

## Training physicians about caring for persons with disabilities: “Nothing about us without us!”

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### Abstract

According to the *World Report on Disability*, physicians worldwide generally lack training about caring for persons with disabilities, thus frequently compromising their health care experiences and health outcomes. Many U.S. physicians are similarly untrained about critical aspects of providing care to persons with disabilities, perhaps contributing to disparities in their care. Recognizing these inadequacies, U.S. medical educators are beginning to develop core competencies for trainees relating to the care of patients with disabilities, including understanding patients' perceptions of their quality of life and skills in providing patient-centered care. Having today's physicians, even when genuinely well-intentioned, retain control over designing disability-related training programs for future doctors may miss critical issues in caring empathically and effectively for persons with disabilities. Involving persons with disabilities in identifying training needs and implementing curricula for future physicians may offer important opportunities for ensuring their competency to provide patient-centered care to persons with disabilities. © 2012 Elsevier Inc. All rights reserved.

**Keywords:** Disability; Physicians; Medical education; World Report on Disability

To maximize their physical and mental health, functioning, and wellness, persons with disabilities need ready access to appropriate preventive, diagnostic, therapeutic, rehabilitative, and supportive health care services and assistive technologies. Given how health care is delivered and financed in the United States, obtaining these services almost universally requires interactions with physicians. For persons with disabilities, physicians' roles providing care and as access gatekeepers come with a catch: with limited exceptions, physicians have little training in addressing the wide-ranging needs of persons with disabilities. They know neither specific clinical needs nor basic fundamentals, such as how to: recognize disability in its full diversity; communicate effectively with persons with disabilities; identify various contributors to disability, including social and environmental factors; and understand where disability fits into individuals' lives, values, preferences, and expectations about their health and futures—essential foundations for patient-centered care.

U.S. physicians are not alone in lacking training about the health and health care needs of persons with disabilities. The *World Report on Disability* highlights this absence and points to other observations worldwide that also ring true in the United States [1], including:

- Persistent societal stigma toward persons with disabilities infiltrate patient-physician interactions, with misconceptions and erroneous assumptions compromising patient care;
- Negative experiences with the health care system, such as experiencing disrespect, insensitivity, and devaluation, may lead persons with disabilities to eschew seeking care and rely upon self-diagnosis and treatment;
- Physicians lack the expertise and skills to distinguish clinical concerns arising from disability from those related to other health conditions; and
- Limited knowledge and understanding of disability deleteriously affect quality of care, contributing to delays in diagnosis and treatment, unsafe care, and inequities in care.

The *World Report on Disability* describes the “human resources”—health care professionals, their training, and

The authors have no funding source or conflicts of interest.

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skill sets—required to treat persons with disabilities worldwide [1]. This commentary draws on these observations and recommendations to discuss training of U.S. physicians; brevity prevents us from discussing parallel issues that arise in training other health care professionals. Specifically, we consider three broad questions: Why is training about caring for persons with disabilities important? What has kept disability training outside most traditional medical education? What can improve future medical education?

### **Why is training about disability important?**

According to the *World Report on Disability*, more than 1 billion persons currently live with disability worldwide, and these numbers are expected to rise with aging populations and growing numbers of persons with chronic, disabling health conditions [1]. In the United States, approximately 54 million persons have disabilities, representing 19% of the civilian, noninstitutionalized population [2]. Numbers of disabled Americans will rise with aging “baby boomers” and perhaps with the growing prevalence of obesity-related disability among young and middle-aged adults [3]. Furthermore, high-technology interventions are prolonging lives of children born with severely disabling conditions. Thus, with increasing numbers of disabled persons across the life span [4], almost every physician providing direct patient care—from treating tiny neonates to centenarians—will likely see substantial numbers of persons with disabilities.

