

Disability Simulations: Using the Social Model of Disability to Update an Experiential Educational Practice

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Abstract

Disability simulation as a form of experiential learning has been a popular way for students to “learn what it is like to have a disability” in many different educational curricula from nursing to recreation. There is a lack of research detailing the efficacy of such activities, and some researchers have noted the possibility of negative results. Due to the inconsistency of how such activities are introduced and debriefed, some researchers feel that the practice should be discontinued. By introducing a new paradigm known as the Social Model of Disability, the outcome of the simulation is altered dramatically. Rather than trying to accomplish some task of daily living, the student is cued to observe social interaction. Given proper direction, students have the opportunity to confront and reintegrate their own attitudes as they view such attitudes and behaviors being expressed toward them during a simulation exercise. Measurement techniques based on the Medical Model of Disability will need to be improved or replaced in order to have consistency from design to outcome. Only then can the long-term viability of the disability simulation be accurately evaluated.

KEYWORDS: *Stigma, disability, disability simulations, social model of disability*

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Using the Social Model of Disability to Guide Disability Simulations

Recreation professionals will encounter people with disabilities throughout their careers in various settings such as physical rehabilitation or community recreation centers. Bedini (1992) claimed that educators in leisure and recreation programs had an “obligation to enlighten students and discourage negative attitudes toward groups that traditionally experience discrimination” (p. 44). When influenced by such negative attitudes, there is a tendency to see a person with a disability as someone who is more dependent, childlike, passive, sensitive, miserable, and less competent than a person who does not have a disability (Linton, 1998, p. 25). Negative attitudes about disability can lead to formation of “dehumanizing stereotypic caricatures” that are inaccurate and may prevent individualized treatment or service (Dovidio, Major, & Crocker, 2000, p. 1).

Although preparatory classwork may include some elements of diversity training, it may be inadequate to help students identify and restructure their own internal attitudes about disability. Education and training on the subject of disability was mentioned as a key element of health care reform by the National Council on Disability (2009) in their report to President Obama. In an effort to shape attitudes among future service providers, many organizations have used some version of a disability simulation exercise. Although such activities can be a powerful tool to influence or modify attitudes about disability, they have a poor track record for efficacy, and thus they have been either promoted or disparaged for decades based on wide-ranging results.

Disability simulations have been criticized for their pervasive use in spite of a reported lack of effectiveness and their potential for negative results among participants (Flower, Burns, & Bottsford-Miller, 2007). Although results vary greatly, French (1992) found that “rather than helping to produce more positive attitudes towards disabled people and to gain a clearer understanding of the meaning of disability, simulation activities do just the reverse” (p. 259). In a meta-analysis of disability simulation research, Flower et al. (2007) found 41 studies that dealt with the subject, but only 10 had relevant data that could yield useful comparisons. Among the 10 studies included, half were conducted more than 20 years ago. The conclusion of this meta-analysis was that disability simulations were an ineffective practice among adults, and the authors cautiously recommended putting an end to the practice as it has been historically implemented (Flower et al., 2007, p. 77). Some researchers have maintained that simulations can be effective, but only under carefully crafted circumstances including preselection, exposure, front-loading, and debriefing (Bedini, 1992; Burgstahler & Doe, 2004; Emes & Legg, 2006).

Simulations as commonly constituted tend to focus on experiencing what it is like to do simple daily tasks in the presence of a limitation or a disability. Participants in these programs focus on the personal journey of adaptation to deficits in mobility or other senses. These short-lived experiences generally have included only limited instruction in skills and techniques. In many cases, the participants discover negative emotions such as embarrassment, frustration, and anger rather than positive insights about disability (French, 1992). Some students apparently reached the conclusion

