concept in a survey format is difficult, and (2) the constantly evolving concept of disability requires survey professionals to continuously develop new measurement approaches to adapt to the newest definitions of disability (Steinmetz, 2002).

In the past, people with disabilities were subsidized through federal and/or state entitlement programs, and the focus was on "fixing" the individuals through medical interventions. Today's Independent Living movement addresses not just the physical aspect of disability, but rather stresses the barriers to inclusion in the social environment that prevent full participation (Marinelli & Dell Orto, 1999). Thus, programs and services have been substantially modified to reflect the examination of, and the removal of barriers in the workplace. Accessibility issues still remain in the social environment, however. "Visitability" is one such concern. Visitability refers to the ability a person with a disability has to visit friends' homes, or places that are not required by law to be barrier-free.

It is easy to extrapolate from just the five definitions here why ADA lawsuits clog the justice system with people who claim disability discrimination, principally in the workplace. The word 'disability' lacks a clear, standardized meaning and has become so bloated in scope that most Americans can, with little effort, stretch a criterion to fit his or her particular situation. Have cynicism and skepticism regarding the disability status of a person, given the host of cumbersome definitions, affected the attitudes and perceptions of people without disabilities toward people with disabilities?

A landmark national survey of 1,000 randomly selected Americans with disabilities was conducted in 2004 by the National Organization on Disability and the Harris Poll organization to gauge attitudes toward, and the socioeconomic status of, people with disabilities. They defined 'disabled':

1. if he or she had a physical disability, a seeing, hearing, or speech impairment, and emotional or mental disability, or a learning disability.
2. if he or she had a disability or health problem that prevented them from participating fully in work, school, or other activities .
3. if he or she considered himself or herself disabled, or said that other people would consider him or her disabled. (National Organization on Disability, 2004)

The results demonstrated that people with disabilities still have pervasive disadvantages over people without disabilities, despite the Americans with Disabilities Act, though slight gains were reported with individuals having a “strong sense of common identity” with other people with disabilities, and a decrease in claims of discrimination in employment. Other significant findings:

- Only 35% of people with disabilities reported being employed full or part time, compared to 78% of those who do not have a disability. Recent studies indicate that it costs a business less than \$300 to accommodate a worker with a disability.
- Three times as many people with disabilities live in poverty with annual household incomes below \$15,000 (26 percent versus 9 percent).
- People with disabilities remain twice as likely to drop out of high school (21 percent versus 10 percent).
- Life satisfaction for people with disabilities also lags: only 34 percent said they are very satisfied compared to 61 percent of those without disabilities.
- People with severe disabilities have much greater disadvantages across all measured areas.
- Regarding health and well-being, 50 percent of the people with disabilities are worried about not being able to care for themselves or being a burden to their families, compared to 25 percent of other Americans. (National Organization on Disability, 2004)

Additionally, of those with disabilities of working age who are not working, 72% say that they would prefer to work (Texas School for the Blind and Visually Impaired, 1998). Identified

barriers to inclusion are transportation, inability to access friends' or relatives' homes, and the fear of losing health insurance and Federal-State disability benefits.

Attitudinal barriers play a central role in employability and socialization and, unfortunately, have not changed appreciably. The "spread" effect was identified by Dembo et al. in 1975 and has been the foundation of much research on attitudes toward people with disabilities. "Spread" refers to the overgeneralization of a disability into other or all aspects and attributes of a person, thereby making inferences about their intelligence, attractiveness, employability, etc. (Olkin, 1999; Wright, 1983). For example, forming the impression of a person in a wheelchair as being less intelligent, or stereotyping a woman with visible cerebral palsy as a less effective parent are examples of the 'spread effect.'

