

Inclusion of Disability in Nursing Education: Rationale and Guidelines

This 3-part document focuses on and presents guidelines for addressing disability in nursing education. The three parts include:

<u>Part I</u> provides: 1) the rationale for the integration of disability-related content in nursing curricula with supporting research findings, as well as; 2) a discussion of the current state of approaches and mandates to addressing disability.

<u>Part II</u> presents: 1) strategic considerations in planning and integrating content about disability in curricula, including issues that could serve as barriers to doing so if not considered, and; 2) addresses basic and universal concepts that are essential for all health care professionals to enable them to provide quality health care to this underserved population.

<u>Part III</u> identifies: 1) specific examples of strategies and approaches to integrate disability concepts and content in the nursing curriculum, and; 2) resources to assist in the process of integration and references related to strategies and resources.

PART I

Rationale: The Need to Include Disability in Nursing Education

Strong evidence indicates that individuals with disabilities, including those with intellectual and developmental disability (IDD), physical disability, psychiatric/mental health disability, communication disability, and sensory disability (vision and hearing loss) have less access to health care than individuals without disability *and* receive health care that is inferior to that provided to non-disabled populations (National Council on Disability [NCD], 2022). As a result, their health status is poorer than that of those without disability. Although there are a number of factors contributing to these issues, including social determinants of health, an important and major factor is the inadequate education and training of health care professionals about disability (NCD, 2022).



Repeated studies have shown that health care professionals from all health care disciplines, including nursing, receive little or inadequate preparation in their educational programs to communicate effectively with individuals with disability, address and overcome the bias and discrimination that affect this marginalized group, and identify and assess the health issues that affect those with disability (Grèaux et al., 2023). The recent COVID-19 pandemic revealed that bias, negative attitudes, and lack of health care professionals' knowledge about the daily lives and health-related needs of individuals with disability resulted in serious discrimination in treatment decisions made during the pandemic (NCD, 2022). Having a disability, specifically IDD, was the strongest predictor for COVID-19 infection and the second strongest predictor for death due to COVID-19 (Gleason et al., 2021), indicating that those with IDD were discriminated against when treatment decisions were being made.

Although multiple calls to action have been issued over the years by national and international organizations and agencies for the education of health care professionals about disability and the health care needs associated with disability, little progress has been made in addressing those calls to action. In February 2022, the National Council on Disability issued a policy brief calling for an all-of-government approach to achieve health equity in the U.S. and its territories for the largest unrecognized minority group in this country: the 67 million people with disabilities (Varadaraj et al., 2021), or one in every four persons.

The need to address disability in health care professions education is compelling. Health care professionals have reported a lack of understanding of the specific health-related needs of individuals with disabilities, lack of knowledge about the legal obligations to provide care to individuals with disability, lack of knowledge about how to communicate with individuals with disability, and lack of comfort in interacting with some groups of individuals with disability (lezzoni et al., 2021). Because of the high prevalence of disability, every health care professional is likely to encounter those with disability in their practice setting. Thus, every health care professional needs to have basic information and education about the care of individuals with disability.

In its 2022 policy brief, the NCD identified the need to recognize essential competencies for health care professionals and recommended those developed by the Alliance for Disability in Health Care Education (ADHCE] 2018) as the basis of those competencies. The NCD acknowledged that some health care professions education programs do address disability in their programs, but indicated that these are few in number as most health professions educational programs do not do so. The NCD called for those programs that receive **any** federal financial support be required to incorporate disability clinical care in curricula or training and



suggested that inclusion of disability-related content be a condition of continued federal support. In anticipation and support of these efforts, Villanova College of Nursing faculty in collaboration with the National League for Nursing have developed new teaching modules and strategies to address the needs of individuals with disability, including those with IDD, one of the most discriminated-against groups.

Current State of Approaches to Integrate Disability in Health Care Education

Education of health care professionals, including nurses, has largely lacked content and clinical experiences related to the health care of individuals with disability. As stated by the NCD (2022), the continued lack of comprehensive disability clinical care education and disability competency training among nursing, medical, dental, and other health care professionals perpetuate health care inequities and discrimination against those with disabilities. Currently, there is no single or "proven" approach to ensure that health care professions' students receive the didactic and experiential content that will ensure that they are knowledgeable about disability and comfortable in addressing disability with patients across the spectrum of disability. Further, no standards yet exist to guide faculty and clinicians who want to ensure that their health care professions students are able to provide quality care to those with disability. In the absence of such standards, the NCD (2022) recently called for model comprehensive disability clinical-care competency curricula to be developed by the U.S. Department of Health and Human Services.