Disabling conditions are diverse, and the role of medical services in their care varies widely. For example, individuals who are born blind or deaf may require little if any medical intervention for these conditions over their lives, sometimes depending on their preferences (e.g., choice of cochlear implants). In contrast, individuals who develop degenerative diseases, such as multiple sclerosis or Parkinson’s disease, generally seek treatments to slow disease progression and functional declines. Mental health disorders, developmental disabilities, trauma and injuries, and chronic health conditions that can become disabling over time (e.g., diabetes, cardiorespiratory diseases, cancers) offer examples where indicated medical interventions vary widely, as do their risks and benefits for reducing disability. Medical interventions also can assist in detection and treatment of secondary conditions related to an underlying disability, such as pressure ulcers, urinary tract infections, and depression. The valuable role that medical interventions can play in many disabling conditions heightens the importance of training physicians about these topics.

Persons with disabilities are especially susceptible to deleterious effects from the social and environmental determinants of health highlighted by *Healthy People 2020* [5,6]. On average, Americans with disabilities—as is true worldwide [1]—are more likely than nondisabled individuals to be impoverished, have low education, be unemployed, live in substandard housing, and experience other

social and environmental disadvantages. These contextual factors can challenge physicians’ efforts to address disease, for example by compromising patients’ health literacy or reducing their financial resources to afford health care, especially if they are uninsured or underinsured. Among its objectives for persons with disabilities, *Healthy People 2020* includes reducing unemployment, increasing the accessibility of new and retrofitted housing, reducing barriers to participating in community activities, and decreasing barriers within health care settings [5].

In addition, *Healthy People 2020*’s emphasis on social and environmental determinants of health parallels the World Health Organization’s [7] and *World Report on Disability*’s conceptualization of factors that contribute to disability [1]—the recognition that disability results from a complex mix of individual factors (personal characteristics, diseases and disorders, impairments, individuals’ abilities to perform activities and participate in daily life) and social and environmental facilitators and barriers. This model of disability suggests critical directions for training physicians about disability: teaching that disability and health must be viewed within the entire context of patients’ lives. This all-encompassing perspective is critical for physicians in providing patient-centered care.

### **Why is disability-related training lacking in medical education today?**

Especially in the Western world, people with disabilities have a fraught history with health care professionals. Relationships with physicians have been especially strained, with doctors since the early 19th century serving as society’s arbiters for who among those claiming disability deserves to get subsistence income (e.g., alms from charities in previous centuries, long-term disability insurance, and workers’ compensation today) [8]. In prior years, physicians were complicit in involuntary institutionalization and forced medical procedures, such as sterilization and electroconvulsive treatments, of persons with disabilities in the United States and worldwide [1,9]. Given their historical devaluation by some within the profession, the lack of medical training about individuals with disabilities is hardly surprising.

In addition, until the 1970s, physicians viewed their goal as “curing” persons with disabilities, explicitly eliminating or treating the very impairments or deficits that defined individuals as “crippled” or “handicapped,” using nomenclature of that earlier era. If cure was impossible, medical precepts required persons to “cheerfully and unselfconsciously” make their own “good adjustment” to loss and deficiencies [10]. By the 1970s, partially motivated by self-help consumerism [11], the disability rights movement located “problems ... 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” [12]. Under this paradigm,

roles of physicians became less clear, as individuals with disabilities increasingly made their own choices about their reliance on traditional medical services. Furthermore, invoking social and environmental factors as determinants of health seems more oriented toward public health rather than standard medical interventions. Until recently, training about social and environmental contributors to health has resided in public health rather than medical schools.

Another factor was the perhaps legitimate recognition among physicians that certain disability concerns fall squarely within the bailiwick of other health professionals, such as physical and occupational therapists. Even so, health insurance typically requires physicians to prescribe these services and authorize reimbursement. Training about therapy for other disabling conditions, such as mental health disorders and developmental disabilities, has generally been similarly limited. One explanation might be the “silos” within which therapy for these conditions can occur (e.g., “carve outs” of mental health from other services, referral of persons with developmental disabilities to social service systems).

Comprehensive care for many persons with disabilities will require interdisciplinary coordination and integrated teams of diverse health professionals. However, training young physicians to function effectively within such interdisciplinary teams has been rare. Historically, physicians led these teams, called all the shots. Medical schools generally did not teach trainees to understand fully the contributions of other health care professionals and ways to integrate care across disciplines to meet the needs and values of patients generally, let alone persons with disabilities.