Olkin (1999, p. 62) identified factors that influence individuals' attitudes towards people with disabilities (PWD):

- *Perceiver characteristics*—Previous contact with PWD (amount and type of contact), information about the disability, general prejudice, authoritarianism.
- *PWD characteristics*—Social skills and attractiveness, comfort with own disability, perceived intelligence, demographics (gender, age, ethnicity, socioeconomic status).
- *Characteristics of the disability*—Disability type and severity, stigma of specific diagnosis, perceived contagion or heritability.
- *Characteristics of the milieu*—Social context and group norms, purpose and consequences of interaction. Whether interaction is observed, value of diversity in organization.
- *Social context*—Mass media, ad campaigns, 'charity' drive portrayals of PWD, availability of role models with a disability, news reports on disability, value of diversity in society.

Olkin (1999) further states that there are some disabilities that remain more stigmatized than others, and there is "... a remarkably stable hierarchy of acceptability of various physical disabilities" (p. 72). Individuals with sensory disabilities (hearing loss, blindness) have the most difficult time securing

employment and in breaking down barriers of discrimination in the social environment. People with highly disfiguring and visible disabilities (i.e. burn survivors) also remain less likely to be integrated in the workplace and socially.

A similar concept was expressed by renowned rehabilitation researchers Szmanski and Trueba (1995). They refer to the process of marginalization as "castification," a concept introduced in anthropology. Castification is fundamentally an institutionalized way of exploiting one social group (ethnic, racial, low-income, or other minority group), thus reducing this group to the status of a lower caste that cannot enjoy the same rights and obligations possessed by the other groups (in Marinelli & Dell Orto, 1999, p. 198).

If disability is viewed from a minority group perspective, people with disabilities are affected by the same oppression and discriminatory practices as other minority groups. Given the high number of individuals in the population who have a disability, conceptualization of people with a disability as a true "minority" group is often disputed. One helpful framework proposed by Stroman (1999) characterizes four criteria necessary for a group to be classified as having minority status. The minority group:

1. Is identifiable either in terms of appearance or behavior;
2. Experiences less access to power so that fewer resources, influence, and control are afforded to it;
3. Experiences discriminatory treatment, often evidenced by segregation and stereotyping; and
4. Sees itself as a separate group.

This framework, while helpful from a civil rights perspective, excludes a large number of people who have invisible disabilities. In fact, 'disability' is often attributed socially solely on the physical characteristics of an individual, or on assistive technology or ambulatory aids that the person uses.

Various models have been proposed by Hahn (1985, in Dell Orto, p. 196) to understand disability. The medical model defines disability in terms of functional impairments. The person with a disability is viewed as an entity to be fixed, or cured by 'experts.' The medical model is the most

disempowering of all the models but, unfortunately, remains a very strong, very stigmatizing perspective on disability.

Hahn's second model, the economic perspective emphasizes the vocational and employability problems of people with disabilities. Individuals with disabilities are viewed as less than full participants in the market economy.

The third model, the socio-political model, is the only model that does not depend on the intervention of professionals to address, or treat, the disability. The socio-political model is at the core of the independent living philosophy. In this model, disability is a product of a person's interactions with the environment. The environment is seen as the "disabling" obstacle, not the individual; examples include attitudes toward people with disabilities, architectural barriers, and inaccessible homes and services. Professionals act in a consultancy role, and treatment goal setting is individualized and driven, when possible, by the client. It is unfortunate that health care providers and to a large extent, insurance companies in the United States, will only support services to people with disabilities as long as 'expert' professionals direct the rehabilitation/service process.

Conclusion

The independent living movement of the 1970s, the passage of the Americans with Disabilities Act in 1990, and the sheer numbers (no matter which definition is applied) of persons with disabilities hold the potential for people with disabilities to amass a critical force to be reckoned with politically and socially. Unfortunately, the fragmentation of the various disability groups and the parochialism that exist makes advocating as a single voice difficult—thus diluting the power of the population of people with disabilities.

Part of the problem lies with the lack of a common definition of disability. If people with disabilities cannot agree on the parameters of the construct, it is unlikely that others will develop one standardized definition. And, until a collective agenda for social and environmental change is universally set, people with disabilities will remain fractionalized.

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