that life with a disability would be sad, miserable, and lonely (Wood, 1990). Among student responses to a disability simulation on a college campus, Wright (1980) found that 17 of the 18 most frequently reported "insights" among student participants were negative. Grayson and Marini (1996) even had a student go so far as to say, "I would kill myself if I really had to stay in a wheelchair" (p. 130). In contrast to that sentiment, not all participants universally report such negative results of their experience. Two studies of note focused a simulation exercise on medical service professionals ranging from doctors and therapists, to social workers and psychologists. These studies used qualitative interviews to debrief the participants. In each case, positive responses (increased empathy and understanding, renewed sensitivity) were mixed in among negative responses (tiring, frustrating) as well as the ambiguous (eye-opening) (Pentland, Hutton, MacMillan, & Mayer, 2003; Peterson & Quarstein, 2001). These studies concluded that the simulation had a beneficial effect for practitioners by giving them a better understanding of impairments and thus prepared them to be better professionals. However, appreciating the limitations of an impairment focuses inquiry on overcoming personal deficits, which ignores the larger picture of disability as a social construct based on opportunity, discrimination, and oppression.

Whenever simulations are focused on deficits and how to overcome and cope with them, the exercise reverts back to the Medical Model of Disability which has been exposed as inadequate to capture the lived-experience of disability by the academic discipline of Disability Studies (Gill, 2001). More recent trends in academic and social dialogue revolve around the social disadvantages of disability and are not focused on ability and function. The lack of opportunity in society may be more limiting than the actual impaired function of a body part. Further, the medical focus tends to give the message that the impaired function must be cured at all costs and that value cannot be reclaimed by an individual until that which is "broken" has been restored. This attitude simultaneously portrays disability as a personal battle of recovery, and alleviates any social responsibility to provide access or opportunity to those whose impairments are permanent.

Social Constructions of Disability

Stigmatizing attitudes are attached to people with disabilities, not simply anyone with a physical impairment. In fact, many people with reduced function in their eyes would be classified as having a physical impairment if the standard is simply "the range considered normal" as promoted by the International Classification of Impairments, Disabilities, and Handicaps (ICIDH). A person with such a common impairment, easily corrected with eyeglasses, is not considered to have a disability by cultural definition, nor are they commonly stigmatized. Disability, however, historically has meant that functional losses "interfere" with normal activities. In the language of the Americans with Disabilities Act (1990) a person has a disability if he or she has a substantial limitation in one or more major life activities. With the rise of Disability Studies as an academic discipline, there has been much debate about using personal functional limits as the defining characteristic of disability. The common ground that creates a "culture" worthy of an academic discipline is not the shared experience of impaired function, but social oppression and outsider status. The Social Model of Disability clearly asserts that society, not bodily function, is what limits people with disabilities. Although the Social Model of Disability has been popular for some time, it is not universally accepted

and even the language associated with the model is still being debated. For example, three organizations see the very definition of the word disability differently:

Disability: In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within *the range considered normal* for a human being. (World Health Organization)

Disability: The loss or limitation of opportunities to take part in the normal life of the community on an equal level with others *due to physical and social barriers*. (International Classification of Impairments, Disabilities, and Handicaps [ICIDH])

Disability: The disadvantage or restriction of activity *caused by a contemporary social organization* which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities. (Union of the Physically Impaired Against Segregation)

In the first definition, the cause of disability is impaired function. In the second definition, disability is caused by a combination of physical and social traits. In the third definition there is no causality attached to the physical body. The full responsibility for a condition of “disability” may be the nature of society itself. In this view, stigmatizing attitudes are aroused not by actual function, but by the perception of difference from the norm and failure to accommodate the full range of human physical expression. Regardless of the definition of “disability,” what remains is the stigmatization of individuals perceived to live with it.

Educational Opportunities

Many college campuses celebrate a Disability Awareness Week. During the week, there are typically various opportunities to learn about physical disability in our culture through film, lecture, or other activities. One of the most visible activities is the experiential-learning oriented disability simulation. Students who stop at the table or booth may take on a disability-oriented task to gain an appreciation for the skills required to function under some form of perceived restriction. Such tasks may be to navigate to a particular location on campus and back in a wheelchair, discovering inconveniently located ramps, trails, and entrances. Other activities simulate vision or hearing loss or the loss of dexterity associated with arthritis. These spontaneous situations do not allow the proper preparation or debriefing necessary and focus on the wrong part of the interaction. By looking at the interface between disability and the physical environment, they can potentially miss the chance to observe the rich interaction of disability in the social environment.