Until such model curricula exist, it is essential that strategies to address the gap in education are identified and implemented. In the absence of a comprehensive strategy to integrate disability in health care professions education, there are several approaches that have been tried and have been successful in doing so. General guidelines for inclusion of content on disability, including IDD, and resources to support inclusion of such content can be used to improve the education of health care professions students across disciplines. General principles include ensuring that individuals with disability, including those with IDD and their family members, are included in the process of integrating disability in the education of health care professionals, based on the principle of "nothing about me, without me." Further, any efforts to address disability across health professional education must include the opportunity for students to interact *directly* with persons with disability, including those with IDD. Bringing an individual with a disability into a class for a one-time discussion of their experiences is inadequate and largely ineffective in enlightening students about the lives and experiences of persons with disability or their experiences in obtaining equitable health care.



Although some health care professionals, including nurses, have highly-developed knowledge and skill in the care of individuals with disability, basic competence in providing care to individuals with disability is needed by *all* health care disciplines (NCD, 2022). The existing gaps in basic knowledge and skill mandate the integration of disability-related content at the generalist level so that *all* health care professionals are competent in interacting with and caring for individuals with disability across all areas of practice and health care.

PART II

General and Strategic Considerations in Planning Disability-Related Curricula Content

Although there are many approaches to inclusion of disability-related content in health care professions' education, the following general suggestions are worth considering to be successful in curricular integration:

- Build inclusion of disability content and experiences, including those related to IDD, into the program's overall objectives and course objectives to emphasize the importance of the topic to administrators, faculty and students. Identify evaluation strategies based on those objectives.
- Approach the integration/inclusion of disability-related content in general and IDDrelated content specifically as applying across the curriculum rather than a single class or course in the curriculum. "One-and-done" approaches are generally unsuccessful and ineffective. Repeated opportunities build competence and confidence.
- Note that elective courses on disability are helpful for students interested in further knowledge and competence related to disability. These courses tend to attract students already knowledgeable about the topic. Thus, instead of addressing disability only through an elective course ("preaching to the choir"), integrate content designed for all students in the program to ensure that they receive needed information about disability.
- Develop a team of faculty across courses or content. No single faculty member is likely
 to have a grasp of all content in the existing curriculum. Thus, a team approach is more
 likely to accomplish the goal of addressing content on disability and identifying where in
 the existing curriculum that content can be best integrated.



- Identify faculty members with interest, expertise or experience related to disability (some may have a disability themselves or a family member with a disability) as members of the faculty team.
- Include individuals with disability and/or disability advocates as team members or as resources for faculty. Their input is essential if the effort to integrate disability content is to be successful.
- Obtain administrative support for ensuring that disability is integrated across the curriculum.
- Acknowledge the time and effort needed by faculty to make any curricular changes. Also acknowledge that all faculty have limited extra time and be considerate of their time.
- Identify resources and supports available to faculty who will and must be involved in addressing curriculum content related to disability.
- Anticipate and acknowledge barriers or resistance to integration of disability and IDDrelated curricular content:
 - Not all faculty have an interest in disability or in ensuring that students are educated to provide quality care to this population
 - Some faculty are likely to believe that the curriculum already does an adequate job of addressing disability (even if it does not do so).
 - Most faculty believe that the current curriculum is too full with no room for additions and some may believe that the topic is not important enough to justify adding disability-related content, including IDD, and experiences to the already packed curriculum (the size of the population of people with disability suggests that inclusion of disability-related content is important).
 - Some faculty may feel inadequate in teaching about disability because of their own lack of knowledge and experience (they likely received little education on the topic when they were students) and implicit bias about individuals with disability, including those with IDD.
 - o Consider that faculty may not know what they don't know about disability.
 - Consider that some faculty may believe that knowing about the cause of the disability (underlying disabling condition) is adequate to addressing inequities that affect those with disability. In actuality, it is not adequate to provide quality care and rarely addresses the concerns of persons with disability or their experiences in obtaining heath care and interacting with health care professionals.
- Have faculty team review content across the curriculum to identify where in the curriculum that inclusion of disability-related content is logical and easiest to accomplish.



- If and where possible, build on experiences that already exist in the program or curriculum and consult with reliable, knowledgeable sources on development of disability-related content.
- Build into the system a method to track inclusion of disability-related content and experiences to ensure that they are threaded throughout the curriculum and that the effort is sustainable.

