



BUILDING HEALTHY COMMUNITIES FOR EVERYONE

**2011 DISABILITY and
HEALTH PARTNERS MEETING**

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Health Care Reform: Implementing Affordable Act

Suzanne Smeltzer, RN, EdD, MSCN, FAAN

Professor and Director, Center for Nursing Research

Villanova University College of Nursing

Villanova, PA





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Health Promotion for Women with Disabilities Project



**5-year Project Funded by
Bristol-Myers Squibb Foundation**





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Health Promotion for Women with Disabilities Project

Overall Project Goal: To improve the health status of women with disabilities





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Specific Project Objectives

To provide information and support that will enable women with disabilities to increase their level of wellness and participation in health-promotion activities

To increase the knowledge about health promotion needs of women with disabilities through research

To increase the awareness and sensitivity of health care providers to health-related needs of women with disabilities





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Strategies used to achieve project goals:

- **Developed a web site and written documents to disseminate information**
- **Provided multiple educational programs for women with disabilities about health issues and health promotion**
- **Provided educational programs to healthcare professionals**





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Strategies used to achieve project goals...

- **Conducted research related to health issues of women with disabilities**
- **Presented results of multiple studies at medical and nursing scientific conferences**
- **Published results of studies in interdisciplinary journals**





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Strategies used to achieve project goals...

- **Collaboration with interdisciplinary groups and organizations to advance shared goals**
 - **Association of Professors of Gynecology/OB (APGO)**
 - **Veterans Association (satellite broadcast on health issues of women with disabilities)**
 - **NC Office on Disability (Provider's Guide)**
 - **NJ Division of Disabilities (education of HCP on abuse)**
 - **Inglis House and regional chapters of National MS Society, Polio Survivors groups, others (education on health issues), Alliance for Disability in Health Care Education**





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Barriers to Health Care

- ❖ **Structural and environmental (inaccessible clinical settings, lack of accommodations, etc.)**
- ❖ **Attitudinal barriers (negative attitudes and stereotyping, demeaning and disabling)**
- ❖ **Lack of knowledge, awareness and sensitivity of health care providers about disability issues**
- ❖ **Lack of attention to disability issues in health care professions' education/training programs**





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Barriers to Health Care

- ❖ Structural and environmental (inaccessible clinical settings, lack of accommodations, etc.)
- ❖ Attitudinal barriers (negative attitudes and stereotyping, demeaning and disabling)
- ❖ Lack of knowledge, skills, awareness and sensitivity of health care providers about disability issues
- ❖ **Lack of attention to disability issues in health care professions' education/training programs...with a focus on nursing education and practice**





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Summary of previous research on disability and nursing education :

- **Attitudes of nursing students often negative (more negative than those of other HCP students; attitudes of nursing faculty even more negative)**
- **A few evaluation studies have examined attitudes after students participate in “disability experiences” (usually limited in time, no long-term follow-up and limited to single nursing programs)**
- **Care has been described in UK studies as demeaning and disempowering**





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Evidence about need for change

Study 1: Integration of disability content in undergraduate nursing curricula

Study 2: Integration of disability content in textbooks used in undergraduate nursing education

Study 3: Nursing care experiences of people with disabilities during hospitalization

Study 4: Integration of disability content in master's degree nurse practitioner programs





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Study 1

Integration of Disability Content in Undergraduate Nursing Curricula

Funding: Bristol-Myers Squibb Foundation Grant





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Integration of Disability Content in Undergraduate Nursing Curricula

Purpose: To determine the extent of content related to disabilities in nursing programs in the US

Method: A mailed questionnaire sent to national stratified random sample of 1,000 schools of nursing

Questionnaire: 35-item survey developed with input from people with disabilities





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Selected research findings:

- **Lack of information about disability in most undergraduate nursing programs**
 - **Little exposure of nursing students to people with disabilities and little attention to disability issues in nursing programs**
 - **Focus on disability, when it occurs, largely on people with disabilities at the extremes of age**
 - **Virtually no discussion of people with pre-existing disabilities**





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Selected research findings...

- **Lack of information about disability in most undergraduate nursing programs...**
 - **Interaction of disability and other health conditions that affect disability are often overlooked, ignored and not addressed**
 - **Illustrated by statements such as: “If is not tested, we don’t teach it.” and “To include disability issues, we would have to take *more important* content out of the curriculum.”**
 - **Most faculty report use of nursing textbooks to teach disability-related content**





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Study 2

Integration of Disability Content in Textbooks Used in Nursing Education

**Funding: National League for Nursing
and Institute of Nursing of NJSNA**





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Integration of Disability Content in Undergraduate Nursing Textbooks

- **To examine coverage of disability-related content in textbooks used in undergraduate nursing curricula**
- **To compare extent of coverage of disability-related content by categories of content and categories of textbook used in undergraduate nursing curricula**





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Integration of Disability Content in Undergraduate Nursing Textbooks

Design: descriptive study; quantitative and qualitative analysis of narrative text

Tool: Key content identified by researchers and HCPs with expertise in disability; validated by people with disabilities