In a campus newspaper account of a disability awareness activity, it was reported that John Doe was a senior sociology major and the secretary of the campus Alpha Kappa Delta club in 2010. He volunteered to man the obstacle course presented to students during “Dis-Abilities Awareness Week” and instructed people how to complete the challenges. He said, “It was great to watch as people realized how hard completing simple tasks can be for people who are disabled.” One of the participants,

Jill, remarked, "It's opened our eyes to how immobilizing disability is" (McCoy, 2010). In another activity on the same campus, the participants played wheelchair basketball. Emily, a special education major, volunteered as a referee for the games. She stated, "Mainly this is just to teach them what it feels like to be in a wheelchair." While the activity may be engaging, moving a wheelchair around on a basketball court does not reflect environmental concerns about access, does not provide adequate training to engage in high level skills such as dribbling or shooting a basketball, and avoids any exposure to socially stigmatizing attitudes.

In contrast, on another campus, recreation students experienced a disability simulation as part of a class that included pre-experience instructions, guidance from a person with a disability and were debriefed afterward. One student having this type of experience wrote: "This activity made me reevaluate my own personal attitude towards those with disabilities. The attitudes I experienced were all attitudes I have more than likely portrayed towards those with disabilities."

The experiences that will potentially enhance student preparation for practice and service delivery are those that address negative attitudes and create opportunity for formulation of new ones. Austin and Powell (1980) studied the competencies needed by entry level community recreation professionals in which they placed 86 competencies into common clusters and then ranked the importance of the clusters. The *attitude* cluster was the highest ranking area of needed proficiency. Aside from recreation service providers, other healthcare educators have similar needs to prepare students to work with people who have disabilities. In this respect, disability becomes a multidisciplinary area of concern. In an editorial written for the *Journal of the Royal Society of Medicine*, Byron and Dieppe (2000) declared that the troubles experienced by people with disabilities "have more to do with culture and environment than they do with biology." After formation of a multidisciplinary committee to study curriculum of the British Society for Rehabilitation Medicine, the panel wrote, "The consensus amongst all stakeholders was that attitudes were the key. Attitudes, attitudes, attitudes" (Byron & Dieppe, 2000). In another study, people with disabilities "identified inappropriate staff attitudes and behaviors as the biggest barrier to accessing health services" (Tervo, Palmer, & Redinius, 2004).

The various organizations promoting greater disability awareness are not focused on simulating daily tasks like spreading peanut butter on bread after taping fingers to tongue depressors but rather on the interpretation of disability and the stigma that so often impairs the fluid interaction of conversation, the exchange of information, or the delivery of quality services. The common need is for future practitioners, including those in recreation, to understand social attitudes in themselves and recognize them in society. But practitioners in health-related fields may feel "just as lost as everyone else when dealing with people with disabilities" (Roush, 1986). As a result of feedback from actual patients who were dissatisfied with their experience in the healthcare system, facilities such as the National Rehabilitation Hospital in Washington, DC began implementing new programs to decrease the negative attitudes and behaviors that sometimes characterize interactions between staff and patients (Kroll & Towle, 2004; Scullion, 1999). While the use of simulation activities is not part of the workshop at NRH, the desired outcome is nearly identical with that of educators, and thus, multiple organizations are interested in documenting a course of action that demonstrates lasting value in terms of improving attitudes about disability.

Beyond Architecture

When disability is regarded as primarily a personal problem related to deficits, the focus remains squarely on the individual to overcome his or her deficiencies. When the social model is used to explore what is really limiting to people with disabilities, the focus turns to issues of human relations that are susceptible to stereotypes and stigma about disability as a life experience. When a person is able to perceive stigma enacted toward them, they may feel alienated from society. The feelings of alienation are characterized as “feelings of frustration, helplessness, loneliness, despair, and lack of gratification with his current overall situation—a general and pervading feeling of futility about the present and the future” (Titley, 1969). These are potent consequences for the social processes that often accompany the physical implications of disability.

