Ethical Legal Feature

Disability Stigma in Rehabilitation

**Contributors: Carol J. Gill, PhD, Shubhra (Sue) Mukherjee, MD, FRCPC,
Rosemarie Garland-Thomson, PhD
Feature Editor: Debjani Mukherjee, PhD**

Introduction

In the 26 years since the Americans with Disabilities Act was passed, we have seen changes in access, knowledge, and a move towards equity for people with disabilities; however, societal attitudes and implicit and explicit biases continue to impact the way that people with disabilities are viewed, represented, and treated. A simple definition of stigma from Merriam Webster is "a set of negative and often unfair beliefs that a society or group of people have about something" [1]. In his classic book, *Stigma: On the Management of a Spoiled Identity* [2], Erving Goffman, a sociologist by training, described and delineated the concept of stigma and how it impacts society. He described complex phenomena that include devaluation and marginalization. Although critiqued and refined over the years, the concept of stigma that Goffman described is a robust and important one to consider. Stigma, and more specifically disability stigma, is part of the social, psychological and ethical context in which physical medicine and rehabilitation (PM&R) clinicians practice.

This column will explore the concept of disability stigma and its impact on the practice of rehabilitation medicine. This idea for a column is based in large part on a course that I teach to undergraduates at Northwestern University called "Disability and Global Health," in which we define, discuss, and consider disability stigma in various contexts around the world. We also discuss disability rights and disability ethics in the United States. One of the first reading assignments for the course is an article by Lerita Coleman, "Stigma—an enigma demystified" [3]. Coleman writes that stigma has at least 3 components:

fear, stigma's primary affective component; *stereotyping*, [stigma's] primary cognitive component; and *social control*, [stigma's] primary behavioral component.

We consider the complexities of stigma and apply it to the settings that we are studying around the world, as well as the local settings and contexts in which students live and learn. For example, in some Asian cultures, disability stigma includes the concept of disability being caused by karmic retribution or disability being associated with uselessness. In general, deeply held beliefs and common cultural practices around the world can perpetuate stigma in various contexts.

Link and Phelan [4] further elaborate and describe the process and components of stigma.

In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labeled persons to undesirable characteristics—to negative stereotypes. In the third, labeled persons are placed in distinct categories so as to accomplish some degree of separation of "us" from "them." In the fourth, labeled persons experience status loss and discrimination that lead to unequal outcomes.

Notably, the act of stigmatizing can be disrupted at any of these levels. For example, negative stereotypes can be acknowledged and dispelled, false dichotomies of "us" versus "them" can be undermined, nondiscrimination can be advocated for, and social justice concerns can take precedence. It is an open question, however, how these potential disruptions translate into the practice of PM&R?

I have invited 3 columnists to reflect upon the following prompt: What implications does disability stigma have for the practice of PM&R? Do cultural notions of stigma held by patients, families and clinicians affect clinical care and outcomes? What guidance can you give clinicians for recognizing, addressing, and/or ameliorating disability stigma?

In the first essay, Dr Carol Gill, a psychologist and professor of Disability and Human Development at the University of Illinois at Chicago, writes about stigma resistance and the role of rehabilitation in addressing stigma. Dr Shubhra Mukherjee, a pediatric physiatrist

and fellowship director at the Rehabilitation Institute of Chicago and Northwestern University Feinberg School of Medicine, then reflects on disability stigma in pediatric rehabilitation and how it impacts her work. The third columnist, Dr Rosemarie Garland-Thomson, a professor of English and Bioethics at Emory University, proposes disability cultural competence as an intervention in disrupting disability stigma. All 3 weave together their own personal experiences and observations and give us pause to consider how our own life experiences, educational training, and emotional reactions impact our practice as health care providers. As always, I

welcome comments on this column and ideas for up-coming columns at dmukherjee@ric.org.

References

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Stigma Resistance as an Activity of Daily Living

Carol J. Gill, PhD
Department of Disability and Human Development, University of Illinois at Chicago

Two individuals who use wheelchairs—I will call them Harriet and Harry—married after graduate school. They raised a child, had long professional careers, and have lived more than 20 years in a home they remodeled for both accessibility and aesthetic appeal. On a beautiful spring morning, they celebrated the end of winter by wheeling to a neighborhood shopping center. After visiting several stores, they arranged their bulging shopping bags securely and headed toward home, remarking on how enjoyable the trip had been. While they waited for the traffic light to change at a major intersection, a woman riding a bicycle pulled up and joined the wait. Noticing a sports team logo on Harry's cap, the cyclist briefly chatted with the couple about the team's chances for a championship.

After a pause, the cyclist asked an unexpected question: "Did you two break out of some place today?" Stunned, the couple was temporarily speech-less. Undaunted, the cyclist assured them that she would escort them across the street. The light changed and as Harry and Harriet approached the other side of the street, the cyclist sped off without a word. After-ward, the couple parsed the incident, trying to make sense of it. Did the cyclist assume that they live in an institution? Did she see them as incapable of crossing the street without supervision? Was it impossible for her to view them simply as fellow neighborhood resi-dents much like herself? The only conclusion on which they agreed was that the morning had ended less enjoyably than it had begun. Disability stigma had swept them off guard.

A paradox of disability is that it is widely known but rarely understood. The complexity of disability as a phenomenon and the layers of elements that interact to produce the experience of disability are underrecog-nized by almost everyone, including many people with

disabilities, their family members, health professionals, and, certainly, most of the public.

At the *personal* level, disability involves the way in-dividual bodies or minds function and, often, physical appearance, eg, limping, facial asymmetry, canes, prosthetics. This is what most people envision when they think of the word "disability." Although many of us who became disabled early in life regard our embodied differences as "normal" for us, disability acquired after many years of living "typically" challenges our adap-tivity. Still, according to disability scholars and activists, this personal, embodied aspect of disability is only the tip of the iceberg; most of the problems of disability, they assert, occur at other levels.

At the *interpersonal* level, persons with disabilities experience problems in the way others relate to them and the roles they get to play in relationships. At the local *environmental* level, they encounter structural and programmatic barriers to participation in the commu-nity. At the broader *societal* level, they confront sys-temic social devaluation and its byproducts, eg, poverty, inferior education, unemployment, health disparities, abuse, denial of sexual expression, social rejection.

At what level does stigma occur? I believe stigma operates at all levels and is ingrained and powerful. I base this answer on listening to the life stories of per-sons with disabilities during 35 years of work as a clinical psychologist, rehabilitation psychology director, and disability studies researcher/professor and on my own experience with physical disability. Over those years, Americans with disabilities have won many policy and legal battles and, consequently, are more engaged in mainstream life than ever, but the fear, stereotypes, and exclusion that characterized disability stigma abound. Even veteran high achievers with disabilities like Harriet and Harry can experience the demoralizing impact of stigma at any time.

Sociologist Erving Goffman theorized that stigma results in "spoiled identity" [1]. A person's very sense of self is eroded by repeated social devaluation. Race