

Understanding Disability

DEFINITIONS OF DISABILITY

Following are some selected examples of definitions of disability and developmental disability. Definitions are developed in many ways. For example, some definitions flow from statutory regulations and some definitions arise from advocacy groups. It may be helpful to charge students individually to define disability, and then as a group reach consensus. This activity may impart to students the diverse views we have when defining disability and the resultant difficulty.

General Definitions of Disability

Oregon Office on Disability and Health

(<http://cdrc.ohsu.edu/oodh>)

Disability is a fluid concept that involves the complex interaction between a person's abilities and the physical and social environment. Secondary conditions are defined as aspects of living that negatively impact a person's ability to achieve optimal health and wellness that emerge from underlying impairment or health conditions.

The Center for an Accessible Society

(www.accessiblesociety.org/topics/demographics-identity/nidrr-lrp-defs.htm)

“It is useful to regard an individual with a disability as a person who requires an accommodation or intervention rather than as a person with a condition or impairment. Because accommodations can address person-centered factors as well as socio-environmental factors...a ‘need for accommodation’ is a more adaptable concept.

International Classification of Functioning, Disability and Health (ICF)

(<http://www3.who.int/icf/begines/bg.pdf>)

“Previously, disability began where health ended. Once you were disabled, you were in a separate category. We want to get away from this kind of thinking.” The ICF is moving towards a biopsychosocial model which recognizes “the interaction between health conditions and contextual factors.” Contextual factors include the environment (i.e. attitudes, legal structures, etc.) and personal factors (i.e. gender, age, coping mechanisms, education, how one experiences the disability, etc.).

The ICF identifies 3 levels of human functioning: functioning at the level of body or body part; the whole person; and the whole person in a social context. Disability involves dysfunctioning at one or more of these levels recognizing levels of functioning as impairment, activity limitation, and participation restrictions.

American with Disabilities Act of 1990

(www.usdoj.gov/crt/ada/adahom1.htm)

A physical or mental impairment that substantially limits 1 or more of the major life activities of the individual; a record of such an impairment; or being regarded as having such an impairment. The term “qualified individual with a disability” means an individual with a disability who, with or without reasonable modifications to rules, policies or practices, the removal of architectural, communication or transportation barriers, or the provision of auxiliary aids and services, meets the essential eligibility requirements for the receipt of services or participation in programs or activities which are provided by a public entity.

Individuals with Disabilities Education Act (IDEA)

(www.ed.gov/offices/OSERS/Policy/IDEA/index.html)

In general, the term “**child with a disability**” means a child:

with mental retardation, hearing impairments, language impairments, 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.

Rehabilitation Act of 1973

(www.dol.gov/oasam/regs/statutes/sec504.htm)

A physical or mental impairment that constitutes or results in substantial impediment to employment.

Assistive Technology Act of 1998

(www.section508.gov/docs/AT1997.html)

Any individual of any age, race, or ethnicity who has a disability; AND who is or would be enabled by an assistive technology device or assistive

technology service to minimize deterioration in functioning, or to achieve a greater level of functioning in any major area of life.

2000 Census

(www.census.gov as reported in WVDD Council Publication: A Reporter's Guide: Reporting About People with Disabilities written by Betsy Southall, edited by Steve Wiseman and Jan Lilly-Stewart)

A long lasting physical, mental or emotional condition that inhibits a person's ability to perform ordinary functions such as walking, bathing, learning, and remembering.

Definitions Specific to Developmental Disability

Developmental Disabilities Assistance and Bill of Rights Act

(www.acf.dhhs.gov/programs/add/DDACT2.htm)

“Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to enjoy the opportunity to live independently, enjoy self-determination, make choices, contribute to society and experience full integration and inclusion in the economic, political, social, cultural, and educational mainstream of American Society.”

“Developmental disability means a severe, chronic disability of an individual 5 years of age or older that (1) is attributable to a mental or physical impairment or combination of mental and physical impairments; (2) is manifested before the individual attains age 22; (3) is likely to continue indefinitely; (4) results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency; and (5) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated. (AAUAP, 1996 as cited in Liese, H., Clevenger, R., Hanley, B. (1999). Joining University affiliated programs and schools of social work: A collaborative model for disabilities curriculum development and training. *Journal of Social Work Education*, 35 (1). Retrieved from Academic Search Premier.

WV Developmental Disabilities Council

(www.wvddc.org)

A developmental disability is a long term physical and/or mental disability that occurs before a person reaches the age of 22 and that results in substantial limitations in at least three of the following areas: self-care, language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency. A developmental delay is a condition marked by a difference between a child's actual development and the expected age of reaching developmental milestones.

National Association of Developmental Disabilities Council

(www.naddc.org)

A developmental disability is a severe, chronic disability that begins any time from birth through age 21 and is expected to last for a lifetime. Developmental disabilities may be cognitive, physical, or a combination of both. While not always visible, these disabilities can result in serious limitations in every day activities of life, including self-care, communication, learning, mobility, or being able to work independently. Such disabilities are almost sure to result in a life of dependence on publicly funded services, unless families receive sufficient support, children receive appropriate education and adults receive appropriate services that enable them to live and work in the local communities.

