

Turning the Disability Tide

The Importance of Definitions

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FORTY MILLION TO 50 MILLION INDIVIDUALS IN THE UNITED States now live with potentially disabling conditions. According to the Institute of Medicine (IOM), this number will likely increase substantially in coming decades.¹ Aging baby boomers will fuel much of this growth as this enormous cohort enters age ranges with the greatest disease and disability risks. Although rates of some serious limitations among elderly individuals have declined,² sobering reports warn of higher rates of potentially impairing conditions among children³ and working-age adults.⁴ These latter trends are multifaceted with diverse contributors, including major therapeutic breakthroughs that now save lives of severely impaired individuals who would once have died and increasing prevalence of overweight and obesity among youth and young adults, along with associated problems such as diabetes. As recent reports suggest, overweight and obesity cause particular concerns not only because they are associated with increased mortality risks,⁵ but also because they increase the risk of functional limitations.^{6,7}

Such predictions carry an aura of inevitability; even baby boomers cannot escape the march of time. Fears that trends will erode individuals' independence and ability to participate fully in daily life, as well as increase medical and caregiving costs, raise the stakes. Can the United States counter the forces that may significantly swell the numbers of individuals living with disability?

Various sectors have mobilized to do just that, with varying levels of success. These include the National Institutes of Health, which has provided billions of dollars for research to reduce mortality and morbidity; the health care delivery system, which provides acute, chronic, and palliative care services; and the Centers for Disease Control and Prevention along with other public health efforts targeting health promotion and maximizing wellness.^{1,7} However, the United States has not yet concentrated its collective resources—its people, public policies, institutions, communities, and dollars—to avert the impending wave of population disability.¹

Finding a basis from which to start this massive mobilization presents a daunting challenge. As have others,¹ we argue that devising strategies to confront disability must first start by defining disability. Definitions implicitly connote

goals, which in turn suggest potential solutions and targets for action. When it comes to preventing or deterring disability, this definition matters.

Brief History of Disability Definitions

It is likely that human societies have always grappled with defining disability. On African savannahs or wherever early peoples congregated to share resources, there were some who certainly could not contribute to communal wealth, physical, sensory, or cognitive impairments prevented them from laboring or fulfilling expected social roles. They needed help simply to survive, and societies offered that help. However, as pressures on charitable coffers grew, practical concerns developed regarding how to determine whether specific individuals deserved assistance. Because people were able to feign physical and mental incapacity for secondary gain, detecting deception has driven individual disability determinations for centuries.⁸

In the early 1800s, new diagnostic tools cast physicians as "objective" arbiters of disability. An initial breakthrough came with Laënnec's 1819 invention of the stethoscope, touted as freeing physicians from patients' reports tainted by prejudice or ignorance.⁸ Other technologies soon followed, including the microscope, ophthalmoscope, spirometer, and radiograph. Proponents of each new technology emphasized its ability to liberate physicians from patients' subjective judgments and its utility for disability certification. Furthermore, new diagnostic tools bolstered dawning recognition of biological causes of impairments and supported medicine's primacy in treating these conditions.^{8,9}

By the late 19th century, the medical model of disability was firmly entrenched. "The *medical model* views disability as a problem of the person, directly caused by disease, trauma or other health condition. . . . Management of the disability is aimed at cure or the individual's adjustment and behaviour change. Medical care is viewed as the main issue."¹⁰ The medical model thus built upon 2 assumptions: first, that individuals should strive, largely through their own efforts guided by physicians, to overcome disabilities; and second, that physicians know what is best for patients. Both

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assumptions often made disability a lonely state—defined and frequently stigmatized by others, with individuals required to “cheerfully and unselfconsciously” make their own “good adjustment.”¹¹

Decades later, social changes upended medicalized notions of disability. Confluent forces, including the independent living movement, self-help initiatives, consumerism, deinstitutionalization, and civil rights campaigns for racial and ethnic minorities and women, catalyzed an incipient disability rights movement.^{9,12-15} By the 1970s, a new paradigm held that “problems lie not within the persons with disabilities but in the environment that fails to accommodate persons with disabilities and in the negative attitude of people without disabilities.”¹³ Disability is “imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society.”¹⁴ This new “social” model of disability diverged importantly from medical model tenets. “The *social model* . . . views the issue mainly as a socially created problem and basically as a matter of the full integration of individuals into society. Disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment.” The issue is therefore an attitudinal or ideological one requiring social change, which at the political level becomes a question of human rights.¹⁰