Basic and Universal Concepts about Disability

There is some general information about disability and basic competencies that are essential for all health care professionals to have. These basic concepts are identified here followed in Part III by discussion of the content needed to ensure that individuals with disabilities receive quality health care. All health care professionals should be familiar with the following:

- Definitions Related to Disability.
- Prevalence of disability across the life span.
- Models of disability and the consequences associated with the use of those models (e.g., medical, social, biopsychosocial, and other models of disability).
- History of disability and disability rights.
- Overview of inequities in health care experienced by individuals with disability and existing barriers to quality health care (attitudinal, communication, physical, programmatic, policy, social, transportation barriers).
- Ableism, bias, stereotyping and diagnostic overshadowing as factors resulting in poor quality health care for individuals with disability.
- Legal implications of the Americans with Disabilities Act, the ADA Amendments Act of 2008, and other legislation related to disability.
- Social determinants of health (SDOH), intersectionality, and disability. Note that disability and limited accessibility are often ignored or underestimated as major SDOHs.
- Disability as a demographic characteristic rather than as an outcome only.
- Overview of types or categories of disability and health issues that are specific to these categories.
- Competencies identified by ADHCE and NCD (and other organizations that focus on disability) as essential to provision of quality health care to people with disability.

These concepts are important to address early in the curriculum as many subsequent issues and discussions are based on them.



PART III

Examples of Strategies and Approaches to Integrate Disability Concepts and Content

The following examples identify concepts and content on disability to consider adding to the curriculum along with suggested strategies for implementation.

- Introduce concepts of communication with individuals with disability in a class early in the curriculum (with videos, case studies, and other available resources).
- Apply and discuss principles of communication and alternate communication approaches to interact with individuals when discussing specific health issues throughout curriculum and categories of disability (communication approaches with those with IDD, dementia, hearing loss, etc.). A single class on communication with persons with disability is inadequate.
- Have students complete an ableism survey or implicit bias survey (usually reveals to students that they are more ableist and have more implicit bias than they realized, providing evidence that ableism and implicit bias against those with disability are common). See information about the Implicit Association Test (IAT) from Project Implicit in the <u>Available Resources</u> section listed below.
- Use simulation principles and strategies to address issues related to disability across settings with individuals with disability included in planning and evaluation of the simulations.
- Invite and train individuals with various types of disability to participate as standardized
 patients or expert patients with disability in simulations (these *cannot* be actors
 pretending to have a disability as they lack authenticity). Individuals with disability,
 including IDD, have been trained to be successful standardized patients or expert
 patients.
- Include standardized patients or expert patients with disability in simulations that
 address a variety of general health issues; not all content needs to be specific to
 disability, although students should be expected to address disability-related issues.
- Include the needs of individuals with disability in course content that addresses sexuality, sexual abuse, sexually transmitted diseases, contraception, pregnancy and childbearing. These issues are often omitted in discussion of disability, yet are of vital concern and interest to those with disability.
- Address pregnancy among women with disability in curriculum content related to obstetrical content, along with biases and negative reactions on the part of health care



- professionals reported by women with disability seeking prenatal/obstetrical care and childbirth education.
- Address the possible need for modifications needed by women with disability for caring for their newborn with recommendations for how to obtain/arrange such modifications (e.g., cribs designed for parents unable to lift a baby over high crib sides).
- Add discussion of unique palliative care and end-of-life issues of patients with IDD, cognitive disability, or other disabilities, including supported decision-making and the limitations of guardianship. (The "Ten Tips" document in the reference list provides important information on caring for persons with IDD needing palliative care and offers resources and references to improve the care for individuals with IDD and serious illnesses.)
- Identify implications for surgical and anesthesia care for patients with IDD and cognitive disability and patients with sensory (hearing or vision loss) disability in discussion of surgical and postoperative care of patients.
- Discuss legal issues related to failure to provide accessible, quality care and accommodations for individuals across disability types and the Americans with Disability Act of 1990 and the ADA Amendments Act when discussing inequities in health care for those with disability.
- Add modifications in history-taking and assessment needed for patients with disability including IDD, cognitive, physical, psychiatric/mental health, and sensory disability (within each section of the curriculum where these issues are addressed as well as in general discussion of history taking and physical and psychosocial assessment).
- Identify and discuss aging in individuals with pre-existing disability as part of discussion of aging and age-related disability. Patients with disability may have early onset of some health issues, such as osteoporosis or dementia.
- Identify the importance of transitions for persons with disability and health care
 professionals' role in promoting smooth transitions (from pediatric to adult health care;
 from home to independent living; from high school to work; from parents' insurance
 coverage to end of that insurance coverage; to pregnancy, childbearing and parenthood;
 and from adulthood to older age and end of life).
- Address assessment and care of individuals with disability who are most at risk for
 violence and abuse in general, and discussion of violence and abuse and the role of
 health care professionals in assessment, care, and follow-up of patients with disability
 who experience violence and abuse.
- Address secondary conditions (health conditions that occur as a result of disability) and comorbidities (health conditions that occur independently of disability and can affect



