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Disability

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Disability

People with disabilities (PWD) are the fastest growing minority social group in the world. Moreover, this group is one in which many, if not all individuals, will eventually join due to accidents, injuries, illnesses, wear and tear on aging bodies, and genetic factors. Disabilities can be physical, cognitive, social, and/or emotional. The disability community overlaps with people of all races, ethnicities, age groups, genders, sexual orientations/expressions, and socioeconomic statuses, although PWD are overrepresented among people who are economically disadvantaged and underserved in health care, environmental safety, nutrition, and other basic needs. While the proportion of people with disabilities increases with age, the majority of people with disabilities remains under the age of 65.

The World Health Organization offers useful definitions to distinguish among terms commonly

used interchangeably by those outside the community of disability. “Impairment” refers to differences and limitations of the physical functioning of the body such as a missing limb, paralysis, or blindness. “Disability” embodies the daily tasks of self-care and independent living, so that people who cannot bathe themselves or are unable to shop for groceries have specific disabilities. Finally, “handicap” refers to the ways in which the social and physical environment limits PWD by erecting or failing to eradicate barriers to full living for those excluded from what is accepted as the normal range of physical functioning; examples include lack of ramps for those who use wheelchairs, or lack of sound amplifying devices for people who are deaf or have impaired hearing. These distinctions are useful for understanding the complex relationship between social norms and the experience of PWD. However, health communication scholars generally follow the customary terminology of the medical establishment, activist communities, and scholars in the field by using “disability” as a blanket category.

Historically, the medical model of disability has defined PWD in terms of their lack of function and physical deviances, framing them as “personal tragedies” and a “social burden” that constitutes a social welfare problem that must be solved through medical intervention, charitable work, or social care. The implication is one of dependency. An alternative model favored by health communication scholars is a social model of disability that frames understanding of disabilities by highlighting the ways in which disability is understood through various cultural lenses as always involving labeling of some people as outside the realm of normal, to the benefit of some and the disempowerment of others. This model is emphasized by nonprofit organizations and advocacy groups dedicated to disability issues that promote the use of inclusive language, accessible public spaces, and accommodating social institutions such as school systems. They also draw attention to the ways in which PWD are represented in film, television, and other cultural media in order to question taken-for-granted assumptions about who PWD are and what they can do.

Health communication scholars explore many facets of disability, drawing on research not only

from within their own field, but also from that of medicine, disability studies, medical sociology, medical anthropology, nursing and allied health disciplines, health psychology, and social work. Health communication research attends to how disability is socially constructed through communication between patients and health care providers; within health care organizations, via social activism and policy advocacy; in daily life; and in the media. The biological basis of impairment and physical differences and their material consequences inarguably play crucial roles in the experience of disability. However, the contributions of health communication scholars focus far less on the physical realities themselves and more on how those physical attributes are assigned meaning, the values that are embodied in those meanings, and the ways in which policies are (or are not) justified through those meanings.

Media and Stereotyping

Scholars across fields have attended to media portrayals of people with disabilities. Many people have little or no contact with PWD, so they gain their knowledge of people with disabilities from mass media. Therefore, it is important to pay attention to how the media shape reality. PWD have been habitually underrepresented on television, and often PWD are shown as “othered” or as different from and inferior to able-bodied individuals. Most images of PWD are negative and portrayed as having some sort of defect, deficiency, dysfunction, abnormality, failing, or medical problem that is located in the individual, not in society, stress, trauma, a character flaw that is disempowering, or “othering” for PWD. In communication, most scholars agree that representation matters—the public portrayals of PWD (i.e., news media and television coverage) can influence public perception and have potential material and symbolic consequences.

Labeling and Stigma

PWD have long been characterized or stigmatized as less intelligent, pitiable or pathetic, violent, evil, nonsexual freakish, “supercrip” (having super human powers or strength as a result of disability or overcoming their disability), eternally innocent (especially for intellectual disabilities), and incapable of participating in community

life. Acquiring a disability has a dramatic effect on one's self-identity. In social theorist Erving Goffman's classic examination of how people dealt with this experience, he referred to this as the practice of adjusting to a visible disability as managing a "spoiled" identity. This view of disability as "spoiling" one's identity is challenged in the Disability Rights Movement. Disability rights activists associated with this movement describe positive affirmation of and pride in identifying oneself as disabled, which has led to a more nuanced view of disability.

The question of who fits within the range of normal functioning has changed significantly over time and is continually in flux in response to shifting cultural ideals; developments in assistive, prosthetic, cosmetic, and reconstructive technologies; and the addition of laws, regulations, and policies. Categorization of PWD has direct, material impact on PWD's access to services, including housing, Medicare/Medicaid health coverage, disability insurance coverage, Supplemental Social Security Disability payments, and vocational and rehabilitation services. For example, the diagnosis of "legally blind" at the level of 20/200 vision regulates who is entitled to government programs that assist those with vision impairment and who is not. Likewise, labeling some children as learning disabled, autistic, or developmentally disabled makes them eligible for specific forms of learning support (e.g., speech therapy) within public school systems.

