



Improving the Quality of Health Care for Persons with Disabilities



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Suzanne C. Smeltzer, EdD, RN, ANEF, FAAN

**Richard & Marianne Kreider Endowed Professor in Nursing for
Underserved Populations**

Director of Office of Research & Evaluation

M. Louise Fitzpatrick College of Nursing

Villanova University

Villanova, PA, USA

suzanne.smeltzer@villanova.edu



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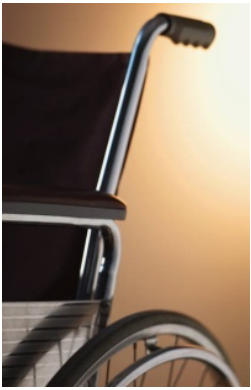
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Why Disability Matters **(or should matter)**



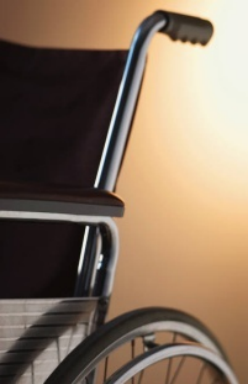
Disability Defined

ADA's Definition of Disability:

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



Another View of Disability

“Disability is a universal experience that affects nearly everyone without exception at sometime in their lives.”

(Kirschner & Curry, 2009)

Models of Disability

Medical and Rehabilitation Models

- Views disability as a problem of the individual
- Goal of health care...medical management...is to cure (or “fix”) the individual or modify his/her behavior
- Health care providers (HCPs) are the “experts”
- Viewed by PWD as promoting dependency and passivity

Social Model

- Views disability as socially constructed and due to failure of able-bodied society to provide access and accommodations
- Disability is a function of the social environment
- Solution or “treatment” is social and/or political change

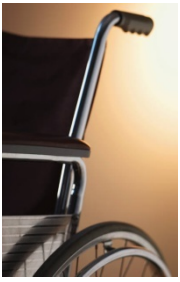
Models of Disability...

Biopsychological Model

- Integrates medical and social models
- Addresses health from a biologic, individual, and social perspective

Interface Model

- Based on the life experience of the person with a disability
- Views disability at the intersection (i.e., interface) of health issue and environmental barriers
- Considers rather than ignores the health issue or medical problem



Disability vs. Disabling Conditions

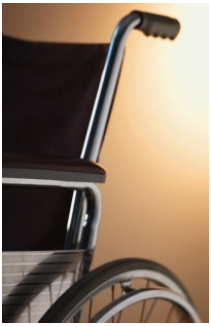
❖ Disability - the day-to-day experience of difficulty performing daily activities and fulfilling social roles because of impairment

❖ Often compounded by environmental barriers

❖ Disabling conditions – the underlying disorders with the potential to lead to disability

❖ Typically include physiological or psychological causes of disability (e.g., SCI, cerebral palsy, spina bifida, stroke, autism)

❖ Knowing details about disabling conditions is IS NOT the same as knowing about disability



Disability-Related Research Trajectory

Began in Post-Doc Fellowship at University of Rochester



Respiratory Issues in MS and Concerns of Women with MS
related to Pregnancy and Reproductive Health Care



Need to Determine What is Already Known from Others'
Research Studies



Common Experiences Reported by
People with Disabilities (PWDs) Across Studies

Common Experiences Reported by People with Disabilities (PWDs) Across Studies Include:

- ❖ Communication between HCPs and PWDs is often ineffective; HCPs fail to communicate directly with PWDs**
- ❖ HCPs often assume that quality of life of PWDs is poor and believe that PWDs cannot be healthy**
- ❖ HCPs often fail to recognize experience, knowledge and expertise of PWDs about their own health and disability**
- ❖ HCPs often have negative attitudes toward PWDs (and more negative toward PWDs with some types of disabilities)**

HCPs addressed in these studies were rarely if ever nurses

Realities in Today's Health Care System

PWDs receive lower quality of health care, less aggressive treatment and are offered few choices.

