

STIGMA AND HEALTH CONDITIONS

PART
III
OF A
SERIES

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(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.

In this section of a series, we address the challenge of building public awareness regarding the impact of stigmatization and what researchers are learning that can be applied to lessen stigmatizing behaviors and build a more helpful society.

Challenging our society to look at and understand how health stigmas impact everyone is a complex endeavor. Motivating people to change is even more so. However, social interactions are becoming better understood, thanks to what researchers are learning about human behavior. This knowledge offers hope that stigmatizing people with health conditions and disabilities can be lessened.)

HEALTH STIGMAS: FACE THEM / REPLACE THEM

Understanding Implicit Bias: Those of us who are vested in lessening the stigma surrounding health conditions can contribute to this change by increasing our understanding of how individuals form ideas and beliefs about others. This understanding is necessary before we can help others to change their ideas and behaviors, like putting on your oxygen mask first before a child's during an airplane emergency.

Stigma experts cite stereotyping as a precursor to stigma of all types. Below the level of human consciousness, stereotyping often begins as a pattern of unconscious thinking researchers call implicit bias. In an article by Jeremy Adam Smith (entitled "Why Teachers are More Likely to Punish Black Students") Smith describes the phenomenon as a bias in judgment and/or behavior that results from subtle cognitive processes that often operate at a level below conscious awareness. Implicit bias contributes to attitudes based on characteristics such as age, appearances, and ethnicity. But if implicit bias happens below the

conscious level, that is without us knowing it is affecting us, is there any hope of changing it?

According to research, the answer is yes. There are practices that can limit implicit bias. In fact, just by reading this information you are changing. Research shows that simply being aware of the existence of implicit bias is helpful. Then if you add new, revised, more empathetic and respectful conscious intentions and goals, you can begin to override your own subconscious associations. We are all growing rather automatically as we experience daily life, but we can also grow intentionally. In order to enhance this growth, everyone needs to put in effort. One intentional way to grow is to practice identifying and contending with all the things that influences stereotyping. For instance, take a hard look at how people are portrayed in magazines and on television. Bring into your own consciousness any subtle stereotyping you discover. Then add to this awareness conscious intentions and goals. In this manner you can begin to override your subconscious associations.

Interesting research from scientists at Northwestern University has demonstrated that our biases need not be set in concrete. This research has shown that using counter stereotyping training techniques during sleep can help alter our implicit biases. Their find-

ings, "Unlearning implicit social biases during sleep," were published in the May 29, 2015 edition of *Science* (sciencemag.org), one of the most prestigious academic journals.

"What our work is doing," said Professor Ken Paller, senior author and professor of psychology, "is opening a discussion if a

person wishes to decrease their bias, there are methods they can use that would have a lasting effect." He stated that another important implication is the research could broaden the discussion of how bias can be combated in society.

Their process begins with subjects participating in counter stereotyping training. After this training, scientists examined the potential to reinforce during sleep what the study participants

Share your experiences of health stigmas at stigma@simonfoundation.org. There is much that needs to be told in order that everyone understands the impact of stigmatization.



had learned. “All we’re doing is reinforcing learning during sleep,” states Paller. “Learning still has to happen.” “...benefits of this counter-bias training can be fragile, subject to reversal when the original stereotypes are again reinforced in typical circumstances, such as through the media,” continues Paller. Although this was a research process, remembering a basic premise coming from it – that we must stay aware of the subconscious inputs and balance their influence – is something we can all work to do in our daily lives.

OVERCOMING THE BYSTANDER EFFECT

Research on a very different topic, the “bystander effect,” also has something to offer in creating a more respectful and compassionate world view. “Bystander effect” research explores who takes action to help another, and what might stand in the way of that action. All of us have heard stories about a young child calling 911 and saving their parent’s life. These stories are highlighted because they portray an action one wouldn’t expect from a young child. But are they really unique? Do the majority of children and adults take action when they see there is a need, or do they stand

by and not offer help in most situations?

The bystander effect exists when being part of a group paralyzes an individual from coming to the aid of someone in need. In her article “Helping Kids Overcome the Bystander Effect,” Kira M. Newman suggests ways to contribute to the creation of a kinder society. Researchers found that five year olds were less likely to help when other children were available, because they feel less responsibility. In one experiment, 95% of the children helped when they were the only ones available to do so, or if they observed that the other children were not physically in a position to help, yet only 55% helped when it was apparent the other kids could pitch in.

Like adults, children assume that one of the other people will likely take action, a phenomenon known as “diffusion of responsibility.” The study’s lead author, developmental psychologist Maria Plotner, states that we can encourage kids to help others more by fostering a greater sense of personal responsibility within them. You can accomplish this by teaching children about the bystander effect and its consequences. Then explicitly communicate responsibility with phrases such as, “I am counting on you”; “I’ll be very proud of

you if you provide help”; or “Remember, helping is the right thing to do.” Modeling the behavior yourself by displaying kindness and help; and providing children with environmental cues – such as posting “It’s my job to help” slogans in schools and other public places – reinforces the idea of taking responsibility.

Whenever we take action (rather than wait for someone else to do it) when observing someone being stigmatized, one by one, we are combating both the bystander effect and the diffusion of responsibility, with responsible behavior.

NIH TAKES UP THE STIGMA CHALLENGE

Perhaps most telling about the important impact stigma has is that this subject has been focused upon by the US National Institutes of Health (NIH). In 2001, the Fogarty International Center of the NIH convened a conference entitled “Stigma and Global Health: Developing a Research Agenda.” The February 11, 2006 edition of *The Lancet* (often described as one of the most prestigious peer-reviewed general medical journals in the world) published an article summarizing this conference.

