

Disability in a Global Context*

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Abstract

Disability is a condition that directly involves over 15% of the global population with reverberations throughout every nation and level of society. The World Bank, World Health Organization, and Gates Foundation emphasize that this population has serious social and economic effects on the stability and development of nations and well-being of individuals touched by disability. This essay places disability in a global context and details the foundational work in the field. Cutting edge research combining biomedical advances, smartphone and computer technology, robotics, artificial intelligence and analysis of social networks and cultural contexts, disability activism and agency, and physical, social, political, and economic environments are examined. Looking to the future, the essay explores the consequences of global population growth, migration, environmental changes, and increased demand for services and technological innovation on the world's disabled population, their social networks, and nations. Lastly, the importance of exploring global disability in all areas of the world while being open to similarities and differences is emphasized.

DISABILITY IN A GLOBAL CONTEXT

Disability is a condition universally found around the world in all segments of society but not always recognized, accepted, or understood. For many, disability is seen as something disgraceful, abnormal, or different—something to be ignored or avoided. Yet, most individuals will personally experience disability in their lifetimes, deal with disabled family members, or confront people with disabilities at school, work, and in public spaces. In a joint effort to better understand disability on a global scale, the World Health Organization (WHO) and the World Bank produced the World Report on Disability (World Health Organization, 2011) that estimated, based on nationally representative data sets from 59 countries, that about 15% of the world's population or more than a billion people live with some form of disability. For each person with a disability, many others in their families and social networks are

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affected. These numbers are likely to increase as the world's population was 7 billion in 2011, is 7.5 billion in 2017, and is projected to be about 10 billion in 2050 (United Nations, Populations Division, 2017).

In a more granulated view of disability distribution and consequences, the Global Burden of Disease Study (Global Burden of Disease 2015 DALYS and HALE Collaborators, 2016) frequently reports on disability-adjusted life years, increased healthy life expectancy, and how these factors relate to national development based on data from 188 countries. Among many consequences, disability has a significant effect on the economic well-being of individuals, families, social welfare systems, and global development. What is equally important is that the assessment of disability distribution and consequences is an organic, real-time exercise due to the emergence of new conditions such as HIV/AIDS, ongoing and new wars, increased numbers of refugees, malnutrition due to drought, increased migration of diseases such as Zika, and lack of effective control over increases in such conditions as obesity, diabetes, smoking, and degradation of the environment. For these reasons, disability cannot be easily avoided, walled off, or ignored.

FOUNDATIONAL RESEARCH

Most of the foundational research on disability is Western centric and medical model oriented. Disability is a complex concept difficult to measure (Altman, 2016). Disabilities can be physical, mental, emotional, sensory, and intellectual. Often individuals with disabilities have multiple disabilities. Disabilities can also originate at birth or occur later in life. Furthermore, impairments and the resulting disability can be episodic such as bouts of depression, migraine headaches or pain, or persistent conditions such as spinal cord injuries and permanent brain damage from a traumatic accident. Initially, disability was defined and measured in terms of physical and mental anomalies that were deemed to limit "capacity to perform" or "loss of function." In the United States, for persons with a disability to receive disability benefits, they had to be certified by a physician that they had a medical condition that limited them or prevented them from working (Albrecht, 1992). The WHO had long been concerned with the international classification of diseases and subsequently with functioning and disability associated with health conditions (International Classification of Functioning, Disability and Health). Both classification schemes begin with body systems but the ICF concentrated on (i) body functions and structures and (ii) activities and participation (World Health Organization, 2001).

A significant reorientation to disability occurred when social scientists pointed out in their research that disability can be a socially constructed concept and that activity limitation and participation can be seriously shaped

by an individual's physical, social, economic, and political environment. Goffman's (1961) *Asylums*, Scott's (1969) *the Making of Blind Men* and the early work in environmental psychology, which argued that social context and place influenced behavior, grounded this perspective. This work, along with that of Nagi (1965) and Zola (1989) in the United States and Barnes (1991) and Shakespeare (2006) in the United Kingdom developed into the social model of disability. As a result, WHO reconceptualized the concept of disability and how it should be measured. This is reflected in its biopsychosocial model, which is more inclusive than that of just medicine where "disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)" (World Health Organization, 2011, p. 4). Thus, disability is now viewed as a result of the interaction between individuals with all of their characteristics and their physical, social, economic, and cultural environments.

The work of the WHO, World Bank, Centers for Disease Control (CDC), and the Ford and Gates Foundations in diverse corners of the world have drawn attention to the fact that disability is distributed globally and can affect health, migration, and economic well-being at remarkable distances (Devlieger & Strickfaden, 2016). In a global economy, disability in the labor force in one part of the world results in productivity losses and places considerable strain on welfare systems along global production and distribution chains (Gifford, 2017).