For more than 2 decades, the World Health Organization’s (WHO’s) attempt to define disability crystallizes these conceptual shifts.^{16,17} In the 1980 nomenclature, the *International Classification of Impairments, Disabilities, and Handicaps*, WHO defined disability as “any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.”¹⁸ This language locates disability firmly within individuals affected by impairments, alongside the related concept of handicap: “disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal.”¹⁸ During the 1990s, as WHO committees prepared revisions of the 1980 edition, defining disability proved troublesome. One revision eliminated the word altogether, noting it caused “misunderstanding between health care professionals and people who experience disablement.”¹⁹

The *International Classification of Functioning, Disability and Health* (ICF), unanimously approved by 190 member countries in May 2001, integrated both medical and social models in attempting to link biological, individual, and social perspectives to provide a coherent view of health (BOX).¹⁰ Explicitly recognizing the role of external forces (physical, social, and attitudinal) in precipitating or mitigating disability represents one of the major contributions of the ICF.¹⁶ Equally noteworthy, the ICF introduced participation in daily and community life as an explicit component of health. This concept shifted the emphasis from strict prevention to maximizing functioning and well-being—perspectives consonant with public health goals in an aging society.²² By presenting disability as a continuum, the ICF emphasized

Box. Definitions of Disability

World Health Organization, 2001¹⁰

“Umbrella term for impairments, activity limitations or participation restrictions,” conceiving “a person’s functioning and disability . . . as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors,” including the social, attitudinal, and physical environments and personal attributes.

Americans with Disabilities Act (ADA), 1990

§3(2) “The term ‘disability’ means, with respect to an individual—(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment.”

ADA Regulations (28 CFR Part 36, §36.104)

“Major life activities include such things as caring for one’s self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working.”

To be substantially limited, an individual’s important life activities must be “restricted as to the conditions, manner, or duration under which they can be performed in comparison to most people.”

Social Security Administration, 2003²⁰

“Inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.”

American Medical Association, 2001²¹

“An alteration of an individual’s capacity to meet personal, social, or occupational demands because of an impairment.”

the universality of disability and stressed its “relevan[ce] to the lives of all people to different degrees and at different times in their lives.”²³

Definitional Divide

While recognizing that further work must refine and strengthen the ICF, the IOM recommends adopting its conceptual framework in all US efforts to monitor and measure population disability.¹ Doing so would explicitly capture social and environmental contributors to disability, according them the same recognition as medical model factors (ie, individuals’ impairments and other deficits). Nonetheless, the IOM acknowledges that a single definition of disability cannot meet societal needs. Just as in earlier eras, society must still decide which individuals merit income support or protection from disability discrimination. These functions require different definitions of disability. Federal and state laws and regulations contain dozens of formal disability definitions for these various purposes.

Several prominent definitions are shown in the Box. They draw from the 1990 Americans with Disabilities Act (ADA), which mandated civil rights protections for individuals with disabilities; the Social Security Administration, which provides income support for qualifying individuals through Social Security Disability Insurance and which benefits disabled workers; Supplemental Security Income, which supports impoverished disabled individuals²⁰; and American Medical Association guidelines, which evaluate permanent impairments used by many workers' compensation programs to assess claimants.²¹ The ADA definition also recognizes that societal attitudes can prove disabling, whereas other definitions firmly locate disability in diseases, disorders, impairments, and other limitations of individuals. The Social Security Administration, for example, maintains detailed medical definitions to adjudicate its massive entitlement programs.^{20,24}

Health insurers and much of the health care delivery system remain firmly rooted in classic medical thinking about disability, which does not offer insight into how individuals with disability might participate in daily activities or community life (eg, by eliminating environmental barriers or using assistive technology). Products and services that might address environmental barriers (eg, grab bars, ramps, mobility aids) or promote participation in daily life (eg, eyeglasses, hearing aids, accessible transportation) generally fall beyond boundaries of insurance coverage.^{1,17}

Implications of Definitions for Addressing Disability

No single definition of disability will likely ever suffice to meet multiple societal needs. Nonetheless, for setting policies that will affect US population health over coming decades, we advocate a definition like that of the ICF, incorporating both medical and social perspectives. This all-encompassing approach leads to fundamentally different goals, solutions, and targets for interventions and therefore offers the greatest hope to guide policies that might stem the disability tide.

Through the broad lens of the ICF, society can acknowledge both the need to cure and to prevent disease and the equally important goal of maximizing participation in daily life. Solutions include changes to improve the fit between individuals and their environments, and targets to achieve such solutions include not only individuals but also families, health care professionals, communities, and society as a whole. Clearly, developing better ways to prevent and treat individuals' functional impairments remains critical to lowering US population disability. Finding technologies that can restore or replace impaired functioning also deserve focused attention. Continuing public health efforts to reduce overweight and obesity, increase physical activity, eliminate smoking and substance abuse, and otherwise promote health and wellness remain key priorities. Changing the physical environment must assume urgency—building completely accessible “healthy” communities, safe and comfortable to navigate across the lifespan.

