

Overview and Introduction to Disability[©]

This Overview and Introduction to Disability is intended to provide nursing students and their nursing faculty with important information needed to use other materials and resources included in ACE.D site.

Rationale for Addressing Disability in Nursing Education Curricula

The population of people with disability has been described as the largest minority group in the United States. Despite the large and growing population of people with disabilities, those with disabilities experience poorer health and receive less access to health care and less quality care than those without disabilities. An important factor related to poor health care and access to care is the lack of attention to disability in the curricula of educational programs that prepare health care professions. This extends to nursing as well as other health care professions. This document is intended to introduce information about disability and individuals with disability with the goal of introducing nursing students and nursing faculty to the health care needs of people with disability so that nursing care is of the same quality provided to patients with all types of disability and in all settings in which health care, including nursing care, is provided.

The Americans with Disabilities Act (ADA) was passed in 1990 to ensure access of people with disabilities to services. However, significant disparities in health status and health care persist, due in part to the lack of progress in inclusion of disability in health care professionals' education. (Peacock, Iezzoni & Harkin, 2015). In response to the lack of attention to disability in health care professions programs, the U.S. Surgeon General issued a *Call to Action to Improve the Health and Wellness of Persons With Disabilities* (USDHHS, 2005). This report was based on inadequate attention to the topic and lack of access of those with disability to high-quality health care. The call specifically noted the need for health care professionals to become knowledgeable about disability. Additional calls to address disability in the health professions highlight the necessity for health care professions educators, including nursing faculty, to begin to address the issue in earnest.

Definitions of Disability and Differentiation Between Disability and Disabling Condition

Although there are many definitions of disability, including more than 60 used by the U.S. government (Krahn et al., 2015), only a few of them are presented here. The Americans with Disabilities Act of 1990 defined a person with a disability as one who (1) has a physical or mental impairment that substantially limits one or more major life activities, (2) has a record of such an impairment, or (3) is regarded as having such an impairment.

The World Health Organization (WHO) defines *disability* as an umbrella term that includes impairments, activity limitations, participation restrictions, and environmental factors. In this definition impairment is identified as a loss or abnormality in body structure or physiologic function, including mental function. A person's functioning or disability is viewed as a dynamic interaction between health conditions (i.e., diseases, disorders, injuries, trauma) and contextual factors (i.e., personal and environmental factors) (WHO, 2001). Instead of the formerly used term, handicap, the WHO uses the term *societal participation* to acknowledge the interaction of people with their environment, making the point that one's environment can either assist or

hinder participation in life activities. The WHO’s definition of disability addresses the reality that the environment may have a greater impact on an individual’s ability to participate in life activities than the individual’s physical condition, mental status, or emotional condition.

In its position statement on disability, the International Council of Nursing (ICN, 2010), defined disability as a physical, mental, sensory, or social impairment that, in the long term, adversely affects one’s ability to carry out normal day-to-day activities. The ICN supports programs designed to integrate people with disabilities in all aspects of daily life --- in the family, school, workplace and community. Its goal is to ensure that nursing education addresses competencies needed for the prevention of disability and the care and rehabilitation of individuals with pre-existing disabilities. The ICN further calls for: fuller understanding of the particular problems faced by people with disability and their families; and promotion of advocacy skills and a knowledge of programs and resources in the community. According to the ICN, the role of the nurse includes assisting, supporting, and advocating for people with disabilities and their families in order to access education, information, and support services that allow them to lead fulfilling lives. Other terms occasionally used to describe people who have disabilities include: “people who are physically challenged,” and “people with special needs”. These terms are not universally accepted or understood and the ICN recommends use of the term “people with disability”.

It is important to note that disability is not the same thing as a disabling condition. While a disabling condition typically refers to the disorder or condition that caused the impairments associated with a disability, the term disability also addresses the effects that a disabling condition has on an individual’s ability to carry out normal day-to-day activities, the role changes that may occur, and the interaction of the disabling condition on the individual’s physical, psychological and social responses to the disabling condition. Disability includes the impact a disability has on an individual’s daily life and current and future health and well-being, ability to participate in self-care or self-management, and the ability to obtain required health care and health screening.

