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I am delighted that the Journal of Nursing Education is beginning to address the experiences of people with disabilities in nursing schools as seen in Donna Carol Maheady’s (1999) article “Jumping Through Hoops, Walking on Egg Shells: The Experiences of Nursing Students with Disabilities.” Almost 25 years have passed, since the implementation of the Rehabilitation Act of 1973, Section 504, and nearly a decade has passed since the protections offered by the Rehabilitation Act were expanded by the Americans with Disabilities Act of 1990 (ADA). While both of these statutes prohibit discrimination against individuals with disabilities seeking admission into institutions of higher learning, historically, higher education has vigorously opposed compliance with 1973 Rehabilitation Act, Section 504 (Longmore, 1995). As a board member of an Independent Living Center, which is considered a leader in the disability rights community, I am a part of the community that pushed for the creation and the passage of the ADA. The disability community is well aware that despite the passage of the ADA, people with disabilities continue to face discriminatory practices when seeking admission to and graduating from professional nursing programs.

Maheady’s study is part of a small, but hopefully growing body of literature attempting to address issues related to admissions, retention, and accommodations for students with disabilities in nursing schools. However, as a health care professional and a woman with a disability, I believe that Maheady’s study is intrinsically flawed in that it fails to depict the paradigm supported by the disability community. Their perspectives are clearly absent in this research study. Dr. Maheady, like many researchers, uses a medical model to conceptualize and define disability. Unfortunately, the use of a medical model for the purpose of this study instead of a social model has negatively affected the research purpose, sample selection, interview questions, observations, document review, data interpretation, summary, and conclusions.

My purpose in preparing this response to Dr. Maheady’s study is multifold. First, two models that are used to study disability issues will be reviewed to illustrate the paradigmatic shift that is occurring in disability studies. Additionally, I will use the social model to critique Maheady’s study and demonstrate the negative behaviors and discriminatory practices perpetuated by the study. Lastly, I will offer recommendations for future education and research related to disability studies in nursing.

MODELS OF DISABILITY

MEDICAL MODEL

A common myth held by health care professionals is that disability is primarily a medical/illness issue. In the context of the medical model, disability is perceived as an individual and/or a medical phenomenon. The medical model supports a construct of disability in which people often cannot conceptualize disability beyond a physical or mental trait that society has labeled a “deficiency” or an “abnormality.” Consequently, according to deeply rooted societal norms and values, these traits are deemed to be in need of prevention, correction, or assimilation. Because people with disabilities internalize negative societal views about their disability, achieving independence and “normality” is the gold standard for “the disabled” to obtain social acceptance. Independence and normality would allow them to overcome their devalued status as a
person with disability and achieve the rank of an “overcomer.” If independence and/or remediation are not attained, disabled people are often considered incapable of participating in community life and are in need of constant medical care because of their impairments (Northway, 1997).

The use of the medical model in Maheady’s study resulted in a pervasive view of the students with disabilities as lacking in some abilities because of their impairments, which in turn seemed to make them a potential liability to their schools. For example, Dr. Maheady stated that “Fortunately, the limitations of the participants did not result in any known harm to the patients they cared for, but the potential threats to patients’ health and safety must be emphasized.” Besides being illegal, this statement degrades disabled students to an inferior status rather than a status of equality within the educational setting. By using the medical model as a paradigm to explain an individual’s experiences related to disability, Maheady is not able to account for the social construction of disability and its effect on the students’ experiences. Moreover, the individuals’ unique physical or mental traits were the focus of the study rather than the societal factors that define these traits as deviant.

The medical model also conflates impairment and disability with the sick role. Consequently, discriminatory norms and values are perpetuated instead of addressing the sociopolitical, cultural, and economic forces that have an impact on disabled people. And, health care providers, educators, and researchers often have attitudes about disabled people that demonstrate a complete lack of awareness regarding the actual disability experience. Accordingly, nursing professionals resist the opportunity to view disabled people as peers or equals—who may actually bring a new set of skills and abilities because of their disabilities. Like race and gender, people are now seeing their disability as a natural part of the human experience. While a disability may be different from average, a disability is in itself neutral. More than just a “pathological” medical condition (physiological and psychological), disability is derived from the interaction between individuals and the environment.

