

# STIGMA AND HEALTH CONDITIONS

PART  
II  
OF A  
SERIES

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.)*

## AN OPPORTUNITY DRESSED IN OVERALLS

The June 1, 2015 issue of *TIME* magazine's article "Bounce Back" focuses on the importance of resilience and offers scientific research that "resilience is essentially a set of skills - as opposed to a disposition or personality type..." It seems that today "thanks to modern imaging, scientists can peer inside the brain in real time to see how, and to what extent, stressful situations change its structure and functions of the brain. They are also learning that training for resilience changes the brain to, well, make it more resilient."

As Ben Franklin once said, "Opportunity is missed by most people because it is dressed in overalls and looks like work." The "opportunity" to learn about, and then practice the ways scientists are discovering to become more resilient, is no exception.

Stress is a major reason that an abundance of resilience is needed in most our lives, and it (stress) can come in many forms. "Some research shows that even feelings of social pain - like rejection and loneliness - zoom along the same neural pathways (in the brain) as fear," the *TIME* article points out. "This notion that I'm going to be rejected or fail or won't be accepted by the group activates the same circuits as if I saw a wolf (referring to the fear early man would have felt)," states Steven Southwick (Yale School of Medicine) a psychiatrist who, along with Dennis Charney (Ichan School of Medicine) authored the 2012 book *Resilience: The Science of Mastering Life's Greatest Challenges*.

Southwick and Charney suggest, as does the *TIME* article that features their work, behaviors that you can teach your children and learn yourself in order to increase resilience. Among them: face the things that scare you (researchers have found this relaxed the fear circuitry in the brain); develop a core set of beliefs that nothing can shake (an example for stigma might be: "Judging a person does not

define who they are. It defines who you are."); develop social support; try to find meaning whenever stress happens; and get regular exercise. Each of these suggestions can help to increase your resilience. In fact, "scientists have learned that working the body's muscles makes people's minds more resilient as well. That's because exercise also spurs the development of new neurons, which are quite literally damaged by stress," Southwick says. Over time, regular exercises can tamp down a person's stress response.

Both authors agree that there is no one path to becoming more resilient and that no one size fits all. However they found from their interviews (with former Vietnam POWs, Special Forces instructors, and resilient civilians from many walks of life) a number of recur-

rent themes that were used as coping strategies for dealing with stress, in addition to the ones stated above. In their book, they refer to these and the following coping mechanisms as "resilience factors": maintain an optimistic, but realistic outlook; imitate sturdy role models; turn to religious or spiritual practice; find a way to accept what cannot be changed; and accept responsibility for one's own emotional well-being.

**Just as there is not one exact way to change ourselves to better handle being stigmatized, there also isn't just one approach to helping society accept differences.**

## EXTINGUISHING FEAR

However, Southwick and Charney do repeatedly single out fear among all these resilience factors, stating: "Fear, whether we allow it to diminish us or enlist it as an ally, has an enormous impact on how we conduct our lives. To become more resilient, sooner or later we will need to face our fears." Here is an interesting thing about fear - it

seems that science can now prove that there is an enormous advantage to getting right back up on the horse before the memory of falling from it (whatever that might mean in your own life) becomes fixed in your long term memory. The authors state: "Research shows that new memories remain unstable or malleable for a short period of time immediately after the event. During this unstable period, memories are being encoded and consolidated into long-term storage through a mechanism that involves the synthesis of proteins. In rats, this malleable period of memory consolidation may last no



longer than an hour or two. In humans the period appears to be longer. If we intervene during this window of time when the new memory is 'unstable,' it may be possible to alter consolidation of the memory."

Until recently it was believed that if you missed this window of opportunity to face the fear, the memory was consolidated into long term storage (in the brain) and became permanent. Recently, neuroscience has found that when a memory is retrieved, once again for a brief period of time, it becomes unstable, allowing for updating and transforming. The goal of course is overcoming a learned fear, a process that scientists call extinction.

Extinction of a fear can be accomplished by various therapeutic techniques and in the not too distant future, perhaps by pharmacologic interventions. What might this research mean for people living with the impact of stigma surrounding health conditions and disability? For one, it may help us to overcome the impulse to retreat into our homes and encourage us instead to face the fear of stepping into the public, where the stares and penetrating questions from strangers lurk. Unpleasant and often traumatic (read depressing, embarrassing, surprising) experiences can lead to the reclusive choice – a choice that, in light of this new information, can now be reconsid-

ered. With improved resilience and the ability to harness fear; even fears that linger into adulthood from childhood traumas in hospitals and doctors' offices, we can make new choices that come from personal strength. Research into handling fear offers all of us hope no matter what our age or the origins or types of fears we harbor.

### INCREASING CULTURAL COMPETENCE

The authors of this article do not mean to imply in any way that everyone with a health condition that can be stigmatized is impacted in life-changing ways. There certainly are many individuals who cope well, may have chosen to be open about their condition, and have become comfortable educating the public when necessary. But sometimes even being comfortable in your own skin just isn't enough as exhibited by the following story.

I ran into an example of this when shopping for carpeting recently. The woman who waited on me offered to carry carpet samples to my car; however, I noted that she became unusually anxious to get the job done when it started to rain and hustled me out of the store. I couldn't help wondering if she thought we'd melt! During my next visit I happened to compliment her new hair color. After glancing furtively around she

said in a hushed tone that she always tells the truth, that it was a wig I was commenting upon, and that she has alopecia. That was the reason she was afraid of the rain, her wigs didn't hold up well in rain. When she was 17 (back in the big hair days) she thought life was over. Today she leads self-help groups for kids with the condition.