### What can improve future training about disability?

The confluence of several forces might push U.S. medical educators to add training about persons with disabilities to their curricula. The population trends noted above, combined with continuing recognition of disparities in health care of persons with disabilities [5,13-16], have led leading medical educators to recommend core competencies for training physicians to care for persons with disabilities. Kirshner and Curry [17] proposed six such core competencies for disability-related training:

1. Framing disability within the context of human diversity across the lifespan and within social and cultural environments;
2. Skills training for assessment of disability and functional consequences of health conditions, considering implications for treatment and management;
3. Training in general principles concerning etiquette for interactions with persons with disabilities;
4. Learning about roles of other health care professionals forming integrated teams to care for persons with disabilities;
5. Understanding legal requirements of the 1990 Americans with Disabilities Act for accommodating

disability in health care settings, along with principles of universal design; and

6. Competency in patient-centered care approaches, including understanding patients’ perceptions of quality of life.

The sixth competency—patient-centeredness, care respecting patients’ values and preferences—aligns with the centrality of patient centeredness within the recommendations for improving quality of care proposed by the Institute of Medicine (IOM) in 2001 [18]. The IOM noted that persons with chronic conditions and disabilities often slip through the fault lines crisscrossing the U.S. health care delivery system; patient-centeredness serves as the “true North” to guide all reforms [19]. In arguing that patient-centeredness should play this critical role, IOM committee member Berwick cited three maxims: “The needs of the patient come first;” “Nothing about me without me;” and “Every patient is the only patient” [20]. The second maxim echoes the frequent refrain of disability rights advocates—“Nothing about us without us!” [21]. The *World Report on Disability* picks up this mantra in what it calls “people-centered services” and emphasizes links to human rights advocacy for persons with disabilities, as articulated within the United Nations Convention on the Rights of Persons with Disabilities [1]. It also specifically recommends that educators “integrate disability education into undergraduate and continuing education for all health care professionals” [1].

Organizations comprised of physicians, persons with disabilities, and other medical educators have begun developing more specific competencies to guide U.S. medical education. The Alliance for Disability in Health Care Education has recently started developing disability-related competencies for undergraduate medical education. This effort began with identifying relevant disability-related knowledge, skills, and attitudes [22]. The National Curriculum Initiative in Developmental Medicine, a cooperative effort among several organizations, has proposed competencies for residency education [23].

Another important impetus comes from the Patient Protection and Affordable Care Act (ACA, P.L. 111-148), signed on March 23, 2010 by President Obama. Embedded throughout this massive law are specific provisions relating explicitly to persons with disabilities, including: “Removing barriers and improving access to wellness for individuals with disabilities” (Title IV, Subtitle C, Sec. 4203); “Understanding health disparities: data collection and analysis,” which requires Secretary of Health and Human Services to survey providers about the number of employees trained in disability and care of individuals with disabilities (Title IV, Subtitle D, Sec. 4302); and “Cultural competency, prevention, and public health and individuals with disabilities training” (Title V, Subtitle D, Sec. 5307). Other more general provisions may also have important effects on persons with disabilities, including mandates for the

establishment of patient-centered medical homes within community health teams (Title III, Subtitle F, Sec. 3502), various provisions relating to persons dually eligible for Medicare and Medicaid, exploration of new financing and delivery models for Medicare (e.g., accountable care organizations), and Patient-Centered Outcomes Research (Title VI, Subtitle D). As these initiatives unfold over coming years, they will likely have important effects on medical education in general and offer opportunities to highlight training concerns relating to disability.

Finally, as noted above, the *World Report on Disability* describes the complicated history persons with disabilities have had with physicians—a sense that many doctors “just don’t get” important aspects of the lives and expectations of persons with disabilities [1]. Persistent health care disparities experienced by Americans with disabilities [5,13-16] suggest a similar dynamic at play in the United States. Because of that, having today’s physicians—even when genuinely well-intentioned—retain complete control over designing training programs for future doctors may miss critical issues in caring empathically and effectively for persons with disabilities. The exhortation “Nothing about us without us!” may therefore also apply to medical curriculum design. Involving persons with disabilities in identifying training needs and implementing curricula for future physicians may offer important opportunities for ensuring their competency to provide patient-centered care to persons with disabilities.