Disability was historically addressed in Western countries medically through the growth of rehabilitation medicine and adjunct interventions such as physical and occupational therapies. During and after WW I and WW II, the Veterans Administration and Vocational Rehabilitation Administration were formed to assist disabled military personnel recover and hopefully return to the labor force. The Vocational Rehabilitation Administration extended this concept to persons in the domestic labor force who were disabled on the job (Gritzer & Arluke, 1985).

Social and behavioral scientists in the 1960s and 1970s recognized that disability was much more than a medical or disease problem and indeed affected all areas of human activity. Within the American Psychological Association, an interest section was formed around rehabilitation psychology. A group of sociologists in the 1970s developed interest sections in social science organizations that grew to become the Society for Disability Studies. Later in the process, scholars in the humanities, history, arts and literature joined the Disability Studies movement to explore how disability is represented in culture and society (Davis, 2014). The CDC built on its historical strengths in epidemiology to ask questions about how disability

fits into a public health perspective where emphasis is on the conditions and environments that produce disability. Some examples are present initiatives in smoking prevention, preventing and controlling obesity, encouraging “healthy” diets including fruits and vegetables, and incorporating consistent exercise into daily life styles. In this context, disability became a central focus of those movements that encourage healthy living, sports and physical activity, walking, and climbing stairs in our everyday lives (Rimmer & Marques, 2012).

As these movements took shape, an additional social movement characterized by the saying “Nothing About Us, Without Us” united activists and human rights advocates. People with disabilities did not want to be treated as dependent and closeted individuals but as active agents in their own rehabilitation and daily lives. Disabled people, particularly academics, advocated for having a say in their lives. They focused on “breaking down barriers” to full inclusion in society, which included mainstreaming students in the classroom, the rights to work, bear children, and vote, modification of the physical environment with curb cuts, power-assisted doors, ramps in place of stairs, and accessible bathrooms and kitchens (Linton, 2007). While the battle goes on, these movements resulted in the Americans with Disabilities Act of 1992, which was imitated by many other nations in the world, and the UN Declaration of the Rights for Disabled People, which recognizes their rights as citizens of countries and the world.

CUTTING EDGE RESEARCH

In the medical and health arena, enormous research strides have been made in combining advances in imaging, genetics, biomarkers, nano-sized medicines and interventions, computer-controlled prostheses, “smart” houses that can recognize through computer sensors the needs and adjustments that residents desire, and accessible, community-based transportation that allows persons with disabilities to get out and about, to be as independent as possible and have control of their own lives. The advances in smartphone technology and apps have given agency back to people with disabilities (Trevisan, 2016). They are better equipped to organize their lives, stay in touch with family, friends, and personal assistants, and summon health care when needed. As a consequence, disabled people are able to live independently in the community as was not possible before. These insights into the daily lives and desires of people with disabilities have also had a significant impact on understanding aging, permitting older people to live independently, and yet be in contact with support services when needed. The artificial intelligence technology behind voice-activated software, self-driving cars, aids in increasing compliance to take necessary

medications, engaging in therapeutic exercise, and organizing and managing one's life all contribute to increasing the level of independence for disabled and elderly people.

In the social arena, the concept and development of social networks has added to our understanding of how humans function in complex social worlds and how to organize lives and produce aids that will improve the quality of lives of individuals and their communities. The theoretical and empirical advances in understanding and utilizing social networks allows health care teams and disabled people and their families and friendship groups to integrate information and care to produce a support system that is centered on the person with disability. As Christakis and Fowler (2011) pointed out in *Connected*, we are keenly affected by our social environment. We are likely to behave like those that are in our social networks and neighborhoods. These insights have deep implications for how people become disabled, whom they relate to, how they deal with their disabilities, how they live their lives, and how much agency they exercise in their daily lives (Albrecht, Devlieger, & Van Hove, 2009). The power of networks builds on the earlier work of Zola, the community housing of L'Arche and the Independent Living Movement designed to keep disabled people in the community by building communities where they can live together independently in a supportive environment (Zola, 1982).

The wide use of social media helps people with disabilities stay connected to the health and social service community, family, and friends in ways not imagined 20 years ago. Individuals can use the internet, data bases, outcomes research, and discussion groups to learn about their conditions, inform their decisions, and seek support. The use of social media in conjunction with computerized information systems also allows people with disabilities to navigate the complexities of the health, insurance, and benefits worlds and better to ensure that they are taking advantage of the resources available to them. These efforts generally result in an improved quality of care at lower prices. People with disabilities are able to unite and do comparative shopping.