Approximately 4 million Americans have developmental disabilities. Developmental disabilities can occur in any family, no matter what the ethnic, economic, religious or political background.

References

Websites noted above and West Virginia Developmental Disabilities Council publication: [A Reporter's Guide: Reporting About People with Disabilities](#) written by B. Southall, edited by S. Wiseman and J. Lilly-Stewart.

MODELS FOR CONCEPTUALIZING DISABILITY

Moral Model
Medical Model

Social Role Valorization

Social/Minority Model
Disability Discrimination Model
Explanatory Legitimacy Theory

Moral Model

This model views disability as linked to sin and evil. (Mackelprang & Salsgiver, 1999) While this view was popular during through the Middle Ages, there is evidence of its existence today. Some may point to biblical references, believing that disability is a “punishment from God” for one’s immoral acts or acts of one’s parents. This view perpetuates discrimination.

Medical Model

This model views disability as a biological (pathological) condition. The disability is located within the person (not caused by the environment). This view perpetuates the concept of the person with a disability as “sick” and dependent on medical services.

Social Role Valorization

Social Role Valorization (SRV) is described as “a high-level and systematic schema, based on social role theory, for addressing the plight of people who are devalued by others, and especially by major sectors of their society” (Wolfensberger, 2000). The roots of SRV can be found in normalization concepts. Since people with disabilities are included as a population found to be devalued by society, SRV is applied to “upgrade the perceived value of the roles such persons already occupy, and/or to extricate such persons from devalued roles” (Wolfensberger, 2000).

Social Role Valorization holds that certain groups of people experience social discrimination and prejudice which leads to negative life experiences. Groups vulnerable to social discrimination include people with disabilities and/or body characteristics negatively perceived by society, people who exhibit atypical behavior, people who live below the poverty line, and people who do not have skills that are valued by society. Negative life experiences include rejection or ridicule, stigmatization, segregation,

limited choices, dehumanization, loss of individual identity, and poverty. These individuals are more likely to be placed in segregated settings engaging in unconstructive activities. Social role valorization seeks to support valued roles for people with disabilities and eliminate stereotypes and other negative life experiences. Examples include assuring that people engage in age-appropriate, constructive activities; moving away from the view of people with disabilities as medically fragile or sick; treating people with dignity and respect and not as objects, cases, or targets of ridicule; and eliminating the view of people with disabilities as menaces.

Social/Minority Model

This model includes the social constructionist view, discrimination view, and independent living movement. (Mackelprang & Salsgiver, 1999) The view is that disability is created by societal definition rather than by a particular condition. The independent living movement emphasizes competence, self-respect, equality, and self-determination.

The Disability Discrimination Model

by Gary May

The Disability Discrimination Model is designed to give professional social workers a way to conceptualize disability so that their work can play a role in the transformation of how people with disabilities are treated in our society. The guiding principle is that disability-related impairment is a social construction rather than an immutable, objective reality. Impairment operates as a set of beliefs supported by theories and practices within society so that deviations from normative expectations in physical and biological construction are defined as limiting and excluding. The Disability Discrimination Model proposes a theoretical model along with a set of practice principles upon which social workers can restructure their practices.

The Disability Discrimination Model necessitates acceptance of an understanding of disability where “disability” and “impairment” are not inherently linked. This theory asserts that the concepts of disability and impairment are socially constructed, and that the “facts” concerning the consequences of disability are not immutable, objective realities, but merely affirmations of a pejorative and stereotypic perspective.

Pfeiffer (JDPS 2000) has stated that “In a flexible social system which fully accommodates a person with a disability, the disability disappears.” This view precludes the simultaneous existence of a disability, which may be defined as the presence of an appearance or functional characteristic that is a departure from normative expectations, and positive connotations that might be associated with the label “disabled”. By so doing, this perspective implicitly validates the traditional medical model where a disability is a negative aberration that becomes the focus of preventive or remedial intervention.

The Disability Discrimination Model contends that being labeled “disabled” is no different from being labeled “female”, “African American”, “Hispanic”, or any other nominal distinction, but for the consequences of the label. Historically, people with disabilities, unlike these other groups, have not been socialized to experience pride and positive connotation with the label “disabled”. We believe that proud, positive connotations can and do accompany the label “disabled” except under conditions where the consequences of the label are constructed as negative, limiting, and pejorative. Consequently, the fact that I have bilateral above the knee amputations (deviation from appearance and functional norms) does not mean that I cannot be proud of my total being including that portion of my body and functionality that is appropriately labeled “disabled”.

As Pfeiffer (2000) suggests, a hospitable environment that accommodates my appearance and functional deviations (read disability), is desirable, but the absence of such an accommodating environment does not mean that I move from a non-disabled state to a disabled state. The absence of such necessary and desirable accommodations merely suggests that the socially constructed environment *causes* impairment. I may still proudly maintain the label “disabled” in either instance.