HCPs are often unable (perhaps unwilling) to address sexuality, pregnancy, childbearing and common health problems in people with disabilities

PWDs encounter serious barriers to quality preventive care, and screening and reproductive care (e.g., lack of accessible equipment such as scales and accessible exam tables)

Research Findings about Attitudes about PWDs of Health Care Professionals

- **HCPs have negative attitudes toward PWDs.**
- **HCP students have negative attitudes toward PWDs.**
 - **Nursing students' attitudes reported to be more negative than other HCP students!**
 - **Nursing faculty have more negative attitudes than HCPs students and than other HCPs!!**

Health Issues of Persons with Disabilities (PWDs)

Directions of Research



Health Issues of People with Disabilities

- Respiratory issues in MS; effect of expiratory muscle training
- Concerns of pregnant women with MS
- Risk for osteoporosis in women with disabilities
- Effect of pregnancy in MS
- Osteoporosis follow-up women/HCPs
- Health promotion interests of PWDs
- Health screening of WWD
- Pregnancy-related issues in women with physical disabilities (eg, attitudes of HCPs, women's experiences during pregnancy, accessibility in health care, L & D experiences, unmet needs pre- and postpartum, OB providers' knowledge about disability, etc.)

Role of Nurses/Nursing in Care of PWDs

- Interactions of PWDs with nursing staff
- Integration of disability-related content in undergraduate nursing programs
- Integration of disability-related content in nurse practitioner programs
- Inclusion of disability-related content in textbooks used in nursing education
- Inclusion of standardized patients with disabilities (SPWDs) in nursing education
- Experiences of PWDs as SPWDs at VU
- Effect of interaction of nursing students with SPWDs on attitudes
- Comparison of attitudes of nursing students with SPWDs to those without SPWD interaction

**Concern about the Quality of Health
Care of People with Disabilities
(with Focus on Nursing Care)**



**Qualitative Study of Nursing Care Experiences
Of People with Disabilities
During Hospitalization**

(American Journal of Nursing, 2012)

Four Themes From Study:

Poor Communication

- Nursing staff ignore people with disability and talk/listen instead to others (family, friends, others)...anyone but them
- PWD needed to explain and re-explain to nursing staff what works and what does not work for them; treated as if they knew nothing about their own disabilities
- They recommended that communication skills be part of the nursing curriculum, especially communication with people with disabilities

Compromised Care

- Disabilities are not taken into account during care due to inadequate knowledge; care not individualized
- Lack of caring, compassion, understanding, patience and respect toward PWD

Four themes...

Negative Attitudes

- ❖ **Seen as low priority, marginalized and as burden by nursing staff**
- ❖ **Feared, ignored and on occasion abused**
- ❖ **Treated as children, as asexual and as uninterested in childbearing**

Fears about Hospitalization

- ❖ **Sense of vulnerability; lack of control over well-being and fear of being hurt while hospitalized**
- ❖ **Fear of being left without assistive devices based on previous experiences**
- ❖ **Fear of leaving the hospital in worse shape than when admitted**

Summary and Conclusions of Qualitative Study

- **Improvement in nursing care of PWDs with disabilities during hospitalization is needed.**
- **Education of nursing students and nurses in practice about care of PWDs is needed.**
- **Ancillary nursing staff are also in need of training about care of PWDs.**

Concerns re Quality of Nursing Care of PWD



What is being taught in nursing education about topic?



