

Why Disability Matters Slide Narrative

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Slide 1 – Title Slide

Overview/Introduction: This narrated slide presentation discusses the rationale for creation of the ACE.D program, as a new component of the National League for Nursing's Advancing Care Excellence (ACE) program. The slide presentation is intended to introduce nursing faculty and nursing students to the topic of disability and provide the rationale for introducing disability content and concepts in undergraduate and graduate nursing education programs. Put another way, this set of slides is intended to answer the question: Why disability matters.

Slide 2 – Learning Objectives 1

Learning objectives:

At the completion of the program, learners will be able to

- 1) identify the rationale for integration of disability content/concepts in nursing education,
- 2) describe the factors leading to the increasing population of persons with disability,
- 3) define disability and identify the major categories of disability,
- 4) discuss models of disability that are empowering to persons with disability and those that are disempowering to people with disability,

Slide 3 – Learning Objectives 2

- 5) identify key research findings related to the quality of health care of persons with disability, in order to ensure that the actions of the nurse are based on evidence,
- 6) identify two federal agencies and professional organizations that have called for health care professions educators to improve the knowledge, skills and attitudes of health care professionals about caring for persons with disability.
- 7) describe the role of the nursing profession and nursing education in the care of patients with disability

Slide 4 – Epidemiology of disability

Prevalence of disability is much higher than most people...including health care professionals...realize. It has been estimated that about 60 million people in the United States and 1 billion people worldwide live with one or more disabilities. That translates into one in every four or five people...20 to 25 percent...of the U.S. population who have one or more disabilities.

In contrast to the view that disability occurs only at the extremes of age...children and the elderly...disability can and does occur throughout the life span. About 14%

of children have a disability and over half of those over 65 years of age have one or more disabilities, with the number of people with disabilities increasing with age. Over 84.2% of frail elderly people in the country have a disability.

It is important, however, not to overlook those who are not children or elderly. While disability occurs in 11% of individuals 18 to 44 years of age...often considered the healthiest and most productive stage of life...and almost a quarter of those between 45 and 64 years of age live with a disability.

These statistics make the population of people with disability, the largest minority group in the country.

Slide 5 – Disability defined ADA

Given these statistics, a logical and important question is how is disability defined. There are a number of definitions of disability...even the U.S. government has over 100 definitions of disability...suggesting that it is not always easy to find a definition that is acceptable to all. However, the Americans with Disabilities Act that was passed in 1990 has a useful definition that appears on this slide.

The ADA defines disability as “A physical or mental impairment that substantially limits one or more major life activities; a record or history of such an impairment; or is regarded/perceived by others as having such an impairment.”

Slide 6 – Disability defined WHO

This slide presents the definition of disability of the World Health Organization. According to WHO, “disability” is an umbrella term for impairments, activity limitations or participation restrictions. In 2000, the WHO moved away from its previous definition of disability being a “consequence of disease” to one that focuses on health and factors that affect health. It describes disability as a person’s functioning and defines disability as a dynamic interaction between health conditions such as diseases, disorders, or injuries and contextual factors, such as personal and environmental factors, that affect health.

Slide 7 – Disability defined ICN

Because this slide presentation addresses nursing and nursing education specifically, it is important to also review the definition of disability of the International Council of Nursing...the ICN... and its position statement on the role of nurses related to disability. The ICN defines 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 persons with disability in all aspects of daily life...in the family, school, workplace and community.

Slide 8 – Disability defined/nursing’s role – ICN

In addition to defining disability, the ICN position paper also identifies the role of nursing and nurses in caring for individuals with disability. The ICN states that

nurses are expected to have an understanding of the particular problems faced by PWD and their families and to have advocacy skills and a knowledge of programs and resources in the community.

The ICN position statement further indicates that nurses are expected to assist, support and advocate for people with disabilities and their families to access education, information and support services that allow them to lead fulfilling lives...and that includes in health care.

Slide 9 – Another view – JAMA

Although not a definition per se, disability has also been described in a 2009 article by Kirschner and Curry as a universal experience that affects nearly everyone without exception at sometime in their lives. In this brief article, the authors identified the need for all health care professionals to have knowledge and skills to enable them to interact and communicate effectively with persons with disabilities. They further indicate that health care professionals' role includes assessment of the health-related needs of individuals with disability with the goal of providing quality health care to them.

Slide 10 – Significance of definitions

It is important to reflect for a moment on these definitions and views of disability to discuss their significance to the care and well-being of individuals with disability. They are relevant because they determine our views and perceptions of and attitudes toward people with disabilities, influence how we treat and interact with people with disabilities in all education, clinical practice, and community sites and settings, and serve as a check on our own attitudes and values about people with disabilities. In addition, our definitions and views influence how we teach others...including nursing students...about disability. Definitions of disability have legal implications in that they determine the eligibility of individuals with disabilities for services and determine what services are allowed and what are mandated by law.