Method: Systematic review of 33 most commonly used textbooks in nursing curricula nationally





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Integration of Disability Content in Undergraduate Nursing Textbooks

Quantitative Findings:

**Ratings of 33 textbooks on disability content
(range of possible scores 0 – 448 on 224 items)**

mean: 7.4 ± 6.9

range: 0 – 66





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Integration of Disability Content in Undergraduate Nursing Textbooks

Qualitative Findings:

- **Virtually no information about disability in most textbooks used in UG nursing curricula**
- **Lack of attention to the health, health care needs, and nursing care of persons with disabilities.**
- **Disability-related content is grossly inadequate in most textbooks used in undergraduate nursing education programs**
- **Of concern is that students who pursue graduate education (nurse practitioners, nurse educators) come to graduate program without solid basis of knowledge related to disabilities (led to Study 4)**





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One could ask: does it matter?





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Study 3

Nursing Care Experiences of People with Disabilities During Hospitalization

Funding: CNR Faculty Development Grant





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Nursing Care Experiences of People with Disabilities During Hospitalization

- **Qualitative study via 6 focus groups of community-residing people with disabilities with hospital experience**
- **35 people with diverse disabilities across spectrum of severity from mild to very severe**





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Poor Communication

- **Nursing staff ignore people with disability and talk/listen instead to others (family, friends, others)...anyone but them**
- **Are unable to communicate with people with disabilities, especially those in wheelchairs or those with communication issues**
- **Participants needed to explain and re-explain to nursing staff what works and what doesn't work for them; treated as if they knew nothing about their own disabilities**
- **They recommended that communication skills be part of the curriculum, especially with people with disabilities**





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Compromised Care

- **Nursing staff have little knowledge about disabilities but do not ask (staff don't know, but think they do); patients have to educate staff about disabilities**
- **Disabilities not taken into account during care due to inadequate knowledge; care not individualized**
- **Lack of caring, compassion, understanding, patience and respect toward people with disabilities**
- **Some nursing staff fear people with disabilities and fear that they will “catch” disability**





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Negative Attitudes

- ❖ **Seen as low priority by nursing staff**
- ❖ **Marginalized and viewed as a burden**
- ❖ **Feared, ignored and on occasion abused**
- ❖ **Stereotyped, stigmatized, and labeled**
- ❖ **Seen as asexual without intimacy needs**
- ❖ **Childbearing rarely seen as relevant**





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Fears about Hospitalization

- **Sense of vulnerability in hospital; lack of control over well-being and fear of being hurt while hospitalized**
- **Previous experiences led to fear about being left without access to their assistive devices**
- **Fear of inadequate care during hospitalization**
- **Fear of being unable to speak for themselves and being ignored if unable to speak up**
- **Fear of leaving the hospital in worse shape than when admitted**





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Study 4

Integration of Disability Content in Nurse Practitioner Programs

Funding: Inglis Foundation and HRSA





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Conclusion

There is an urgent need to improve education and training of nursing students at all levels of education (undergraduate and graduate) levels and nurses in practice about care of people with disabilities





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Possible Solutions/Vision for Future

Identify competencies for *all* health care disciplines related to high quality of care for people with disabilities, including nursing

Develop teaching strategies to change knowledge, attitudes, and skills of students to prepare them to provide high quality care to all people with disabilities

Need to do so *without major disruption of existing curricula*

Assess own attitudes, those of students and faculty peers about people with disabilities

Assemble information or repository of materials for nursing faculty to use to address the issues and support them in their use





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Possible Solutions/Vision for Future...

Identify and utilize faculty champions to expand interest among faculty

Identify thought leaders who have experience and interest...personal, family, or professional...with issues in people with disability to join in changing current practice and education

Need to change view across the discipline...education and practice... that disability is unimportant or already adequately addressed

Need to influence educational and national policy to ensure change (licensure, certification requirements, standards of practice, etc.)





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Possible Solutions / VU CON / Present

HRSA grant for integration of disability content in graduate (NP) level nursing education *with a national impact*

- Physical assessment and history taking
- Communication skills
- Scenarios, case studies, standardized patients
- Use reflective exercises (stories of PWD)
- Involve PWD in classroom discussion of issues and experiences
- Ensure all students have clinical experiences and contact with people with disabilities
- Evaluate effectiveness of teaching strategies
- Disseminate materials and strategies widely





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Possible Solutions / VU CON / Future

Application for HRSA grant (in review) for integration of disability content in undergraduate level nursing education *with a national impact*

- Physical assessment and history taking
- Communication skills
- Scenarios, case studies, standardized patients
- Use reflective exercises (stories of PWD)
- Involve PWD in classroom discussion of issues and experiences
- Ensure all students have clinical experiences and contact with people with disabilities
- Evaluate effectiveness of teaching strategies
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Health Promotion for Women with Disabilities Project of Villanova University College of Nursing

<http://www.nursing.villanova.edu/WomenWithDisabilities>



suzanne.smeltzer@villanova.edu