- anyone) in assessment of individuals with disability and in preventive screening and health promotion efforts.
- Utilize community-based facilities and programs for student experiences to learn about and communicate with individuals with disability in non-acute care settings. Person-toperson contact with individuals with IDD and other disabilities is essential for health care professions students to become comfortable interacting with those with all types of disability and learning about their life experiences and health care preferences.
- Emphasize the need for modifications in strategies needed to teach patients with disabilities about actions needed to ensure positive outcomes (e.g., discharge instructions, postoperative care, caring for newborn, etc.). This is an important component of communication.
- Incorporate the need for health promotion and disease prevention among those people with disabilities as part of health promotion content for all people.
- Address the day-to-day lives of individuals with disability during students' home care
 and community-based experiences; only if one understands the daily lives of individuals
 with disability will health care professionals be able to address their health and related
 issues.
- Develop collaborative relationships with community-based organizations and agencies that provide services to those with disability, including IDD, and utilize these organizations and agencies for student placement to ensure interaction of students and individuals with disability outside acute care settings.
- Incorporate disability-related considerations in discussion of acute as well as chronic or long-standing health issues, such as stroke, myocardial infarction, acute traumatic events, COVID-19 and other infections such as HIV/AIDS and pneumonia. Discussion of conditions that *cause* disability is necessary but not sufficient to address the day-to-day experiences of people with disability who experience these disorders.
- Discuss the impact of acute injuries (e.g., traumatic brain injury [TBI], spinal cord injury [SCI], amputation) or acute medical conditions (e.g., cardiac disease, stroke, pulmonary disease) on the lives and access to health care of individuals with new disability due to acute injuries or acute medical conditions.
- Discuss the impact of long-standing/previous injuries (e.g., traumatic brain injury [TBI], spinal cord injury [SCI], amputation) or long-standing medical conditions (e.g., cardiac disease, stroke, or pulmonary disease) on the daily lives and access to health care of individuals with disability due to their long-standing health issues. (The fact that a person had a stroke, cardiac, amputation, SCI, or pulmonary health issue many years ago does **not** negate its impact on a person's ability to access health care currently.)



- Establish relationships with other health care disciplines in teaching and clinical experiences to ensure that students across disciplines learn from and work with other professionals to improve the health care of individuals with disability.
- Add the effects of climate change and natural disasters on individuals with disability
 when discussing this topic along with needed supports for those unable to use facilities
 and transportation systems that remain inaccessible.
- Discuss modification of consent and data collection procedures to include individuals with disability, including those with IDD, in all relevant research studies.
- Develop course test questions that include individuals with disability and concepts related to addressing health equities for those with disability
- Use available resources (see suggestions below) and specific modules for further detail about categories of disability.
- Discuss the economic implications of disability on the person with disability, their family, and society.

Available Resources

Although no standards exist for integration of disability-related content in the education of health care professions students, a number of resources are available that can be consulted for ideas about how to do so and to obtain and review strategies others have developed and used multiple approaches to integrating disability content. Examples include:

- ADEPT-CARE: Exploring Disability in Healthcare: A pilot, student-led initiative to improve care for persons with disabilities via a novel teaching tool.
- Advancing Care Excellence for Persons with Disabilities (ACE.D) from the National League for Nursing (includes materials, resources, and teaching strategies for nursing faculty to increase their own knowledge and slides to use to teach students)
- American Academy of Developmental Medicine & Dentistry National Curriculum Initiative in Developmental Medicine
- Anti-Ableist Medical Education: Meeting the Challenge. The Hastings Center.
- Villanova University M. Louis Fitzpatrick College of Nursing <u>Caring for People with</u>
 Disabilities: The Nurse Practitioner Tool Kit
- Core Competencies on Disability in Health Care Education (2019) from the Alliance for Disability in Health Care Education, Inc.
- Council on Social Work Education <u>Curricular Resource on Issues of Disability and</u>
 Disability-Competent Care
- Developmental Disabilities Nurses Association Practice Standards of Developmental Disability Nursing



- <u>Equity Access</u>: Online Nursing Education on Care for People with Disabilities (three interactive modules for student use: Disability and Health Care, Advocacy, and Accessibility)
- IntellectAbility Curriculum in IDD Health Care eLearn Course
- Project Implicit Implicit Association Test
- MedlinePlus: Developmental Disabilities and Oral Health (The National Library of Medicine's collection of links to government, professional and nonprofit/voluntary organizations with information on developmental disabilities and oral health)
- <u>Nurse Registration Programmes Standards and Requirements</u> (Nursing and Midwifery Board of Ireland, 2023)
- <u>Partnering to Transform Health Outcomes with Persons with Intellectual Disabilities</u>
 (<u>PATH-PWIDD</u>); includes multiple resources related to inter-professional curricular and practice-learning materials on IDD
- Penn Dental Medicine <u>Persons with Disabilities Presentation Series</u>

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