Changing the social environment (ie, societal attitudes toward disability) must start by putting medical model thinking into its proper perspective. If each person or close family member will someday experience disability, finding solutions should not be a lonely individual struggle. It requires the efforts of everyone to make his or her particular societal and environmental niche more welcoming and accommodating to all.

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REFERENCES

1. IOM Committee on Disability in America. *The Future of Disability in America*. Field MJ, Jette AM, eds. Washington, DC: National Academies Press; 2007.
2. Freedman VA, Martin LG, Schoeni RF. Recent trends in disability and functioning among older adults in the United States. *JAMA*. 2002;288(24):3137-3146.
3. Perrin JM, Bloom SR, Gortmaker SL. The increase of childhood chronic conditions in the United States. *JAMA*. 2007;297(24):2755-2759.
4. Bhattacharya J, Choudhry K, Lakdawalla D; Institute of Medicine Committee on Disability in America. Chronic disease and trends in severe disability in working-age populations. In: Field MJ, Jette AM, Martin L, eds; *Workshop on Disability in America: A New Look. Summary and Background Papers*. Washington, DC: National Academies Press; 2006:113-142.
5. Flegal KM, Graubard BI, Williamson DF, Gail MH. Cause-specific excess deaths associated with underweight, overweight, and obesity. *JAMA*. 2007;298(17):2028-2037.
6. Alley DE, Chang VW. The changing relationship of obesity and disability, 1988-2004. *JAMA*. 2007;298(17):2020-2027.
7. Gregg EW, Guralnik JM. Is disability obesity's price of longevity? *JAMA*. 2007;298(17):2066-2067.
8. Stone DA. *The Disabled State*. Philadelphia, PA: Temple University Press; 1984.
9. Linton S. *Claiming Disability: Knowledge and Identity*. New York, NY: New York University Press; 1998.
10. World Health Organization. *International Classification of Functioning, Disability and Health*. Geneva, Switzerland: World Health Organization; 2001.
11. Goffman E. *Stigma: Notes on the Management of Spoiled Identity*. New York, NY: Simon & Schuster, Inc; 1963.
12. Fleischer DZ, Zames F. *The Disability Rights Movement: From Charity to Confrontation*. Philadelphia, PA: Temple University Press; 2001.
13. Olkin R. *What Psychotherapists Should Know About Disability*. New York, NY: Guilford Press; 2001.
14. Oliver M. *Understanding Disability: From Theory to Practice*. New York, NY: St Martin's Press; 1996.
15. Shapiro JP. *No Pity: People With Disabilities Forging a New Civil Rights Movement*. New York, NY: Times Books; 1994.
16. Whiteneck G. Conceptual models of disability, past, present and future. In: Field MJ, Jette AM, Martin L, eds; Institute of Medicine. *Workshop on Disability in America: A New Look, Summary and Background Papers*. Washington, DC: National Academies Press; 2006:50-66.
17. Institute of Medicine Committee on a National Agenda for the Prevention of Disabilities. *Disability in America: Toward a National Agenda for Prevention*. Pope AM, Tarlov AR, eds. Washington, DC: National Academies Press; 1991.
18. World Health Organization. *International Classification of Impairments, Disabilities, and Handicaps*. Geneva, Switzerland: World Health Organization; 1980.
19. *ICIDH-2 International Classification of Impairments, Activities and Participation: A Manual of Dimensions of Disablement and Functioning, Beta-1 Draft for Field Testing*. Geneva, Switzerland: World Health Organization; 1997.
20. Social Security Administration Office of Disability Programs. *Disability Evaluation Under Social Security*. Washington, DC: Social Security Administration; 2003. Social Security Administration publication 64-039.
21. Cocchiarella L, Andersson GBJ, eds. *Guides to the Evaluation of Permanent Impairment*. 5th ed. Chicago, IL: American Medical Association; 2001.
22. Albert S. *Public Health and Aging: An Introduction to Maximizing Function and Well Being*. New York, NY: Springer Publishing Co; 2004.
23. Ustün TB, Chatterji S, Kostansjek N, Bickenbach J. WHO's ICF and functional status information in health records. *Health Care Financ Rev*. 2003;24(3):77-88.
24. Institute of Medicine Committee to Review the Social Security Administration's Disability Decision Process Research; National Research Council Committee on National Statistics. *The Dynamics of Disability: Measuring and Monitoring Disability for Social Security Programs*. Washington, DC: National Academies Press; 2002.