STIGMA AND HEALTH CONDITIONS

BY CHERYLE B. GARTLEY WITH MARY RADTKE KLEIN

(Authors’ Note: While some of this article has been written in the first person as a matter of style, and due to the fact that one of the authors lives in the world of the stigmatized, it is really a joint enterprise.)

Whether a person is born with a health condition, or living with one acquired at any age, stigma in any of its various forms very often accompanies health challenges and disabilities, usually when they have a publicly recognizable aspect. And for many, the stigma can be more difficult to cope with than the disability or health condition itself.

Stigma, as attached to differences of the human body, is described in the 1963 classic book by sociologist Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity*. In it Goffman states: “The term stigma, then will be used to refer to an attribute that is deeply discrediting...” “Spoiled Identity” encompasses in two words an expanded definition put forth in another academic book *The Social Psychology of Stigma* where stigma is defined as “(1) the recognition of difference based on some distinguishing characteristic, or “mark”; and (2) a consequent devaluation of the person.”

No matter which of the many definitions of stigma selected, we all recognize immediately when stigma is directed at us, our child, or someone we care deeply about. There are many ways to stigmatize. All too common among them are the verbal messages, such as: a perfect stranger inquiring “what is wrong with your eye (or hand, or leg, or foot)?”; descriptions by the media such as “confined to a wheelchair” (versus “uses a wheelchair for mobility”); adjectives such as “blind man” (versus “a man who is blind”); and deafening words such as “crippled” and “retarded.” Verbal messages of stigma are so common that many of them have become entrenched in the public’s vocabulary and are no longer even noticed, except by the recipient, or those of us sensitized to the damaging effects of stigma. They can also be so very subtle. For example, take Diane Sawyer’s reporting on President Obama’s first inauguration. Having hurt his back packing, the outgoing Vice President was using a wheelchair. To millions, Sawyer expressed the opinion that being such a proud man, the Vice President wasn’t happy to be seen in this manner. The stigmatizing nature of her observation was probably unintended, yet a clear and negative message was delivered.

What can be done to unlock the prison of fear, the tendency to prefer isolation to careless ridicule? We believe in a two-pronged and simultaneous attack on stigma. The first approach is designed to change the atmosphere in society, to shine a light on reactions, and improve the “cultural competence” of unaffected people. In this case, cultural competence would include teaching the unaffected about “our” differences so that the general public can interact with more skill and competence when faced with a disability or health condition they know nothing about.

Non-verbal messages are also included in the stigma armamentarium. Most potent of all may be staring and double takes. Without a word being said, these actions can impact the quality of life of the recipient. So harsh is the impact for some that they are unwilling to enter into society, because they have found there is no such thing as an uneventful trip to the grocery store or running other errands – trips that most take for granted can be accomplished in peace and anonymity. Those who have a visible health condition are never safe from “stranger danger” (staring, questions, pointing) as they go about the normal activities of daily living.

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The second approach is increasing the capabilities and resilience of those who are stigmatized because of visible differences, in anatomy, behavior or adaptive equipment.

Due to the ongoing efforts of many, including non-profits, in the health arena, celebrity spokespersons, and executives in industry (whose products are purchased by consumers with stigmatizing health conditions), our society is increasingly being exposed to the concept and appearance of differences. Michael J. Fox made the full symptoms of his disease obvious when he appeared before the US Congress without taking his Parkinson’s medication; Dove’s beautiful campaign featured insightful commentary on the perception of beauty; Depend’s Underwareness Challenge is tackling taboos with inclusion and humor; and Chicago’s Access Living’s sponsorship of a Disability Pride Parade, are all examples of the growing efforts to
celebrate differences and defeat the stigma that surrounds changes in the human body. Rick Rader, MD, this publication’s Editor in Chief states: “The last word in difference should be - what difference can I make?”

