

Brief Historical View of Disability and Related Legislation[®]

Disability is not a new concept and not something that has emerged as a result of increasing numbers of people affected. Rather, disability is an ancient concept that has existed for as long as people have existed. Although disability has not changed, our views of the meaning of disability have changed over time-for the better.

Early Views of Disability

In the medieval era, disability was considered a punishment from God for one's sin or misbehavior or that of one's ancestors. Others over the centuries have viewed disability as the work of the devil. Disability was seen as a failure, deformity or defect of the individual. As a result of the myths about disability, people with disabilities were feared and often stigmatized, shunned, abused, or condemned. People with visible disabilities were even used for entertainment (e.g., court jesters or oddities in circuses and freak shows). Children and adults with severe disability were kept at home, isolated and hidden from public view. They were often denied what others received, including education, care, employment, and a place in the family or in society. They were considered "different" and their differences were viewed negatively. Disability was viewed as inability and those with disabilities were often viewed as a burden to their families and to society as a whole. In societies that required travel to escape danger or to obtain food, children and adults with disabilities were often abandoned. In some societies, adults and children with disabilities were forced to beg on the street for money because they had no other means of support or were pitied by others. Unfortunately, this still exists in some countries. Many persons with disabilities were powerless to do anything else and institutionalization was often the only option for those with disabilities to receive care and food.

People with disabilities have been considered sick or unhealthy. Being healthy and having a disability have been perceived as a contradiction in terms. Disability was seen as an issue blamed on the individual with a disability. Quality of life of individuals with disability was often seen---and still is by some---to be poor by others who have very negative views about disability, even though only an individual can determine the quality of life of his or her own life.

Changing Views about Disability

By the 1800s disability began to be viewed as an issue that had individual health and public health implications, as well as social and policy implications. Disability was seen as a medical problem due to disease, trauma, or other health conditions. This generally led to the medical model of disability, which viewed disability as an issue of the person with a disability. The goal of medical management was cure of the disabling condition or modification of behaviors of the individual with a disability. The medical model viewed physicians as the experts who knew what was best for those with disabilities. Those with disabilities were not seen as capable of knowing what they needed in the way of health care and other services.

More recently, disability has been viewed as a result of environmental and societal factors that serve as barriers to the ability of persons with disabilities to participate fully in their communities or families or to obtain the care and services they need. Individuals with disability, their families, and advocacy groups have viewed disability as a consequence of an inaccessible environment and rejected the medical model in favor of other models, such as the social and biopsychosocial models of disability that address barriers to health care from different perspectives.

Health Care for Persons with Disability

Policies and laws that extend back to 1857 have promoted the inclusion of individuals with disabilities in society. Many of the early policies and laws addressed employment or income

support, housing, and transportation rather than health and access to health care. Those federal agencies that addressed disability focused largely on its prevention, with little attention paid to the health of individuals with existing disabilities. Although not the first federal legislation to address disability, the Americans with Disabilities Act (ADA), was the first comprehensive civil rights law designed to prevent discrimination of people with disabilities in employment and access to public and private services. The ADA, signed into law on July 26, 1990, was enacted for inclusion and nondiscrimination based on disability in employment, government services, public accommodations including medical facilities, telecommunications, and other services, such as insurance. The ADA was amended in 2008 to ensure broad coverage of individuals who fit the definitions of the ADA of 1990. The overall purpose of the ADA is to provide a national mandate for the elimination of discrimination against persons with disabilities. Its goals are identified in Chart 1.

Chart 1. Goals of the Americans with Disabilities Act
<p>The Americans with Disabilities Act was designed to meet four goals for persons with disabilities:</p> <ol style="list-style-type: none"> 1) Equal employment opportunities, 2) Full participation in the community, 3) Independent living, 4) Economic self-sufficiency. <p>http://www.ada.gov/cguide.htm</p>

The Healthy People Initiative, which preceded the ADA by more than a decade, was established in 1979 by the U.S. Department of Health and Human Services (USDDHS) to establish, promote and monitor national health objectives. Initially, the focus on disability was again limited to its prevention. The initiative paid little attention to individuals with existing disabilities. *Healthy People 2010*, released in 2000, established for the first time national health objectives specifically related to health of people with existing disabilities. Instead of focusing only on prevention of disability, *Healthy People 2010* also identified the importance of promoting the health and well-being of individuals with disabilities, including prevention of secondary conditions that directly or indirectly arise from the primary cause of disability.

Despite passage of the ADA in 1990 and greater attention to disability in the Healthy People Initiative beginning in 2000, progress in achieving the equality in services for people with disabilities has been slow. In response to lack of adequate progress in meeting national health objectives, the U.S. Surgeon General’s Office published a call to action calling for action to address the health care needs of individuals with disabilities (Chart 2). The second goal specifically addresses the need for health care providers to have the knowledge and skills to provide care improve the health and well-being of those with disabilities.

Chart 2. U.S. Surgeon General’s Call to Action to Improve the Health and Wellness of Persons with Disabilities
<p>The Surgeon General’s Call to Action identified four overarching goals to be achieved:</p> <ol style="list-style-type: none"> 1) People nationwide understand that persons with disabilities can lead long, healthy, productive lives; 2) Health care providers have the knowledge and tools to screen, diagnose, and treat the whole person with a disability with dignity;

3) Persons with disabilities can promote their own good health by developing and maintaining healthy lifestyles;

4) Accessible health care and support services promote independence for persons with disabilities.

U.S. Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities (U.S. Public Health Service, 2005, p 2).

Current Status of Health Care for Persons with Disability

Although gains have been made in access to services, some barriers and disparities remain in areas of employment and income, housing, transportation, education and health care. Persons with disabilities continue to receive fewer services, including health care, than those without disabilities. The care they receive is often of lower quality than that provided to individuals without disabilities. Some persons with disabilities have been refused care because they have a disability. Lack of inclusion of disability concepts and content in the educational programs of the health care professions has been identified as a major reason that the health care of persons with disabilities is not equal to that of those without disabilities.

The Patient Protection and Affordable Care Act, commonly referred to as the Affordable Care Act (ACA), signed into law in 2010, has the potential to improve access to health care for persons with disabilities. The ACA provides Americans with disabilities the security of knowing that they will not be denied health insurance because they have a disability, will not have imposed lifetime dollar limit on health benefits, and will have coverage for preventive care like mammograms and other cancer screenings. However, barriers to care, including physical, communication, and attitudinal barriers as well as others, persist and indicate that more work needs to be done to improve the health care for persons with disabilities.

An important strategy to improve the health care of people with disabilities is to integrate the topic of disability into the education of health care professionals, including nursing. There have been multiple calls to do so. The International Council for Nursing (ICN) has clearly articulated the role of nurses and the nursing profession in its position statement. The position statement clearly defines disability and identifies strategies to maximize the effectiveness of nursing care for individuals with disabilities. In collaboration with Villanova University College of Nursing faculty, the National League for Nursing (NLN) is addressing the topic of disability in nursing education through its Advancing Care Excellence for People with Disabilities (ACE.D) Program to improve the health care and health status of individuals with disability.

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