## References

- [1] World Health Organization and The World Bank. *World Report on Disability*. Geneva: World Health Organization; 2011. pp. 77-79.
- [2] US Census Bureau. Facts for Features: 20th Anniversary of Americans with Disabilities Act: July 26, 2010. Available at: [http://www.census.gov/newsroom/releases/archives/facts\\_for\\_features\\_special\\_editions/cb10-ff13.html](http://www.census.gov/newsroom/releases/archives/facts_for_features_special_editions/cb10-ff13.html). Accessed February 25, 2012.
- [3] Alley DE, Chang VW. The changing relationship of obesity and disability, 1988-2004. *JAMA*. 2007;298:2020-2027.
- [4] Institute of Medicine, Committee on Disability in America Board on Health Sciences Policy. *The Future of Disability in America*. Washington, DC: National Academies Press; 2007.
- [5] US Department of Health and Human Services. *Healthy People 2020. Disability and Health*. Available at: <http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=9>. Accessed February 25, 2012.
- [6] Iezzoni LI. Public health goals for persons with disabilities: looking ahead to 2020. *Disabil Health J*. 2009;2:111-115.
- [7] World Health Organization. *International Classification of Functioning, Disability and Health*. Geneva: World Health Organization; 2001.
- [8] Stone DA. *The Disabled State*. Philadelphia: Temple University Press; 1984.
- [9] Longmore P, Umansky L, eds. *The New Disability History. American Perspectives*. New York: New York University Press; 2001.
- [10] Goffman E. *Stigma. Notes on the Management of Spoiled Identity*. New York: Simon and Schuster, Inc.; 1963.
- [11] Shapiro JP. *No Pity: People with Disabilities Forging a New Civil Rights Movement*. New York: Times Books; 1994.
- [12] Olkin R. *What Psychotherapists Should Know About Disability*. New York: The Guildford Press; 1999.
- [13] US Department of Health and Human Services. *The Surgeon General’s Call to Action to Improve the Health and Wellness of Persons with Disabilities*. Washington, DC; 2005.
- [14] National Council on Disability. *The Current State of Health Care for People with Disabilities*. Washington, DC; 2009.
- [15] Agency for Healthcare Research and Quality. *2010 National Healthcare Disparities Report*. AHRQ Publication No. 10-0005. Rockville, MD; 2011.
- [16] Iezzoni LI. Eliminating health and health care disparities among the growing population of people with disabilities. *Health Aff (Millwood)*. 2011;30:1947-1954.
- [17] Kirschner KL, Curry RH. Educating health care professionals to care for patients with disabilities. *JAMA*. 2009;302:1334-1335.
- [18] Institute of Medicine, Committee on Quality of Health Care in America. *Crossing the Quality Chasm. A New Health System for the 21st Century*. Washington, DC: National Academies Press; 2001.
- [19] Berwick DM. A user’s manual for the IOM’s ‘Quality Chasm’ report. *Health Aff (Millwood)*. 2002;21:80-90.
- [20] Berwick DM. What ‘patient-centered’ should mean: confessions of an extremist. *Health Aff (Millwood)*. 2009;28:w555-w565.
- [21] Charlton J. *Nothing About Us Without Us: Disability, Oppression and Empowerment*. Berkeley, CA: University of California Press; 1998.
- [22] Minihan PM, Robey KL, Long-Bellil LM, et al. Desired educational outcomes of disability-related training for the generalist physician: knowledge, attitudes, and skills. *Acad Med*. 2011;86:1171-1178.
- [23] Holder M, Tyler C. National Initiative in Developmental Medicine; Draft Curriculum. Paper presented at Health Professional Education in Intellectual and Developmental Disabilities. Association of University Centers on Disabilities. Washington, DC; May 25, 2011. Available at: <http://www.aucd.org/docs/ncbddd/May%202011%20ID%20Surveillance/Holder%20Tyler%20NCIDM.pdf>.