Students can be better prepared to become future practitioners if they are given opportunities to confront their own attitudes toward disability. These attitudes are subtle and so ingrained that gaining insight requires more than simply talking about them in a lecture setting. A better context for the discussion would be to have a person with a disability describe real life experiences (Ison, McIntyre, Rothery, Smithers-Sheedy, Goldsmith, Parsonage, & Foy, 2010). Even better still would be to have students feel these attitudes expressed toward them, and debrief their observations afterward (Herbert, 2000; Karraker, 1993). To quote an old Celtic expression, “Some things are better felt than telt.” The wide range of personal experiences represented and debriefed in the classroom discussion allows for differing levels of stigma to be exposed and confronted. Students who chose to simulate different representations of disability ranging from crutches, wheelchairs, and orthopedic boots to sensory impairments can find commonality in the responses or debate the interpretation of behaviors observed in real social settings.

Preparing students prior to their role play assignment is a critical step. Without preparation, the student may focus on learning how to “pop wheelies” in a wheelchair. “Unless the simulation is prefaced with a clear discussion of why we are doing this and what we hope to learn and is followed by a conscientious debriefing about critical thinking processes and values, norms, and social change, the simulation has merely served as recreation” (Karraker, 1993, p. 136). Unguided activities that Karraker decries solely as recreation or perhaps entertainment, however, are accompanied by “a risk for long-lasting unintended negative results” (Burgstahler & Doe, 2004). Common to many experiential learning styles is the essential debriefing that solidifies learning and contextualizes the experience which make it more likely to have lasting impact (Katula & Threnhauser, 1999).

A key element to a successful simulation as identified by Burgstahler and Doe (2004) is to clearly identify the objectives and illustrate potential challenges that participants may face. Perhaps many instructors are unsure themselves as to what these challenges may look like in terms of changing the focus from architecture (drinking fountains, curbs, bathrooms) to social attitudes. Based on the work of Smart (2009) and Siller, Chipman, Ferguson, and Vann (1967) a student may experience the following 10 attitudes expressed toward him or her during a role play assignment.

Lowered expectations. People who have impairments are often regarded as being capable of less. The expectations can become an excuse to the person with a disability or a potential employer. In some cases, this interaction can trigger a self-

fulfilling prophecy where the person performs to the expectation ascribed to them. While this is a highly individualized judgment, the central tenet is that a person with a disability is not held to the same standard as others.

Interaction strain. The discomfort and fear associated with *how* to interact with a person who has a disability leads to shorter conversations, less eye contact, and conversation that is impersonal or based on trivial small talk.

Rejection of intimacy. Some individuals are uncomfortable around people with different bodies or using various types of equipment. Perhaps the unknown etiology of the disability makes it difficult to touch or be close physically with that person. Perhaps the most obvious expression of this idea is when a person with a disability is accepted as everyone's friend, buddy, or confidante, but never thought of as a romantic interest or date.

Generalized rejection. In some cases, rejection of disability results in avoidance of contact altogether. There may even be resentment about "those people" being in public situations rather than staying home. Derogatory or negative thoughts about disability may not be based in reality, but passed on through socialization.

Authoritarian benevolence. This demeaning attitude is based on the premise that people with disabilities need caregivers. Some social messages contained in this "sweetly disgusting" interaction are based on supposed immaturity, childlike incapacity, and loss of independence. The message is clearly one of superiority that infers, "I'll take care of you."

Emotional consequences of disability. Perhaps the typical product of Hollywood movies, there is a tendency to treat individuals as volatile powder kegs, in loose control of his or her emotions. At one side of this polarity are individuals who are seen as maladjusted, angry, or irritable. At the other pole, individuals may be seen as emotionally downtrodden, needy, depressed, or even suicidal. Some disabilities such as mental illness are constantly linked with crime and violence. Clearly, avoidance of people at either end of the spectrum makes sense from the perspective of personal safety or that of being encumbered (sucked in) and unable to maintain appropriate boundaries with someone so emotionally needy.

It could happen to me. The anxiety that arises in a person who suddenly has a clear view of their own vulnerability to an altered life state is real and perhaps based in existential dread. Certainly, disability can strike anyone through injuries and accidents, and the resulting fears about loss of lifestyle can shape social interactions. A common reflexive judgment about disability is that of, "I could never live that way."