Disability activists are also in a much stronger position to advocate for their interests and become internationally visible. The change from compliant, fairly uniform, or even undiagnosed "patients" to highly visible, informed, and organized groups lobbying and intervening on the part of disabled people and their families is stunning (Iriate, McConkey, & Gilligan, 2015). Disability activists have helped to insure that the public, politicians, and government bureaucrats are aware of their existence, needs, and demands (Nakamura, 2013). These activists have made their presence known through the United Nations, European Union, Americans with Disabilities Act, Special Olympics, and a host of cultural events in which

people with disabilities are the central characters in plays, novels, media stories about disabled immigrants, and the effects of displacement, drought, and war.

Scholars in the arts and humanities have added to the discussion of disability by examining how disability has been understood and portrayed across history and culture. For much of history people with disabilities were hidden from view unless they had special privilege (Stiker (2013). Snyder and Mitchell (2006) show how people with disabilities were viewed as biologically deviant and as not “normal.” Society saw them as “defective” and subject to laws of eugenics, which during the age of the Nazi’s, for example, made them undesirable and the object of regulations, which for many meant isolation in camps or even death in the eugenics movement during WW II. In a careful historical analysis, Stargardt (2015) points out that more disabled people were eliminated by lethal injections or in the crematoria than native German Jews. Under this type of regime, people with disabilities were to be identified and regulated, which still resonates in some levels of society around the world today (Weiss, 2007). They and others, such as Erickson (1966) in *The Wayward Puritans* point out how disabled people have fought a long battle in charting a passage from living in a disciplinary society to one based on acceptance and self-regulation. Classic books in this tradition, such as Charlton’s (1998) *Nothing About Us Without Us*, Frank’s (1995) *The Wounded Storyteller*, and Frank’s (2000) *Venus on Wheels*, take the point of view of individuals reaching out to redefine themselves in the larger society. Iezzoni and O’Day (2006) go further arguing that inclusion and accessibility involves more than building ramps and improving access to the present health care system. True inclusion means cultural acceptance and access to services and civil liberties enjoyed by the larger population.

This leads us to considering fitting people with disabilities to their physical, social, and cultural environments. Rather than taking the present as a given, contemporary scholars and researchers examine how to build a physical and social environment that is welcoming to people with differences, including disabled people. These issues and accomplishments take us into a society in which all citizens are accepted in their richness and difference. At the core, these debates are about who is human, a citizen, has fundamental rights and is accepted into the larger society (Bloemraad, Korteweg, & Yurdakul, 2008).

LOOKING AHEAD: KEY ISSUES FOR FUTURE RESEARCH

The issues on the horizon repeat those seen earlier in history and add a current stage of urgency to the place of disabled people in society. Looking ahead to 2050, world demographic trends demand a close watch by

researchers and increase pressure on disability policy makers and activists. During this period, the world population will grow to almost 10 billion people, life expectancy will most likely continue to increase because of better public health, and more countries will implement national health care systems. The absolute numbers of people with disabilities will increase, placing increased economic and service strains on national, medical, and social welfare systems. The complexity of the changes is critical to understand and plan for (Coleman, 2006). Population growth in the EU, Japan and the United States, Canada, Australia, and New Zealand will be less than at a replacement rate while that of Africa and some Asian and South American countries will continue to increase above replacement rates. As a result, the young labor force needed in the job markets of many developed countries to generate GDP (gross national product) and care for the aging populations will have to come from immigrants or from a massive program of robot assistants and use of artificial intelligence. Even if this is the case, governments or perhaps public/private partnerships will have to plan for, fund, and operate these systems. The world population growth in the next 30 years most likely implies a concomitant increase of the numbers of disabled people distributed globally (Saika, Bora, Jasiloionis, & Shkolnikov, 2016). The thorny part of this demographic scenario is that at the time that many developed countries are becoming more nationalistic and inward looking, they will need a younger labor force to keep GDP growing and considerable numbers of service workers to care for an aging population and increased numbers of disabled people. Researchers at the Global Burden of Disease project and the Gates Foundation are aware of these issues but more work needs to be done worldwide to monitor and respond to these problems. Furthermore, researchers can produce data and make informed forecasts about the future but the public and politicians need to be educated to work from real data and outcomes research. This has caused considerable concern among scientists who see that social policies and political actors are not always receptive to scientific evidence. There is a cost to not responding to impending demographic changes.

A second set of research efforts would redirect the traditional perspective from the disabled individual to social networks and social relationships. Disabled people do not live in isolation or just with other disabled people but in a society where they deeply touch the lives of their family members, spouses, friends, neighbors, and coworkers. From this perspective, people who interact with disabled people often become “co-owners” of the conditions and challenges they pose. Since this produces a multiplier effect, in all likelihood up to a third of the world’s population is in some manner impacted directly or indirectly by disability. Yet this raises a paradox. How can it be that conditions that are so common are seen as rare? For most

people, disability is not of personal concern until it happens to them or someone close to them. Past analyses of disability have profited from the concepts of shame, stigma, and marginality to explain how people with disabilities do not make it to the center stage of life nor merit prolonged attention.