Article authors Keusch, Wilentz, and Kleinman talked not only about the indi-

vidual costs of stigma, but also how society pays. They state: "Indeed, stigma dies hard and society pays for the extent to which it continues to condemn and ignore the plight of stigma victims. It pays in the loss of productive citizens and the denial of fundamental human rights to them, and others associated with them; in the costs of untreated or poorly treated disease that progresses to disability and death because the victim (of stigma) was afraid or delayed in coming forward; and in the cost of the epidemic spread of infectious disease – as is happening in the case of AIDS in China, India, and Russia."

The article also points out that increased awareness of the impact of stigma is leading to a re-look at health stigmas and the pressing need for more research.

The authors referenced several papers presented at the "Stigma and Global Health" conference. Reading through even a few of these quickly leads one to the conclusion that health related stigmas bring pain and other consequences equal to, or even far greater than the disease processes or injuries (by birth, war, or accident) themselves. Stigma is a plague that affects everyone, either directly or indirectly.

Family members and friends do not escape stigma's impact. When out in public with someone who has a stigmatizing health condition that is visible, they too often cannot avoid stranger danger. For example, family members are often asked by a waiter what another member of their family would like to order simply because a wheelchair is in the mix.

It may come as a surprise to readers that, both subtly and openly, some doctors stigmatize their colleagues. This is often exhibited by assumptions that physicians who specialize in certain areas of medicine do so because they couldn't "cut it" in more prestigious specialties, or that they selected their specialty because they didn't graduate near the top of their medical class.

It is hard not to hope the law can offer some protection in all of this. Unfortunately, unlike many things that laws can protect us from, laws prevent little when addressing health related stigmas. Scott Burris's paper, "Stigma and the Law" (presented at the NIH conference) points out that, "Law is most commonly seen as a tool for blunting the effects of stigma by protecting health information and prohibiting discrimination based on a health condition." Laws can prohibit behavior, but not the attitudes and the beliefs that motivate the behavior. Also, for the law to be helpful in any circumstance, there must be a legal system in place that effectively enforces them. And it is not just in developing countries that this may be lacking. For instance around the topic of disability, "...research has shown that most disability discrimination complaints are never investigated by government enforcement agencies." Using the law means having the financial ability to do so, and dollars can often be very scarce when living with illness and disability.

What are the lessons learned from this conference? According to Keusch, et al: "Given the universal nature of stigma, its strong irrational and emotional roots, and the deeply felt responses it engenders in both discriminators and their targets, how is it possible to overcome the problem? ...No single approach, based on appeals to social justice, human rights, medical science, or to law and education, will suffice...Instead it is more likely that a combination of social, political, and economic will, imbued perhaps by

the actions of charismatic movers and shakers, is necessary for society to reach the tipping point –when the pendulum swings away from stigma to de-stigmatization." In a future where ordinary citizens are expected to experience space travel, and phones will be charged through the air without having to plug them in, does it seem too much to expect an environment where people live stigma free?

JOINING THE CONVERSATION

Mahatma Gandhi once said: "If we could change ourselves, the tendencies in the world would also change. As a man changes his own nature, so does the attitude of the world change towards him. We need not wait to see what others do." We who are stigmatized, need not wait to see what others do. We can take a stand like so many others before us have done for other just causes. The question is how?

In her book "Turning to One Another: Simple Conversations to Restore Hope to the Future," Margaret J. Wheatly, PhD, an organizational behavioral consultant, states: "There is no more powerful way to initiate significant social change than to start a conversation." The capacity to participate in creating social change is different for each of us...some can march, some write letters to the editor, some give speeches, but what Dr. Wheatly has articulated is something every single one of us can do – Join. The Conversation.

We'll make it easy for you. Share your experiences of health stigmas at stigma@simonfoundation.org. There is much that needs to be told in order that everyone understands the impact of stigmatization... so tell us about the humorous experiences you've had with your fellow man; or how you answer the penetrating questions from strangers; or what you've done to increase your resilience in order to lessen the impact of stigma on your life; or whose tires – wheelchair, bicycle, or car – you've let the air out of in frustrated retaliation over a case of human stupidity!

Don't forget to add a list of those you consider great role models and anything else you'd like to share – we want to hear what's important to you... and with your help, we promise to start a conversation, in fact myriads of conversations, like no other! •

ABOUT THE AUTHORS:

Cheryle B. Gartley is Founder and President of The Simon Foundation for Continence; co-author and editor of the first book for the layperson on incontinence, "Managing Incontinence: A Guide to Living with Loss of Bladder Control," published in English, Spanish, and Japanese. She has published widely, including articles in journals such as *The Lancet*, *Urologic Nursing*, *Exceptional Parent*, and *Social Work Today*. She is the co-founder of the International Continence Society's Continence Promotion Committee; Simon Canada (now the Canadian Continence Foundation); and the American Restroom Association. She also sits on several governing and advisory boards. Mary Radtke Klein has been a long-term care consultant and trainer with nearly 30 years of experience in advocacy, consumer education, assisted living development and staff training. She worked closely with State regulators and providers to identify best practice procedures that work in the real world and to promote improved quality of life for residents in a variety of long term care settings. She is a popular presenter at workshops and conferences, and continues to write and serve on industry advisory groups and the boards of not-for-profit organizations.