Prevalence of Disability in the U.S. and By Age Groups

It is estimated that more than 60 million people in the U.S. population have a disability, which represents 1 in every 4 or 5 (20% - 25%) individuals. The global estimate of the prevalence of disability is 1 billion people (WHO, 2014c). Disability occurs across the life span as indicated by the following table. When a family member has a disability, it affects everyone in a family because of health issues, costs of health care, the ability of the individual to attend school or to work, and caregiver responsibilities. Table 1 provides the prevalence of disability by age group and demonstrates that disability occurs across the life span.

Table 1. Prevalence of Disability by Age

Age Group	Disability Prevalence Rate
Children	13.9%
18-44 years of age	11.0%
45-64 years of age	23.9%
≥ 65 years of age	51.8%
65-74 years of age	44.8%

75-84 years of age	63.7%
≥ 85 years of age	84.2%

U.S. Department of Labor/Bureau of Labor Statistics. (2015).

Types of Disability and Secondary Conditions

As previously defined by the International Council of Nurses, disabilities can be physical, mental, sensory, or social in nature. Thus, disabilities include impairments of physical or mental health, cognition, speech, language, or self-care. They can be present at birth (e.g., Down syndrome, spina bifida, muscular dystrophy, deafness or vision impairment) or occur at the time of birth (e.g., cerebral palsy) due to birth injury. Those disabilities that are present at birth or at a very young age and occur in children are often considered developmental disabilities.

Acquired disabilities are those that occur after 22 years of age due to trauma, non-traumatic disorders, or progression of a chronic health issue over time. Examples of acquired disabilities include those that affect sensory function (e.g., adult-onset hearing or vision loss), stroke, spinal cord injury, amputation due to injury or as a result of chronic disease that affects circulation, arthritis, or progression of neurological disorders such as multiple sclerosis. Disabilities can also be related to aging; individuals with disabilities may experience physical and functional changes associated with aging at an earlier age than those without disabilities (see Aging with a Disability Resource for further details).

Secondary conditions are disorders that can occur because of the presence of a disability and because of a narrow margin of health or safety often experienced by people with disabilities. These include disorders such as pressure ulcers, alterations in renal, urinary and bowel function, bone loss, infections, and depression. The risk of or presence of secondary conditions often requires careful assessment and use of strategies to prevent or manage them. Secondary conditions can result in prolonged hospitalization, deterioration in health, and loss of independence if not managed or prevented.

Although disabilities may result in dependence of people with disabilities on others for assistance and care, the majority of people with disabilities, including those with severe disabilities, are often able to live in their own homes and function and contribute to their families and to society. Many live at home independently while caring for children and aging parents and maintain full-time employment or obtain an education. Occasionally home modifications are needed to enable them to continue to live and function in their homes. Others may require other living arrangements in order to receive required care and services. All deserve dignified care from health care professionals.

Barriers to Health Care Experienced by Persons with Disability.

Although the Americans with Disabilities Act (ADA) mandates access of people with disabilities to health care, barriers to that access continue. Among the most difficult barriers to access to overcome are negative attitudes and stereotyping of individuals with disabilities by health care professionals who judge the quality of life of individuals with disabilities. While this is common, only those with disabilities are in a position to determine the quality of their lives. Health care

providers who stereotype individuals with disabilities are less likely to encourage preventive health screening and other promotion strategies. In addition, health care professionals, including nurses, may have even more negative attitudes toward certain groups of people with disabilities, including those with developmental disabilities, cognitive/intellectual disabilities, and psychiatric/mental health disabilities.

Use of inappropriate communication strategies is another barrier to the ability of individuals with disabilities to receive effective health care. See Teaching Resources, Effective Communication with Persons with Disabilities, for a discussion of strategies to interact appropriately with patients with disabilities.

Other barriers are structural in nature and include lack of accessible health care offices and facilities (narrow doors that make entry in a wheelchair impossible, no accessible parking limited to those with disabilities, absence of restroom stalls that accommodate wheelchairs, heavy doors that cannot be opened by people in wheelchairs or those who use other assistive devices, and absence of grab bars and elevated toilet seats). In addition, there is often a lack of accommodation by health care professionals to communicate with individuals who have a hearing or other communication impairment. Failure of health care professionals to make reasonable accommodations also serves as a barrier to health care for people with disabilities.