Study #1: Integration of disability-related content in UG nursing curricula
(*Nursing Education Perspectives*, 2005)

Study #2: Inclusion of disability-related content in textbooks used in UG nursing curricula
(*Nursing Education Perspectives*, 2005)

Study #3: Integration of disability content in NP programs
(*Journal American Academy of NP*, 2014)

Summary of Findings Related to Nursing Education on Topic of Disability:

- **Disability content largely invisible at both undergraduate and NP levels and in textbooks widely used in nursing education.**
- **Some faculty say they are teaching about it; responses suggest otherwise.**
- **Faculty report that “more important” content would have to be deleted AND disability is not a very important issue.**
- **Students are not tested on it; therefore, it is not taught.**
- **Some faculty admitted that they never thought about the topic before participating in the study.**

Reports and agencies calling for improved knowledge, skills and attitudes of health care providers about care of PWDs and to improve their health care:

- ✧ **U.S. Surgeon General Reports (2002, 2005)**
- ✧ **Institute of Medicine Report on Disability (2007)**
- ✧ **National Council on Disability Report (2009)**
- ✧ **World Health Organization World Report on Disability (2011)**
- ✧ **International Council of Nursing Position Paper (2000, 2010)**
- ✧ **Patient Protection and Affordable Care Act (2010)**

Despite these multiple calls, nursing as a discipline has been largely silent on the issue of addressing disparities in care for PWD.

Integration of Standardized Patients with Disabilities in Villanova's Undergraduate Nursing Curriculum

1) Overall goal: to improve knowledge, skills and attitudes of UG nursing students to improve care of PWD

KEY: **Without requiring curriculum revision**

KEY: **Without increasing faculty members' workload**

2) Obtained small grant from Association of Standardized Patient Educators to support the program

3) Used existing simulations used in the College of Nursing and integrated scenarios with PWD as “patient” (having patients with real/actual disabilities is **extremely** important to ensure authenticity)

4) Project team created 3 short videos on communication with SPWDs; shown in classroom with debriefing

3) Oriented faculty to scenarios with emphasis on the **importance** of SPWDs giving feedback to students about interaction.

Moving VU's Standardized Patients with Disabilities in Undergraduate Nursing Curriculum to National Level

1) Need for persistence (7 years) in working with NLN to develop and add Advancing Care Excellence.Disability (ACE.D) to its website.

2) Several schools of nursing around the country piloted ACE.D; pilot uncovered an issue: “since it is an old disability, it doesn't matter much”. Instructions changed to address this: it DOES matter

3) Expanded our materials (communication videos with SPWD and unfolding case studies) and provided many resources about disability for NLN website to prepare faculty to teach disability-related concepts and content.

- General disability information**

- Pregnancy in women with disabilities**

- History of disability**

- Communicating with persons with various impairments**

(physical, sensory, cognitive, speech, intellectual and developmental disabilities)

- Multiple teaching strategies/resources (slides, scenarios)**

Reaching Other Faculty to Increase their Knowledge about Disability and Need to Address in their Nursing Curriculum

- 1) Presenting research findings from our work and providing faculty development programs in a number of schools of nursing (alas, one school at a time)**
- 2) Serving as consultant to other colleges of nursing and faculty interested in the issues**
- 3) Writing about it and speaking about it whenever and wherever possible about the topic.**
- 4) Issued a call to action for nursing education, practice, organizations, etc.**

Another Call to Action

(Issued 3-22-16 at AACN Deans & Directors Annual Meeting)

Nurses...

Nursing as a discipline...

Nursing education and nursing faculty...

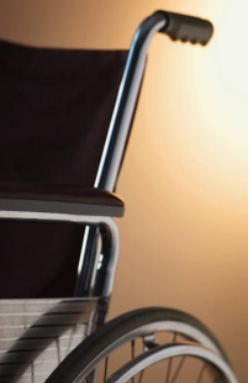
Nursing organizations and agencies...

Accrediting organizations

Certification organizations

Licensing boards

...all have the potential to take the lead to ensure that next generations of HCPs, including nurses, are prepared to care for PWDs.

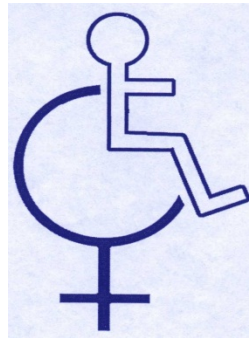


Considering Disability...

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Questions, thoughts or comments?



Suzanne.smeltzer@villanova.edu

610-519-6828