The intent of the ADA is to address the external factors, such as, architectural and attitudinal barriers that impede or prevent people with disabilities from participating in educational endeavors. Unfortunately, continued use of the medical model to examine experiences and issues related to disability does not challenge the discriminatory behaviors and practices experienced by disabled people. The medical model also perpetuates a common, but erroneous perception of people with disabilities as inherently “less than,” as was seen in Maheady’s study. And, the medical model has been criticized because it fails to measure sociopolitical, economic, and cultural factors that impact a person’s ability to perform or engage in social roles. Because traditional views have not adequately explained the experiences of people with disabilities, the disability community questions the utility of conventional interpretations. Disability scholars propose alternative views that create a framework for examining factors (social, political, economic, and cultural) affecting their experiences (Oliver, 1998).

SOCIAL MODEL—TRANSFORMING VIEWS OF DISABILITY

Much of the research to date regarding people with disabilities has been nonparticipatory and has excluded people with disabilities from the research process. Consequently, disability has been very narrowly defined. As we begin to hear from people with disabilities, our understanding of the nature of disability is being transformed and we realize our need to reconceptualize and restructure our perceptions and attitudes about disability per se. People with disabilities often state that the most difficult thing to deal with is not their disability, but, how people react to them. So, the “problem” is not really the disability, but rather society’s reaction to individual
differences. Disabled people are now examining the restrictions placed on them by society instead of focusing on the “limitations” that are defined by society—not necessarily by the person with the disability. An understanding of disability within the context of social oppression theory, offers a balanced view and an opportunity to identify social and political strategies for challenging disabling discrimination.

While the content and methods of nursing curricula can influence the nature and quality of patient care, professional education concerning disability has been harshly criticized for promoting (and failing to challenge) negative stereotypes associated with disabled people. Negative stereotypes are illustrated in Dr. Maheady’s study by the derogatory comments made by the participants’ peers, faculty, and employers. For example, a participant with a back injury reported that a peer said, “People like you shouldn’t bother taking slots from people like us who don’t have disabilities.” And, one student stated that “My clinical instructor told me that some of the students are complaining that you’re not getting the same experience as they are.” Another participant with a back injury reported that some potential employers stated to her “Who wants a nurse with a bad back? Be real!”

Negative attitudes have the potential to jeopardize the care and the health status of disabled people (Lindgren & Oermann, 1993). Therefore, nurses must be taught how to accept disabled people as equal individuals, before respectful interactions can occur and health care goals can be achieved. In reading the comments from these participants regarding the treatment that they received from their peers and faculty, clearly our nursing institutions continue to graduate nurses who do not understand disability. Thus, across all levels and areas of nursing education, educators need to address behaviors of nursing students that reinforce stigma associated with certain characteristics to avoid becoming “stigma coaches” to disabled people. Before change can occur, nurse educators and nurse researchers need to develop an understanding of disability culture and disability identity.

To suggest that the participants in this study were a threat to patient safety is incredibly disingenuous and undermines their efforts to convey the discrimination, hazing, and abuse that they experienced during their nursing education. Had a social model been used to examine the participants’ responses, the interpretations would differ substantially. For instance, the real safety issues would be those that concern the students with disabilities. The experiences conveyed by disabled people in this study depict a less than optimum learning milieu in nursing schools.

SOCIAL MODEL AS FRAMEWORK TO INTERPRET STATEMENTS

Maheady reports that the negative attitudes experienced by participants had an impact on their self-esteem and confidence, adding more stress to their educational experiences. Moreover, participants eloquently revealed a shocking number of incidents related to discrimination and abuse on the part of faculty, staff at clinical sites, and fellow nursing students. However, despite participants’ repeated efforts to convey the horrific types of attitudinal barriers, the researcher continually shifted the focus back to the individuals’ impairment and safety issues related to their disability. This inability to capture the “lived experience” of nursing students with disabilities illustrates a limitation of the medical model as an approach to conceptualize the study. A participant who uses a wheelchair even stated, “Our biggest barriers are not physical, they’re mental. .. not every nurse needs to give shots...use all 10 fingers...or walk into a room.” Here again, the use of a social model would foster a more accurate understanding of the experiences of disabled people.

