Stigma Reduction in Philadelphia

Timothy Clement 24 April 2014

And yet, we whisper about mental health issues and avoid asking too many questions. The brain's a body part, too. We just know less about it. There should be no shame in discussing or seeking help for treatable illnesses that affect too many people that we love. We've got to get rid of that embarrassment. We've got to get rid of that ***stigma****. —Barack Obama 6/3/2013*

What is mental health stigma? It is obviously an important topic in mental health if the President of the United States saw fit to mention it in his opening remarks at the National Conference on Mental Health. But if you ask ten people, even ten mental health professionals, you will get ten different responses. The Scattergood Foundation knows the answer to the question and knows that reducing stigma is of paramount importance to improving outcomes for people with diagnosable mental health conditions. That is why we have a Fellow on Stigma Reduction.

Is stigma shame or embarrassment, as the President implied in the above quote? Shame and embarrassment are certainly part of the stigma equation, but stigma is not equivalent to shame or embarrassment, nor does it

comprise those two things. Shame and embarrassment are effects of stigma, not stigma itself.

So what is stigma then? The research community defines stigma as stereotypes, prejudice and discrimination (Corrigan & Watson, 2001). Shame, embarrassment and even fear can and often do result from stigma, but they are some of its outcomes, not its components. While this may seem captious, it is actually critically important that stigma not be conflated with its effects. Without proper problem definition, an adequate solution is unlikely. Take the following analogy:

A car accident is a phenomenon that involves at least one car colliding with another object. The object could be a car, a guardrail, a tree or even the road itself if the car happens to overturn. Death and injury can result from a car accident, especially when the accident is serious. But what if someone chose to actually define a car accident as death and injury? That is a different definition than what is listed above and can reasonably be dismissed as incorrect, but it is the working definition for this particular person.

Now, let's say that this same person wants to reduce car accidents, so he focuses on improving seatbelts and airbags, which certainly do reduce death and injury. Improving seatbelts and airbags is very worthy, and should be pursued regardless, but how many car accidents will be averted with this approach? The answer,

of course, is that he will never prevent a single car accident by improving seatbelts and airbags. He will reduce death and injury to be sure, but many accidents will still result in death and injury even with optimal seatbelt and airbag technology. While this may be a sound approach for saving some lives, it is a fundamentally ineffective way to reduce car accidents. In fact, it does not work at all for that purpose.

By defining stigma as shame or embarrassment, as the President and many others seem to do, there is very little chance in reducing what actually comprises stigma—stereotypes, prejudice and discrimination. Focusing efforts on easing embarrassment and diminishing shame is noble and important, but it does not have any effect on the public stigma that is woven into the fabric of our culture.

Stigma reduction is so important because stereotype endorsement and prejudicial attitudes towards those with mental illness are very high in the United States. The General Social Survey—a nationally representative survey conducted every two years—found that 62 percent of Americans would not want to work with someone diagnosed with schizophrenia. Fifty-three percent of Americans would not want a family member to marry someone with depression (Pescosolido, Martin, Long, Medina, Phelan, & Link, 2001).What is most distressing about these statistics, and many others like them, is that they have not improved in recent decades despite

concerted attempts to reduce stigma. Stigma is stubbornly persistent and it is more than just a matter of social justice or morality. Stigma is one of the driving forces behind a major public health catastrophe: untreated mental illness.

In the United States, 26 percent of adults have a diagnosable mental health condition. However, only 30 to 40 percent of them seek treatment (Corrigan, 2004). Stigma has been identified by numerous studies as one of the leading obstacles to help-seeking behavior, along with poor mental health literacy (Henderson, Evans-Lacko, & Thornicroft). In an article from last May in the American Journal of Public Health, the authors stated:

Descriptive studies and epidemiological surveys suggest potent factors that increase the likelihood of treatment avoidance and discontinuation of service use include (1) lack of knowledge about the features and treatability of mental illnesses, (2) ignorance about how to access assessment and treatment, (3) prejudice against people who have mental illness, and (4) expectations of discrimination against people who have a diagnosis of mental illness.

Another discouraging reality is that even when people do seek treatment, stigma can often be a factor that leads to poor treatment adherence. That is, people who perceive higher levels of stigma in society are less likely to stick with treatment (Parcesepe & Cabassa, 2012).

Interestingly, studies have also found that people who harbor prejudicial attitudes are less likely to seek or comply with treatment if they themselves have a diagnosable condition (Hunt & Eisenberg, 2010). In other words, if I think people with schizophrenia are dangerous and I do not want to be near them, I am less likely to seek care if I have a diagnosable condition than if I wasn't prejudiced.