In the previously cited examples of women, African Americans, Hispanics and others, we do not insist that they relinquish identity or proud adherence to the labels that connote their group’s deviation from the ordinary. Nor do we suggest that they no longer occupy a role and status within their labeled group if they experience an accommodating social system. Indeed, great effort is expended to insure that everyone understands the value of diversity (read deviation) in contemporary U.S. culture. Not so when disability is the issue. Here, the focus is on restoring the person labeled disabled so they no longer deviate from normative expectations. There is no systematic effort to identify sources of pride or to instill positive connotations on being “disabled”.

The implications for social workers and other intentional helpers are profound and require a “working with” orientation with the disabled client v. a “working on” orientation. From this working with perspective, the client system is not merely the collection of difficulties or clinical symptomatology, but is one component of an interactive system that may produce impairment. Solutions, then, are not to be found solely in the person with the disability, but in the larger social environment.

Decisions about what needs to be done and who should do it are reached through collaboration and consultation not merely clinical practice or psychotherapy. The Disability Discrimination Model asserts that the “client” system is victimized by poor quality social interaction, not by their personality or behavioral characteristics.

The Disability Discrimination Model makes an essential distinction between disability and impairment and views impairment as a socially constructed phenomenon. From this perspective, disability becomes disabling, or impairment, where an observed or perceived atypical appearance or functional characteristic intersects with a negative, stereotypic, limiting expectation set. Typically, the possessors of the atypical appearance or

functional characteristics are labeled “disabled”, and the holders of the negative, stereotypic, limiting expectations are labeled “non-disabled”. Such a depiction allows the person with a disability to continue to “own” and even celebrate the disability, and implicitly, membership in the disability culture, and explains deferential treatment, and limiting elements of the social and physical environment.

Interventions are enacted in a broader field and necessarily include the important human elements of the client’s experience. These other important human elements will need to be educated about the importance that they have in the quality of life of the client. Resistance to this novel perspective is likely, as the insidious influence of the traditional victim blaming perspective is substantial.

Explanatory Legitimacy Theory

In their book, Rethinking Disability (Brooks/Cole, 2004), Depoy and Gilson define disability as a contextually embedded, dynamic grand category of human diversity. Thus, who belongs and what responses are afforded to category members are based on differential, changing, and sometimes conflicting judgments about the value of explanations for diverse human phenomena. This approach to defining disability differs from previous schemes in which disability was determined by the presence of a medical condition that caused permanent limitations in one’s daily function. Explanatory legitimacy theory makes the distinctions among descriptive, explanatory and the axiological or the legitimacy dimensions of the categorization of human diversity and identifies the relationships among these elements. Thus, disability analyzed through the lens of explanatory legitimacy, is comprised of the three interactive elements: description, explanation, and legitimacy.

Description emphasizes the full range of human activity (what people do and do not do and how they do what they do), appearance, and experience and is comprised on two intersecting dimensions (typical/atypical and observable/reportable). Typical involves activity, appearance, and experience as most frequently occurring and expected in a specified context. Atypical refers to activity, appearance, and experience outside of what is considered to be typical.

Observable phenomena are activities and appearance which fall under the rubric of those which can be sensed and agreed upon. Reportable phenomena are experiences which can be known through inference only.

To illustrate the two axes, the use of a wheeled device for mobility would be observable and atypical for young adults, but would be observable and typical for infants. Pain would be reportable since it can not be directly observed and verified.

Explanation is the set of reasons for atypical doing, appearance, and experience. Explanation provides the basis on which one judges eligibility for category membership. For example, “homeless” is a description of one’s living situation and may have many

explanations. However, if the explanation is drug addiction, the response may be different than if the explanation is the experience of abuse and oppression or even if the explanation is Hurricane Katrina. Relative to disability, Depoy and Gilson look at medical-diagnostic explanations and constructed explanations. Medical explanations view descriptive atypical phenomenon from a pathology perspective. This explanatory model, locating the explanation within an individual, might beget treatment and rehabilitation as a response. Constructed explanations identify the explanation for atypical description as a set of limitations imposed on individuals (with or even without diagnosed medical conditions) from external factors such as social, cultural, economic, political and other environmental influences.

The target for change from this explanatory perspective is the social environment since the disabling factors are not seen as located within individuals. From a constructed perspective, concepts of self-determination, inclusion, power, and justice become important. The authors note that “one may be disabled by a legitimate medical-diagnostic, social barrier, or political powerless explanation”.

Legitimacy is defined as “the set of differential judgments that place explanations for atypicality within or outside of disability status”. “Disability is determined not by the explanation but by the set of beliefs, value judgments, and expectations attributed to the explanation.”

Legitimacy can come from outside the individual in such forms as medical, legal and policy determinations that one is a member of the disability category. This type of legitimate membership in the category of disability may determine one’s eligibility for treatment, medical benefits, protection under nondiscrimination laws or eligibility for various programs and services. Determinations for “eligibility” for the death penalty and rationales for abortion or assisted suicides are effected by value judgments related to disability. Legitimacy can also come from within - how one identifies oneself. Related to this explanation are issues of disability as culture, disability identity, self-determination, and disability studies.

Explanatory Legitimacy Theory can be applied to professional practice, social change, and social justice. The authors emphasize that “the primary purpose of professional activity should be the improvement of experience and social justice within the diversity of people and communities

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