**THE CHANGING CULTURE?**

There have already been some changes in attitudes about difference over the years. But what is the cart and what is the horse? Do individuals wearing artificial limbs and shorts in the heat of summer do so because they are personally comfortable not covering up in long pants? Or do they do so because society has “accepted” artificial limbs as a fairly common way to achieve mobility? Whatever the answer, these changes happen at a snail’s pace as indicated by the fact that for decades the word “cancer” was seldom spoken. Those with cancer stayed mum for fear of being both stigmatized and ostracized – a situation which still exists in many developing countries today. It was not that long ago in the 1980’s that Jory Graham, fighting cancer herself, began her syndicated Chicago Tribune column, “A Time to Live.” She related an example of the stigma surrounding cancer, describing an upscale private dinner party in a Gold Coast mansion where the dinner table gleamed with china and crystal, except for a single place setting of paper plates for the person with cancer. Today, America has walks in communities from coast to coast in order to fund cancer research, and it is common to see television advertising promoting cancer treatments and treatment centers.

But are we really seeing a generalized change just because the word cancer is now spoken out loud, and individuals no longer cover prosthetics with long pants? Has society changed, or is stigma simply been actively diminished in very particular instances, while continuing to raise its head in hundreds of other common circumstances? When looking closely, it seems it just might be the latter, as indicated by some of the interesting results of a recent Simon Foundation for Continence Survey. *(See sidebar)* It seems that there is a need to address not just the stigma associated with one condition at a time, but rather a broad attack on the behavior of stigmatizing in general. We need to launch an effort to build the kind of cultural competence that motivates all individuals to replace stigmatizing behavior with an effort to see and respect each individual. More on that later.

**RESILIENCE TRUMPS STIGMA**

Since over the ages, society has persisted in greeting their fellow humans with stigma, we may not be able to change social attitudes quickly enough to protect ourselves or the next generation from the effects of being stigmatized. That likely being the case, fair or not, one way forward to stop this damage is to build in ourselves, those affected and those who care about them, resilience to spare.

Tania Luna and Lee Ann Renniger, two of a smattering of researchers in the world who study the psychology of surprise, have much to offer about how to increase resilience in their new book *Surprise: Embrace the Unpredictable and Engineer the Unexpected* (2015). How does this relate to stigma? It relates because no matter how much we come to expect it, stigmatizing behavior can still be a surprise. Not that those of us with a stigmatized health condition are in denial, but rather it’s that whenever we walk out our door we never know...
The responses help to highlight the challenges of understanding what conditions attract the most stigma and, more important, why. The public exposure and education generated by the AIDS epidemic over the last 30 years might account for its high ranking. Or it could be its frequent connection with homosexuality, despite current trends toward acceptance. But this result is still surprising, given that public identification of someone with AIDS is increasingly difficult with current medical management.

Furthermore, other once-highly stigmatized conditions, like cancer, while the subject of similar public attention and education, are ranked considerably lower. Many of the other top-ranked conditions are physically obvious, such as facial disfigurement, obesity, and cerebral palsy; yet again other highly-ranked conditions are more subtle, such as mental illness, fecal or urinary incontinence, and cancer. Adding further to the complexity is that relatively few respondents ranked highly, other conditions that are easily observed in public, such as use of a wheelchair, white cane, or guide dog. People participating in the survey were not simply ranking conditions that were easily observed, but appear to be influenced by a variety of factors that result in stigma being attached to various health conditions.

When given the chance to comment, respondents noted several conditions not included on the list presented in the survey. Top among them were: skin disorders (including vitiligo, severe acne, dermatitis; other skin discoloration); Tourette’s syndrome; addictions; and stroke. The survey struck a nerve with many respondents and elicited comments such as: “I think your list should have been divided between apparent and non-apparent (visible and hidden) conditions. Some hidden impairments, once made visible or known, are far more stigmatized than others. I’d say, for instance, severe mental illness is far more stigmatized than almost anything else once made apparent.”

Responses were primarily from the United States, with a much smaller number of participants from Canada, Australia, Japan, the United Kingdom, and other countries in Europe. Participants tended to be older, with the largest reporting age of 55 to 64; well-educated, reporting college attendance or completion; female (67 percent); and Caucasian (with a significant minority Asian). Many of the participants seemingly were motivated to participate in the survey due to being personally affected by stigma due to health conditions – when asked if they or family or friend were affected by this type of stigmatization, 78 percent answered yes.

The results of this very preliminary survey make clear the importance and complexity of understanding which conditions are most stigmatized and why.