What an ideal candidate to be interviewed for our work on stigma, and she readily agreed. However, the next time I returned to the shop with my calendar in hand to schedule the interview, she informed me that her boss had told her she couldn't be interviewed - he didn't want that kind of attention to his store, worried what his customer might think. He cautioned her that he could lose business. Desperately needing the job, she was now fearful of risking the interview.

This is why no matter how well each of us grows to handle the stigma that comes our way, we also need to develop increased cultural competence in the broader society. It cannot simply be a matter of addressing the response to one condition at a time (cancer, incontinence, Parkinson's, AIDS, artificial limbs). Society needs to face its instinctive behavior and replace its fears with information and respect if we are to lessen the stigma that surrounds so many health conditions.

## EACH ONE TEACH ONE

Just as there is not one exact way to change ourselves to better handle being stigmatized, there also isn't just one approach to helping society accept differences. Growing our empathy muscles may offer a good place to begin – such an interesting concept. A young friend and mother said on her Facebook page that she is often asked how bringing so many different foster children (of different races and disabilities) into their home affects her natural and adopted children. Recently she wrote the following : “You guys... I could just cry. (The happy kind of tears.) Juliet (age 5) just made a get well card for the baby (their current foster child who was in the hospital). It says ‘I hope you are hopping home for Easter soon. You are very joyful to the whole family. I hope you are getting well soon.’ People ask how our kids are affected by fostering. This is how they are affected. They have the opportunity to love more. They’ve developed the important ability to see and appreciate color in other people. They’ve grown their empathy muscle. They’ve practiced welcoming children of different abilities and special needs. They’ve learned how to gracefully let go. Yes... fostering has absolutely had an effect on my children.” What stands out to me among these heartening words regarding accepting differences is “...grown their empathy muscle,” certainly a path forward and a challenge to teach the world in this day and age when the news is all about mean girls and bullying.

Satisfying the natural curiosity everyone has might also help to increase cultural competence in promoting understanding and acceptance, rather than stereotyping based on differences. You may be familiar with the popular phrase, “each one teach one.” According to one source, this saying originated in the United States during slavery, when African Americans were denied education, including learning to read. Many, if not most slaves were kept in a state of ignorance about anything beyond their immediate circumstances, which were under control of their owners. When a slave learned to read, it became his duty to teach someone else, spawning the phrase, “Each one teach one.”

Imagine if, instead of reacting to stigmatizing behavior with fear or resentment, there existed a growing legion of resilient folks who didn't mind in the least answering questions or reacting with information about their health-related differences. Think of the wave of education that would seep into interactions across this country! If stereotyping is the root of stigmatization, then it follows that overpowering stereotyping with confidence and knowledge (about yourself or your child) would dissolve stigma. Ben Franklin said: “Tell me and I forget, teach me and I remember, involve me and I learn.”

While you may not currently be able to stretch your imagination to picture yourself capable of such a response to being on the receiving end of stigma, a line from the movie *The Imitation Game* exploring the life of Alan Turing (a British war hero that broke the Nazi's code) may help: “It is people who no one imagines anything of who do things that no one can imagine.” Make a list of information and responses to have at your fingertips. My son has cerebral palsy. He has trouble controlling his muscles, and he is great at math...he understands every word you say...he writes software. Give people good direction: Can you hold the door for me? Thanks. Confront their fear and or curiosity with information and move on. I was burned in a house fire, but it doesn't hurt. Can I help you find the book you are looking for?

## THE LAST WORD IN DIFFERENCE

Returning to Dr. Rader's statement that, “The last word in difference should be - what difference can I make?,” let's look at how we can all make a difference. Some readers may already have the ability to turn a stigmatizing experience into a “teachable moment” and, if so, hopefully do so at every turn of event. Not everyone can or wants to contribute to social change in this manner. However, please consider teaching us!

## JOIN US IN OUR EFFORT TO FACE AND REPLACE STIGMA

Make a difference by adding your story to the mosaic being created of America's story of stigma. We'd love to hear from you about all or any of the following: your suggestions regarding how stigma can be lessened; what one aspect of stigmatization would you most like to see eradicated; techniques you use in your own life for coping with strangers who stare; answers and techniques you use for coping with strangers who ask inappropriate personal questions; how you have defeated fear; accomplishments no one would guess you've made despite a health challenge; and anything else you'd like to share. Please email your input to: [stigma@simonfoundation.org](mailto:stigma@simonfoundation.org) (If you wish to remain anonymous we will respect your wishes, just so indicate.) We'll keep you on our email list and update you periodically regarding “Health Stigmas: Face Them, Replace Them”, The Simon Foundation's group of endeavors dedicated to diminishing stigma related to health conditions and disability.

Another small step you can take to improve the broader cultural competence is to dash off a quick tweet, text, email...whenever you notice someone in the media who has depicted a competent, interesting person with a health-related condition that is too often stereotyped in the normal course of events. Comment on that good portrayal. There are many examples— television shows about detectives who are deaf, or forensic technicians and intelligence officers who use wheelchairs. Or the opposite, when someone is stereotyped, whether a character on a television show or a real individual in a news story, do the same. Stand up. Say something. Together we can make a difference. •

*(Editor's Note: Part 3 of “Stigma & Health Conditions” will appear in EP magazine's February 2016 issue.)*

### 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.