ABUSE AND CRUELTY

The experiences presented by Maheady reflect hostility and abuse from other students, faculty, and potential employers toward the participants. If the abuse wasn’t
picked up by the faculty or administration, the researcher had an obligation to recognize this as abuse and provide the study participants feedback that they were exposed to abuse. For example, in Maheady’s study a “participant with a back injury explained that other students teased her a lot while she was in a body cast. She said: It snowed a lot...and they would push me over the snow bank and I couldn’t get up...they would razz me and say she’s a turtle...can’t get out of her shell.” The use of the social model would have prompted the researcher to query the participant as to whether she experienced this as abuse and a personal assault. Recommendations could have been made to the participant regarding support for this abuse. To label their experiences as “teasing” negates and re-imposes society’s able-ist devaluation of the individual and sanctions the abuse. (Able-ism is prejudice directed toward people with disabilities—similar to racism and sexism.) When students and faculty make such comments they should be reprimanded and possibly dismissed from the nursing institution. They are not prepared or competent in the care of disabled persons.

Additional comments reported by Maheady that illustrate the cruelty and abuse experienced by the nursing students with disabilities include the following examples. “She misses lots of clinical days, and she still gets an A.” “She’s a squeaky wheel that uses her disability to her advantage all the time.” “You can’t be a nurse, you’re in a wheelchair.” Participants also reportedly “revealed many comments about the lack of support from and pessimistic attitudes held by staff members, physicians, and employers.” A fellow student recalled her experiences with a participant and stated that “She gets special attention from the faculty and students.” “Most of the students really resent her.” As educators and researchers, we must challenge these types of comments as negative stereotypes associated with disabled people.

DISCRIMINATION

Some of the experiences documented by Maheady demonstrate blatant discrimination directed at the participants of the study. For instance, a director of nursing reported “My concern is that it’s so obvious in her speech, and she doesn’t think that people can tell. I think she’s in denial.” Although, perhaps the student chooses not to call attention to her speech, it is unlikely that she is unaware of her speech.

An additional disconcerting example involved an observation of a participant with a hearing impairment. Maheady reported that “a patient called out the student’s name four times. When she was told her patient was calling her...” the student replied “Good thing you heard her, I didn’t hear her at all.” The researcher noted the admission guidelines from the student’s university stated that “An individual that poses a direct threat to the health or safety of others may be denied admission or progression.” According to Maheady, this student went on to graduate from the program with honors. The interpretation of this observation is completely against the spirit and intent of the ADA. Why are we having patients yell? At what arbitrary point do we say that this is outside the range of “normal” hearing? This is why we have call buttons and beepers. The students in this study were not given accommodations, they were set up first by faculty, then by the researcher—the motives appear deceitful. Another participant with a hearing impairment actually reported feeling that she had been “set up by a faculty member to fail.” These reports and observations noted by Maheady need to be challenged as discriminatory behaviors and practices directed toward people with disabilities.

The comments conveyed by Maheady reflect a need for faculty, students, and potential employers to learn about disability before they teach students with disabilities or provide care for people with disabilities. Having an adequate knowledge of disability
culture would improve treatment toward disabled students and disabled nurses. Moreover, people with disabilities would also probably receive less discriminatory treatment in health care systems. As noted by a national disability rights activist, “I certainly would not want the nondisabled peers of the participants in this study to take care of me when they graduate!”

PROTECTION OF HUMAN SUBJECTS

People with disabilities have a long history of being used and abused by researchers to further goals that the disability community does not necessarily embrace. In addition, an implicit role of a disabled person often includes dutiful participation in research and treatment efforts to ameliorate one’s disability and respectful cooperation in any activity that may provide a cure. With the paradigmatic shift in disability studies, using the experiences of people with disabilities without interpreting and acknowledging their experiences of abuse is no longer acceptable practice. Similar to other minority groups, researchers have an obligation when bringing out the voices of individuals with disabilities, to acknowledge their experiences and be prepared to provide them with appropriate resources. Was the student with hearing impairment who explained “with tears in her eyes, that she was always picked last to participate in a group” given any follow-up support? When she went on to say that a peer told her, “I don’t believe you can’t hear, you can hear anything that you want” provided with any resources to deal with these experiences? For this student, the first comment conveys that she’s inadequate as an able-bodied person. Yet, the second comment de-legitimates her as a person with a disability. Consequently, she is living in an ideological prison between two locked doors—this effectively silences her.