In contemporary life, there is considerable migration from rural communities to urban metropolises. In the digital revolution, transactions take place not face to face in a community but anonymously over the internet. Social media permit contact to be depersonalized without sight, sound, smell, or context. Twitter allows complex ideas to be reduced to 140 characters and texting encourages emotions to be expressed by emojis. On Facebook, a central controlling concept is being “friended.” What does this sort of “friending” mean for an elderly parent or disabled person rather than a personal visit or joining family and community events in person?

The rise of artificial intelligence in human service industries ranging from assisting physicians diagnose and treat complex conditions to planning and monitoring complex treatment plans and medication compliance by electronic sensors adds to this sense of loss of control, oversimplification of emotionally laden experiences, and being “distanced” where one is out of sight and mind. The consequences for their quality of life are discouraging. In discussing “difference” in society, Solomon (2012) concludes that intimacy with different people and conditions fosters understanding, acceptance, and accommodation. Yet this does not happen being isolated in homogeneous groups, being emotionally “distanced,” treated as a case in a computer algorithm, or rejected if unable to meet the norms of others. These issues bear upon disabled people as well as the larger society and cry out for analysis and solutions to reintegrate “different” people into a larger society.

The next set of future research issues regard the use of emergent technology pertaining to disability. At a time when robots are likely to replace workers in manufacturing industries and artificial intelligence systems are taking over much of the work in the service industries, where will people find jobs (Friedman, 2016)? Typically, most workers that care for disabled people are in low-paying jobs. The people most agreeable to working in these jobs for these salaries are minorities and immigrants. Yet, the demand for services comes at a time when we are preventing and drastically controlling immigration and not well educating minorities for jobs of the future.

Japan is responding to these problems by developing personal care robots to support persons with disability and older people. While there are promises in this direction, there is also the issue of human support. Are disabled people and the elderly content with just dealing with robots and artificial intelligence supports or do they need more human and emotional

contact to have physical, emotional, and mental well-being? These issues require research.

Research on the body will expand in breadth and depth. There is a strong tradition on the sociology of the body, psychological work on brain–body interactions, exciting work on the regeneration of tissue and limbs, replacement of body parts and cognitive-computer interfaces. Future work will combine what we know about the body, computers, artificial parts, medicine, and biology in producing integrated work where these different advances can be combined to prevent disabling conditions and improve the daily functioning and well-being of disabled people (Kurzweil, 2005).

Our understanding of disability has been very Western centric. A large and disparate body of research is coming from developing countries and the Southern Hemisphere (Grech & Soldatic, 2016). In the past, we have typically taken Western models and understandings of disability and imposed them on studies and service systems in other parts of the world when, in fact, there is much to be learned from how others define, interpret, and respond to disability (Booyens, Van Pietzen, & Lorenzo, 2015). Types of disability and responses to them differ by culture and country (Elo, Mehta, & Huang, 2011). For instance, in Africa and Asia people with disabilities such as blindness and cognitive impairments are seen to have special powers or to be avoided. A woman from Zambia was thought to be dangerous and a witch because she had epileptic seizures (Albrecht, Devlieger, & Van Hove, 2008). Others are seen to be socially useful in business transactions. Spinal cord injured men in Kinshasa who used wheel chairs were seen as a valuable asset in business because, by local laws, they could transit the Congo River and on their way take goods back and forth between Kinshasa and Brazzaville. This facilitated local commerce (Devlieger & Nieme, 2011). In another example, the meanings and treatment of leprosy have changed and evolved so that today the disease is seen and treated differently in South Africa, Indonesia, and Hawaii. Even in one country, such as the United States, there is considerable discussion and conflict about what to do with the Pere Damien Leper Colony on the Island of Molokai (Devlieger, 2016). Likewise, becoming disabled in a conflict zone has different meanings than becoming disabled in an auto accident. The point is that there is much to be learned by doing field work across to world to supplement the knowledge of disability that we have from large, international surveys and pooled data from health care facilities.

By definition and as observed in field work, the physical, social, economic, and political environment has tremendous influence on how people acquire disabilities and how they to respond to them (Altman & Barnhardt, 2014). We need to know much more about the interplay between people with disabilities and their environments (Srivasta & Kumar, 2015; Zuurmond, Nyapera, Mwenda, Kisla, & Palmer, 2016). Climate change is an example of

how environments affect disability and disabled people. Aside from natural disasters such as flooding, drought, and a geographical redistribution of disabling diseases, climate change forces people to migrate and take their conditions with them. Research on the effects of climate change on disability and economic development has been encouraged by the World Bank but much work needs to be done in this area. Constructing barriers to the migration of people will not prevent disease and disability redistribution. The related fluidity of disability in terms of causes, conditions, and outcomes is an important matter for research. These musings examine what disability is, how it is defined, the work that was fundamental to our knowledge on the topic, and what some of the important issues for future work are.

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