In order to provide appropriate, high-quality health care to individuals with disabilities, health care professionals, including nurses, need to be aware and able to refer patients to facilities and settings that are accessible to them. Sign language interpreters and use of alternative communication methods are essential strategies that can overcome many of the barriers that people with disabilities encounter in the efforts to obtain needed health care. Nurses need to use their assessment skills to evaluate the effect of disabilities on patients' health and health care. Further, it is important for nurses to evaluate the ability of patients with disabilities to use the education that is provided and make appropriate modifications in teaching strategies when needed, using communication devices, assistive learning devices, large print and Braille educational materials and audiotapes when education is considered essential to patient care. For further information about assessment of individuals with disabilities, refer to the Resource, Assessment of People with Disabilities Checklist.

REFERENCES

Americans with Disabilities Act of 1990. www.ada.gov/pubs/ada.htm

Americans with Disabilities Amendments Act of 2008. www.access-board.gov

Patient Protection and Affordable Care Act. (2010): S.3590, 111th Congress, 2nd Session.

Drum, C. F. (2014). The dynamics of disability and chronic conditions. *Disability and Health Journal*, 7(1), 2-5. doi:10.1016/j.dhjo.2013.10.001

Iezzoni, L. I., Kurtz S. G., & Rao, S. R. (2014). Trends in U.S. adult chronic disability rates over time. *Disability and Health Journal*, 7(4), 402-412. doi:10.1016/j.dhjo.2014.05.007

International Council of Nurses. (2010). Prevention of disability and the care of people with disabilities [Position Statement]. Geneva, Switzerland: Author. Retrieved from <http://www.icn.ch/publications/position-statements>

Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons with disabilities as an unrecognized health disparity population. *American Journal of Public Health*, 105(S2), S198-S206. doi:10.2105/AJPH.2014.302182

Peacock, G., Iezzoni, L.I., & Harkin, T. R. (2015). Health care for Americans with disabilities---25 years after the ADA. *New England Journal of Medicine*, 37(10). 892-893. doi:10.1056/NEJMp1508854

Sharts-Hopko, N. C., Smeltzer, S., Ott, B. B., Zimmerman, B., & Dufin, J. (2010). Healthcare experiences of women with visual impairment. *Clinical Nurse Specialist*, 24(3), 149-153. doi:10.1097/NUR.0b013e3181d82b89

Smeltzer, S. C. (2007). Improving the health and wellness of persons with disabilities: A call to action too important for nursing to ignore. *Nursing Outlook*, 55(4), 189-193. doi:10.1016/j.outlook.2007.04.001

Smeltzer, S. C., Avery, C., & Haynor, P. (2012). Interactions of people with disabilities with nursing staff during hospitalization. *American Journal of Nursing*, 112(4), 30-37. doi:10.1097/01.NAJ.0000413454.07369.e3

US Department of Labor/Bureau of Labor Statistics. (2015). *Persons with a disability: Labor Force Characteristics—2014*. Washington, DC: Author.

US Department of Health and Human Services, Office of Disease Prevention and Health Promotion. (2010). *Healthy People 2020*. Washington, DC: Author.

US Department of Health and Human Services. (2005). *Surgeon General's call to action to improve the health and wellness of people with disabilities*. Rockville, MD: Author.

World Health Organization. (2001). *International classification of functioning, disability and health—ICF*. Geneva, Switzerland: Author.

World Health Organization. (2013). *Global action plan for the prevention and control of noncommunicable diseases, 2013-2020*. Author.

On-line Resources

AbleData, www.abledata.com

Alliance for Disability in Health Care Education, Inc., www.adhce.org.

American Association of the Deaf-Blind, www.aadb.org

American Association on Intellectual and Developmental Disabilities (formerly American Association on Mental Retardation), www.aaid.org

American Foundation for the Blind, www.afb.org

American Speech-Language-Hearing Association, www.asha.org

Americans With Disabilities Act National Network, www.adata.org/

Arc of the United States, www.thearc.org

Association of Late-Deafened Adults (ALDA), www.alda.org

Center for Research on Women With Disabilities (CROWD), www.bcm.edu/crowd

Centers for Medicare and Medicaid Services (CMS), www.cms.hhs.gov

National Aphasia Association (NAA), www.aphasia.org

National Center for Learning Disabilities, www.ncld.org

People with disabilities and the Affordable Care Act (ACA), <https://www.healthcare.gov>

Through the Looking Glass, www.lookingglass.org

United Cerebral Palsy (UCP), www.ucp.org

United Spinal Association, www.unitedspinal.org

Women With Disabilities, Health Promotion for Women With Disabilities Web Site, Villanova University College of Nursing,
<http://nurseweb.villanova.edu/womenwithdisabilities/welcome.htm>

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