Up to this point, the information presented falls into the category of bad news. However, at the Scattergood Foundation, we have a project that can be characterized as good news. The Scattergood Fellow on Stigma Reduction works to educate the public and professionals in numerous fields about stigma and the proven methods by which it can be reduced. The Scattergood Fellow also offers consultation and evaluation services to organizations that employ stigma-reduction strategies and to organizations that would like to implement evidence-based methods. And, as part of the Foundation's recognition that stigma reduction and mental health literacy are distinct but intertwined concepts, we have created the Scattergood Mental Health Literacy Principles, in conjunction with consultation from Dr. Larry Davidson from the Program for Recovery and Community Health at the Yale School of Medicine.

Since the project's inception in July 2013, the Scattergood Fellow has conducted 21 stigma workshops that have reached approximately 600 individuals. Among the

organizational backgrounds represented were inpatient and outpatient mental health service providers, mental health advocacy groups, peer-support organizations, health care providers, public health professionals, homeless outreach, policy advocates, attorneys and law students. The content of these workshops is tailored to the organization in question, and it is highly recommended that a facilitator from the organization be involved in the presentation so that conversation and honest reflection about organizational stigma are possible. However, certain information is covered in all workshops regardless of the organization involved: the definition of stigma, differentiation of stigma from its effects, stigma's effect on help-seeking and treatment adherence, health implications of stigma and proven methods to reduce stigma.

In addition to accurately defining stigma, it is critically important to use proven methods to reduce stigma. And it is absolutely necessary to evaluate the outcomes of stigma reduction interventions using valid and reliable instruments. For this reason the Scattergood Foundation offers consultation and evaluation services to organizations that are trying to reduce stigma in the community and to organizations that would like to engage in stigma reduction. As mentioned above, stigma has not diminished in recent years, but this is not because effective stigma-reduction methods fail to exist. There are effective strategies that have been shown to meaningfully

diminish stigma (Corrigan, Morris, Michaels, Rafacz, & Rusch, 2012.) Unfortunately, these methods are underutilized, and instead, unverified or even invalidated strategies are often employed. The Scattergood Fellow consults with organizations to make sure they are using the proven strategies and that they are implementing these strategies properly. Outcomes are then measured with verified instruments and tested for statistical significance. Well-intentioned efforts are a good start, but evidence-based practices and outcome evaluation are imperative for programmatic success that can be replicated.

The Scattergood Foundation also believes that while stigma and poor mental health literacy are barriers to people's seeking effective treatment, mental health providers must ensure that when people do seek help, they receive compassionate, empathetic and respectful treatment so that they continue to seek care. This is why we created the Scattergood Mental Health Literacy Principles. The principles are a set of benchmarks for mental health organizations that emphasize the importance of providers' being knowledgeable and resourceful, recognizing the shared humanity of clients and practitioners and offering responsive and proactive care. The Scattergood Mental Health Literacy Principles will be hosted on the Scattergood website. Here providers read the principles, pledge to uphold them and direct their employees to read and pledge to uphold them as well.

Unfortunately, treatment adherence for mental health care is low, and therefore providers must go the extra mile to create a welcoming environment that encourages clients to seek care in the face of widespread societal prejudice against those who have diagnosed conditions.

The Scattergood Foundation recognizes that stigma is an embedded problem within our society and something that interferes with mental health care. In conjunction with the above solutions we are providing, integrated care is essential to reducing the harm caused by stigma. The remedies we offer will take years if not decades to efface mental health stigma from our culture; that is the unfortunate reality of solving a problem that is extensive and so firmly entrenched within all segments of the population. Integrated care, however, circumvents some of the obstacles to care that stigma presents. Most people with diagnosable conditions do not seek mental health care, but seeking help specifically for a mental health issue is unnecessary if screening and some level of treatment are provided in a general health setting. Treatment adherence may still be an issue, but integrated care offers a workaround to the stigma problem, if not an outright solution. This is why we are staunch advocates of integrated care and will continue to champion the idea that health care should focus on the whole person at all times rather than creating a false dichotomy between mind and body.

Stigma is a tremendous problem that faces our country,

and it's an issue of both social justice and public health. Public prejudice against people with mental health conditions remains stubbornly high despite attempts to mitigate stigma. However, there are methods that are proven to reduce stigma, and these methods work in the real world. The Scattergood Foundation knows about these strategies and is committed to assisting other organizations as they try to learn about and diminish stigma.

To set up free consultation and training about stigma and stigma reduction, contact the Scattergood Fellow on Stigma Reduction at tclement@scattergoodfoundation.org.

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