The violation and betrayal experienced by the participants in Maheady’s research perpetuates the abuse that many disabled people experience with professionals who do not perceive the experiences as abusive and discriminatory. In the protection of human subjects and as a nurse with a professional code of ethics (Silva, 1995), the researcher has an ethical obligation to at least recognize if not address potential areas of abuse and discrimination for participants with disabilities. Moreover, in this type of situation, researchers should assume some responsibility by ensuring that appropriate follow-up is available to these participants.

When research is conducted with disabled people, the researcher must be acutely cognizant of the abuse issues that most disabled people have experienced, especially in health care settings. Should research participants report incidents of abuse and researchers fail to recognize or address the abusive nature of the incidents, they in turn become participants in the abuse cycle. The occurrence of these abusive and discriminatory behaviors in a professional nursing education program is unacceptable. But future participatory research with people with disabilities absolutely must adopt a higher standard to break the cycle of abuse experienced by many people.

RIGHTS, DISCRIMINATION, AND OPPRESSION IN NURSING EDUCATION

Maheady noted that many of the participants in her study felt that their experiences gave them great insight into the needs of their patients and their experiences made them better nurses. Also, Maheady reported that they seemed to know what to do without having to be taught. So, why are we focusing on safety concerns for this group of students? A more pertinent question is how can we recruit and retain more students with disabilities.

Use of the social model of disability can broaden our understanding of disabilities beyond a view that disabled people are objects of pity or in need of “fixing.” A social model allows us to perceive them as valuable professionals whose skills and talents are needed and wanted by the nursing profession. In a social model of disability, the
presence of physical and social barriers, including discriminatory behavior, prevent people from taking part in society, not their “impairments” (Northway, 1997). Thus, action is focused on identifying and eliminating barriers. Furthermore, experience and subjectivity are viewed as central to the research process and disabling barriers is the key research issue (Oliver, 1998).

Despite the fact that disabled people have described oppression in health care settings by nurses since the mid 1970s, to date, nurse educators and the nursing literature in the United States have largely ignored equal rights and discrimination issues pertaining to people with disabilities. Goodall (1992) suggests that people with disabilities increasingly view health care professionals as part of their experience of oppression. Instead of “helping” people with disabilities, health professionals have unintentionally become the “instruments of devaluation” (Scullion, 1999). Disabled people describe feelings of being violated, transgressed, and infringed upon by the health care personnel in charge of their care (Liljestro, 1997). One classic example that has been reported by wheelchair users across various types of health care institutions (including acute care and rehabilitation institutions) is the removal of a personal wheelchair by nursing personnel from their hospital rooms.

Disabled people also report that they feel their bodies are often perceived as objects, because of the way nurses and other health care personnel interact with them and handle their bodies. Nursing curricula need to address the features of the health care professions that cause feelings of being violated among disabled people. Including nursing students with disabilities will be beneficial in breaking down some of these barriers. Incorporating nursing students with disabilities is similar to including other minority groups in the nursing profession. Like other minority groups, disabled people would like to have the option to choose practitioners who share their identity as a disabled person.

The disability civil rights movement provides an opportunity to address issues relating to rights, discrimination, and oppression in nursing education, which is being done in other countries, such as the UK and Australia. People with disabilities are now a protected class in civil rights legislation. The disability community wants a common respect and the opportunity to build bonds with their health care providers.

FINAL CONCERNS

Being clear on the conceptual framework and definition of disability in examining ADA issues would have avoided several major concerns with this study and the interpretations of the findings. For example, use of the term “special” when referring to students or accommodations is offensive. The ADA prohibits discrimination on the basis of disability in employment, state and local government, public accommodations, commercial facilities, transportation, and telecommunications. So, I’m unclear as to why the author repeatedly refers to the accommodations as being “special.” The word special isolates a concept as being distinguished by some unusual quality, which is exactly what the ADA seeks to prevent. “Special” means “segregated.” As noted by disability scholar, Simi Linton (1998): language matters!