Slide 11 – Characteristics of disabilities (1)

There are several characteristics of disabilities that we need to keep in mind as we consider disability as an important topic for nursing education. Disabilities range in severity from very mild so that they may be merely inconvenient for the person to very severe in which technology, such as ventilators, may be needed for one's survival. Although very severe disabilities are less common than those that are of lower severity, there is nevertheless a growing number of people whose disability is very severe and who continue to be contributing members of families and society as a whole.

Disabilities vary in type and include physical impairment, sensory impairment with visual or hearing impairment, psychiatric/mental health disabilities, cognitive/intellectual and developmental disabilities, disabilities that affect communication, and combinations of any or all of these types of disability.

Slide 12 – Characteristics of disabilities (2)

Disabilities vary in visibility. Some are invisible to others and some are visible to others because of obvious presence of assistive technology, including wheelchairs, canes, crutches, hearing aids, service animals, or ventilators.

Disabilities are seen across all settings, including hospitals, clinics, and rehabilitation settings and long-term care facilities or assisted living, where one might expect to see any number of people with disabilities. Persons with disabilities, however, may also be seen in OB settings, community settings, group homes and in their own homes.

Because individuals with disabilities are found in all settings, it is imperative that all health care professionals, including nurses, be knowledgeable about health issues and nursing care for persons with disabilities. It is **not** relevant or appropriate to say, “I don’t need to know about disability...I won’t be seeing or caring for patients with disabilities in my practice.” Each of us will see individuals with disability and we must be prepared to provide appropriate, high quality care to them.

Slide 13 – Characteristics of disabilities (3)

Another very important characteristic of disability is that the number of people with disability is increasing in size. A number of factors are responsible for the recent and future increase. These include the advances that have been made in health care and the resulting survival of people with disabilities across the lifespan. For example, the survival of premature and very low birth weight babies, individuals with pre-existing disabilities such as spinal cord injury and stroke. Although babies who are premature or very low birth weight are surviving at an increasing rate, many of those who do survive may have disabilities that range from mild developmental delays to very severe disabilities requiring round-the-clock care.

The survival of people who are chronically critically ill results in growing numbers of individuals with disabilities who require quality nursing care. An example of a chronically critically ill patient is one with chronic obstructive lung disease who is hospitalized periodically for temporary ventilatory support because of exacerbation of lung disease or the development of pneumonia.

With unhealthy lifestyles, there is a growing number of individuals with chronic disease and obesity and increasing numbers of elderly and frail elderly. As we saw from an earlier slide, the percentage of individuals with disability increases with age so that the frail elderly are at high risk for disability.

Lastly, there is a growing number of people in the United States and around the world who experience traumatic injury because of mass shootings, bombings, traffic crashes, and natural catastrophes. Although the news reports usually focus on the number of individuals killed in those events, often many more are injured but survive with either short-term or long-term disabilities. We often do not hear about

the number of people severely injured and likely to experience disability as a result of these events.

Slide 14 – Common Research Findings Across Disciplines

Now that we have an understanding of the scope of disability and its causes, it is important to identify issues that affect health care of individuals with disability. A growing number of studies have revealed that people with disabilities...abbreviated here as PWDs...receive less health care and health care that is inferior to that of individuals without disabilities. Some have even reported being refused health care because they have a disability. Individuals with disabilities often have a thinner margin of safety or health than those without disability. For example, an upper respiratory infection or cold may be uncomfortable or inconvenient for most of us. However, for someone with a high spinal cord injury or a severe musculoskeletal disorder that affects the thorax, an upper respiratory infection may result in pneumonia and result in hospitalization.

Despite passage of the Americans with Disabilities Act in 1990 mandating accessible facilities and accommodations for individuals with disabilities, many health care sites, such as offices, imaging centers, even hospitals, continue to be inaccessible to persons with disabilities. This includes steps, doorways that do not accommodate someone in a wheelchair, lack of accessible weight scales for individuals who are unable to stand on a scale, and absence of adjustable exam tables...to name just a few of the barriers that individuals with disability frequently encounter. Individuals with disabilities have not been weighed in years because of lack of accessible weight scales, including pregnant women with disabilities.

Many studies have demonstrated that health care professionals, including nurses and nursing faculty, have negative attitudes toward persons with disabilities. This is almost a universal finding and in fact is one of the biggest barriers those with disabilities face. Negative attitudes often result in negative encounters between people with disabilities and health care professionals.

Slide 15 – Calls to Address Disability among HCPs

In an effort to learn more about nursing care of patients with disabilities during hospital stays, we conducted a focus group study with 35 people with diverse disabilities across the spectrum of severity, ranging from mild to very severe.