The *Diagnostic and Statistical Manual of Mental Disorders*, the guide to diagnosis of mental and emotional conditions (many of which are considered to be disabilities under the Americans with Disabilities Act of 1990), undergoes periodic revisions that shift the boundaries of what psychologists and psychiatrists consider to be normal functioning, continually constructing new diagnoses to describe the mental conditions of some people, and at times restoring other groups (e.g., homosexuals) to within the bounds of the mentally normative. Moreover, in addition to regulating access to services, labeling and categorizing of PWD performs symbolic functions. While being offered a label for a heretofore unintelligible set of symptoms or conditions can be a relief and a validation for some people, others feel marginalized by labels that reduce them to nothing more

than a diagnosis instead of a full person. Furthermore, stigmatizing labels form the linguistic justification for social exclusion.

Health Care for PWD

Historically, disabilities have been constructed as biological truths, with the medicalization of bodies resulting in problems being viewed as discrete diseases that only legitimate agents (e.g., health professionals) are capable of discovering, naming, and treating. Beyond the impacts on medical care, very little is known about the communicative experiences of PWD in health care contexts. An awareness of the significant communicative impacts of disability exists in other contexts (interpersonal relationships), and the import of communication processes in health care is well established, so further study of communication and disability within this context is warranted, as well. Research studies have investigated the factors that affect the ability of people with different types of disabilities to communicate with their health care providers.

Dissatisfaction with health care is high for people with disabilities (e.g., ease of getting to doctors, follow-up care, and access to specialists were higher for PWD than people without disabilities). Health care professionals may focus on disability rather than other aspects of a patient's health, which may lead to dissatisfaction. The importance of effective health care communication between health care providers and people needing health care is well established. PWD are at risk of not being able to communicate effectively with their health care providers and this might directly compromise their health, health care, and right to participate actively in decisions about their health care. Effective communication between people who need and people who provide health care is fundamental to the delivery of high-quality health care services. Effective communication improves people's immediate health and their overall health outcomes and helps ensure that people's rights, concerns, and needs are respected. When PWD are in a hospital setting, there are potential risks for discrimination, receiving suboptimal health care, compromising their right to be actively involved in their health care, and having poorer long-term health outcomes than people without disabilities.

Intersections of Identity

Intersectionality is a term used by feminists and other critical theorists to describe the complex ways in which multiple identities—gender, race, age, sexuality, religion, disability, and so on—overlap and intersect. PWD may experience intersections of marginalizing identities that leave them vulnerable to discrimination and to social exclusion. At the same time, PWD may have privileged identities as white, heterosexual, and with high educational attainment that may benefit them when seeking services or in socializing across a wide variety of communities. Men with disabilities face stigmatization as not being masculine, particularly regarding their abilities to engage in sexual activities and to support themselves (and family members) through paid work. Women with disabilities experience high rates of sexual violence, and may be judged as unfit mothers in spite of demonstrated capacity to care for a child. PWD who are lesbian, gay, bisexual, transgender, or otherwise nonheterosexual (LGBTQ) often find themselves excluded from some LGBTQ communities that do not prioritize accessibility sufficiently, while at the same time encountering some intolerant disability communities that reject their sexual identity or expression. They may have difficulty accessing services from agencies that operate on assumptions of a heterosexual nuclear family. PWD are overrepresented within communities living in poverty, and because people of racial minorities are also overrepresented among the poor, PWD may encounter multiple levels of oppression and marginalization.

Social Support

Social support includes verbal and nonverbal communication that is designed to provide instrumental material assistance (e.g., a ride to an appointment), informational support (information about a condition, symptoms, treatment, coping strategies, and available resources), and emotional support (listening, comforting) to another. PWD may need support to accomplish tasks of daily living, relying on personal care attendants who are paid workers or on family and friends for the assistance that they need. Cultural discourses on families of children with disabilities reflect commonly accepted assumptions of lower quality of life among these families. Yet more recent research on

families with a child with disabilities documents significant resilience and resistance to accepting a diminished personhood status for their children. Mothers acknowledge sources of stress while also normalizing their daily lives as being more similar than different from those of other parents. Many PWD and their caregivers find emotional and informational social support through both face-to-face and in online support groups where they can connect with others facing similar challenges. Research shows that social support helps caregivers and PWD to have higher quality of life, less depression, and better coping strategies.

Reclaiming Disability

Discourses of difference sustain the separation of PWD from community life. Disability sport and art has long been of interest to scholars. Communication scholars have argued that participating in disability arts or sports is itself a communicative act. Most of the work has covered media coverage of disability sport, art, and popular images associated with these activities. Similarly, the use of disability sport and art as therapy and rehabilitation and participation in these activities can lead to increased self-esteem and/or change in worldview. Several communication scholars argue against a “therapy” model and maintain that art and sport filters life through the pieties of human perspective and/or disrupts patterns of domination. Representations of disability by PWD have the potential to challenge stereotypes, while acknowledging the continuing hold and power of these images over their own narratives, and can redress inequities experienced by PWD. Other scholars in communication have explored sexuality and masculinity and their performances in art and sport. Others have explored organizations that have found ways to include PWD as productive organizational members and counter medical model understandings in which disability is something that needs to be fixed or cured.

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See Also: Families, Communication With; Health Activism and Public Health; Stigmatization; Support

Providers and Persons With Disabilities, Decision Making Between.

Further Readings

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