Functional limitations/SPREAD. Anyone with an obvious disability is thought to have other limitations. Interpreting more restrictions than reality is based on the idea that disability is an identity rather than a characteristic of an individual. There is a tendency to pile on other problems. For example, a person who does not speak clearly is often thought to have cognitive disabilities as well.

The economic threat. People who have disabilities are sometimes derided because they represent a drain on society through entitlements. In a society that is based on productivity, those who do not produce represent a drain on the system. Some have complained about regulations regarding architectural access based on the Americans with Disabilities Act as burdensome and bad for business. There are those who see special educational programs as being cost prohibitive. Social justice is never

the most economical position to adopt, but unless someone sees access or education as a civil right, he or she will resent any mandates handed down from “big government.”

Measurement of Attitudes Assigned to Disability Status

Even when programs are thought to be well organized and have potential for lasting effect, there remains the difficulty associated with measuring attitudes about disability. If attitudes are to be the dependent variable in these studies, then measuring attitudes is critical to an examination of the effectiveness of simulations. Several scales have been used to assess stigmatizing attitudes about disability over the past four decades. Such scales were developed at a time when the language used and the focus of the inquiry was guided by the medical model that casts disability primarily as personal limitations. Such instruments may not be the best choice to assess understanding of disability from a social interaction perspective. There is a newer tool that has recently been developed that uses a social vignette to cue the respondent into seeing a social interaction. This tool is the Multidimensional Attitude Scale (MAS) toward persons with disabilities (Fidler, Vilchinski, & Werner, 2007). After establishing the setting, the subject answers questions that represent emotional states, behaviors, and cognitions. The vignette very clearly establishes the social nature of the hypothetical interaction. It states,

Imagine the following situation: Joseph/Michelle went out for lunch with some friends to a coffee shop. A man/woman in a wheelchair, with whom Joseph/Michelle is not acquainted, enters the coffee shop and joins the group. Joseph/Michelle is introduced to this person, and shortly thereafter, everyone else leaves, with only Joseph/Michelle and the man/woman in the wheelchair remaining alone together at the table. Joseph/Michelle has 15 minutes to wait for his/her ride. Try to imagine the situation.

While this new scale may have promise, it has not been widely tested and has no history to point toward any necessary modifications in questions, language or methodology. Any tool that is used to assess the efficacy of simulation activities that are guided by the Social Model of Disability should also be based on the same model.

Although criteria can be presented to improve the disability simulation as an exercise to modify behaviors, the ineffectual assessment of such simulations is a tremendous liability that casts doubt on any result heretofore published and begs the consistent efforts of disability researchers to find an appropriate measure that can move the research literature along in ways that contribute to educational practice, service delivery and in-service training.

Recommendations for Practice

The use of disability simulations has not consistently been shown to be an effective way to improve or modify attitudes about disability. Still, there is a deep-seated emotional desire to engage people through this experiential role play methodology. Intuitively, educators believe it can be an effective tool and “more revealing than an entire chapter in a textbook” (Glazzard, 1979, p. 102). To date, however, there is not enough accurate data to warrant inclusion or elimination of the practice among educators in various multidisciplinary fields that prepare future professionals to work

with and among people with disabilities. This can be attributed to poor design of such activities or poor measurement of attitudes with existing psychometric measures. Once a reliable instrument is available, the long debated question can then be answered regarding the efficacy of the disability simulation or role play exercise.

Using the Social Model of Disability to explore the experience of disability in society is important because it helps focus interventions on attitudes, which are reported as being more limiting than physical impairments (Canadian Union of Public Employees, n.d.; Murphy, 1987). The use of simulations, in context of the Social Model of Disability, focuses insight away from disability as a personal, private experience and allows the participant to examine social bias, stereotypes, labeling, and interaction strain. Seeing attitudes enacted toward them, however briefly, enabled some participants to see interaction as enabling or foreclosing opportunities for full participation. Under these conditions the participant learns more about himself/herself and the social construction of disability and less about coping with the physical effects of an impairment. When a participant sees the bigger picture, then they may truly gain some insight about what it means to *live in society* with a disability rather than simply to live in one's physical environment with a disability.

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