Slide 16 – Resulting themes 1 & 2

Four themes resulted from the analysis of the focus group data; this and the next slide summarize the major findings related to these four themes.

Poor communication was a major issue---and is in most studies of the interaction of persons with disabilities and their health care providers. In this study, nursing staff did not know how to communicate with patients with disabilities and often ignored the person with a disability and talked instead to the family, friends, or other accompanying persons with the patient.

Patients reported that they had to explain and re-explain to nursing staff what worked and what did not work for them. They were treated as if they knew nothing about their own disability even if they had lived with it for their entire lives. Because of the problematic communication with nursing staff, the members of the focus groups recommended that communication be made part of the nursing curriculum...of interest because communication IS almost always a part of the nursing curriculum.

The second theme related to lack of consideration of patients' specific disability. As a result care was not individualized. People with disabilities in the study reported lack of caring, compassion, understanding, patients and respect toward them by members of the nursing staff.

Slide 17 – Resulting themes 3 & 4

The third and fourth themes are identified on this slide. Negative attitudes of nursing staff toward were reported by members of the focus groups. They felt that they were seen as low priority and a burden to nursing staff. Some nursing staff seemed to fear being around them and they felt ignored and reported on occasion abuse by members of the nursing staff. They were treated as children and as if they were or should be asexual and uninterested in childbearing.

The last theme was fear about hospitalization because of a sense of vulnerability, lack of control over their own well-being and fear of being hurt while hospitalized. Based on their previous hospital experiences, the feared being left without the assistive devices they needed to get around and to take care of themselves, including wheelchairs, walkers, and crutches or canes.

Lastly they feared that they would leave the hospital stay in worse shape than they were in when admitted to the hospital.

Slide 18 – Consequence of Negative Encounters

Because of negative encounters, many people with disabilities delay seeking health care unless and until it is absolutely necessary for them to do so. They avoid hospital stays if at all possible. This results in inadequate health care, including preventive health screening such as gynecologic exams, mammograms, and other routine assessments. As a result, treatment may either be delayed or not received at all. Further, there may be a low level of participation of individuals with disabilities in health promotion activities because of failure of health care providers to recommend appropriate preventive screening and healthy behaviors.

The ultimate result is poor health status among some people with disabilities, isolation, and psychological issues, such as depression.

Slide 19 – Calls to Address Disability among HCPs

As one strategy to begin to address the lack of quality health care for persons with disabilities, there have been numerous calls from important organizations and agencies for health professions education, that is medicine, nursing, dentistry and the other health professions, to prepare their students and graduates to care for patients with disabilities. To date, these have included two U.S. Surgeon General reports, the Institute of Medicine, the National Council on Disabilities report, the World Health Organization World Report on Disability, and most recently, the Affordable Care Act of 2010.

Despite the multiple calls for the health professions educators to prepare future health care professionals to provide quality health care to persons with disabilities, these programs have not responded adequately. Only a handful of schools of medicine and dentistry have responded. And fewer than a handful of schools of nursing have done so.

Slide 17 – Nursing education's response

In an effort to investigate what schools of nursing in the US are doing to prepare nursing students---future nurses---to provide quality care to patients with disabilities, Smeltzer and colleagues conducted three related studies. They studied \undergraduate nursing programs and nurse practitioner programs and textbooks commonly used in undergraduate nursing programs across the country. This slide summarizes the results of these 3 national studies:

Disability was found to be largely invisible in both the undergraduate and graduate nurse practitioner programs and almost totally lacking in textbooks widely used in undergraduate programs.

Although some faculty reported that they did teach about disability in their nursing programs, their responses to other items in the surveys suggested otherwise.

Faculty reported that in order for them to consider integrating the topic of disability in their nursing programs, more important content would have to be delete. They further indicated that they did not consider disability to be a very important issue.

Faculty indicated that because students were not tested on the topic of disability in NCLEX or nurse practitioner certification exams, the topic is not taught in the nursing programs.

Lastly, nursing faculty admitted that they had never given thought to the topic of disability until they participated in the study and completed the survey.

Slide 18 – Another view of disability

So we come back to this slide, which puts in perspective a strong rationale for beginning to address disability in nursing education. As indicated earlier, the number of people with disability is increasing in the United States and globally and

will continue to do so. Further, as Kirschner and Curry stated in their JAMA article in 2009, "Disability is a universal experience that affects nearly everyone without exception at sometime in their lives."

As a caring profession, nursing as a discipline and as nursing faculty whose role it is to prepare our students and graduates for nursing practice we have a professional, ethical and moral obligation to ensure that our students are ready to provide quality care to this population. To do less is contrary to last line of the Nightingale Pledge that most of us recited upon completion of our initial nursing education: "With loyalty I will devote myself to the welfare of those committed to my care." This includes persons with disabilities.

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