Dr. Maheady has a section titled “disclosure.” The point of this section seems to indicate that nursing faculty need to be aware that some nursing students are being admitted without disclosing their disabilities. This comment is reprehensible given that 1) students are not legally obligated to self-disclose; 2) students cannot be expected to disclose their disability status when they perceive the possibility of sanctioned reprisal or loss of status, and, 3) policies and procedures regarding faculty identification of students with suspected disabilities is illegal.

The 1998 National Organization of Disabilities (NOD)/Harris national survey of Americans with disabilities by Louis Harris & Associates documented that less than half
(45%) of adults surveyed said that people generally treated them as an equal after they learned they had a disability. The results reflect a decline from 47% in 1994 and 56% in the 1986. Consequently, for many people with “nonvisible” disabilities, “passing” as a nondisabled person is an advantageous option for pursuing educational and employment opportunities. Given the oppression that many disabled people experience from nurses, I would certainly not recommend that any student with a disability self-disclose in nursing education programs. As evident from this study, it can and will be used against the student with a disability.

One final comment relates to the discussion concerning patient safety. Dr. Maheady is correct in stating that the potential threat to patient safety is a major issue in nursing education. But patient safety is an issue for ALL nursing students not just “these students” with disabilities. To single out people with disabilities as a separate group is illegal. Maheady only “proves” that nursing students with disabilities are a threat, because that is her axiom. However, using the social model to interpret the data, the results actually suggest the opposite in that the nursing students with disabilities are far better than their nondisabled peers. The students with disabilities are intrinsically more knowledgeable in some areas, more determined, and more empathic. And, they are far less dangerous than nursing students who would push someone into a snow bank and laugh at them!

RECOMMENDATIONS

Maheady’s research adds yet another study to the traditional disability research that is oppressive to disabled people and has failed to assist them in their struggle for civil rights and full participative citizenship. Moreover, curricula using a medical definition of disability will fail to recognize the social determinants of the disability experience. Substantial progress can be made only if professional education, clinical practice, and research makes a fundamental shift in the way people with disabilities are viewed. In light of the concerns expressed by disabled people regarding the limitations of the dominant theories of disability, researchers are advised to adopt and incorporate the social model of disability into research studies. Use of the social model of disability would require researchers to examine critical external factors impacting the lives of disabled people.

One course of action is of paramount. We absolutely must incorporate the perspectives and values of the disability community into the discussion as we grapple with the policy issues related to the implementation of the ADA in nursing education. And, we must attend to correcting the historical and contemporary oppression of people with disabilities. Policies and guidelines must not be made on the basis of outdated medicalized views of disabled people.

Secondly, by incorporating disability studies (a minority perspective) into nursing curricula, we can begin to dispel the notion that disability is a “pathological” medical condition (or physiological or psychological impairment). By recognizing that disability is derived from the interaction between individuals and society, we will begin to identify environments that are either welcoming or excluding. As illustrated in Maheady’s study, the environment was not welcoming for any of the participants. In fact, the exclusionary environment prompted the students to “jump through hoops and walk on eggshells,” a requirement that is not expected of students without disabilities.

Third, we need to be very clear as to what comprises an appropriate accommodation for students with disabilities. Dr. Maheady makes references to several accommodations for students that are actually not accommodations. Nursing schools need to collaborate with the disability community and ADA specialists with disabilities to identify “reasonable accommodations.”
Fourth, in using a social model for disability research, the questions that academicians should be asking relate to the following: 1) how can we recruit and retain people with disabilities into the nursing profession, and 2) how can we provide an educational program that is instructional for students and creates an accepting environment. These questions offer direction for the use of research funds and instructional resources to improve professional education for people with and without disabilities.

Lastly, journal readers are urged to re-read Dr. Maheady’s article and insert any other minority group every time “a person with disability” is mentioned. This exercise will explicate the degree of discrimination presented in this article. For example, “There is a place for nurses with <insert any other minority group> within the profession, but educators and employers must be aware of individuals’ limitations to make appropriate accommodations that will promote patient safety.”

Many of the statements referring to nursing students with disabilities presented in Maheady’s article are not acceptable. Moreover, if you follow the advice suggested in this article your academic institution will be legally liable. We must, as a profession, address our prejudices toward people with disabilities and recognize the value and viability of the hard-won rights of people with disabilities. We must accept and accommodate people with disabilities as nursing students and professional nurses.

**ADDED MATERIAL**

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**REFERENCES**


