

THE MENTAL ILLNESS BIAS

Why it hurts, and how we can stop it

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Raise your hand if you know five people in the world.

"Well, if you know five people, your life is touched by mental illness," says Ann Marie White, director of the Office of Mental Health Promotion and assistant professor of psychiatry at the University of Rochester Medical Center.

Not only will one in five adults in the United States experience mental illness in a given year, the National Institutes of Health also reports that "one in 25 will experience a serious mental illness that substantially interferes with or limits one or more major life activities."

"Rarely will you have a conversation with anyone where they don't have mental illness in their family or their workplace or their faith community," says Pamela Harrington, executive director of Bring Change to Mind, a non-profit organization co-founded by actress and activist Glenn Close dedicated to encouraging dialogue about mental health and to raising awareness, understanding and empathy.

Bring Change to Mind "is trying to illuminate to everyone that mental health is something that affects us all," Harrington explains.

According to Patricia Woods, president and CEO of the Mental Health Association of Rochester and Monroe County, "The reality is, people are interacting with people with mental illness all the time and they have no clue."

The roots of stigma

Stigma acts as a mark of disgrace or a perception of a negative attribute. It can come from the community, family members, friends, colleagues, even health care providers. Some people living with mental illness self-stigmatize.

It happens in part because mental illness is often misunderstood.

"You don't see it physically, so you don't understand it," says Patricia Sine,



Patricia Sine and Donna Leigh-Estes of the National Alliance for Mental Illness (NAMI) Rochester. MARTHA CLEMENT ROCHFORD

executive director at the National Alliance for Mental Illness (NAMI) Rochester. "Sometimes people see behavior that they don't understand, and unfortunately, sometimes they pull back."

Stigma is largely based on fear, and "people tend to be afraid of the unknown, and that's unfortunate," says Donna Leigh-Estes, NAMI Rochester's director of Community Education, Outreach and Training. "Usually, you begin to learn about mental illness only when it affects a member of your immediate family."

Some anti-stigma efforts try to humanize people's impressions of mental illness through personal interactions and storytelling.

"As a mental health community, we have encouraged people to be open," Woods says. "Once you know people

who have a mental illness, it changes the whole perception of what a mental illness looks like."

Correcting misconceptions

Because so much is misunderstood about mental illness, awareness needs to start with some basic facts:

■ Mental illness is not a myth

Mental illness is real, diagnosable and treatable. "Some people 'don't believe' in mental illness — and that's potentially lethal," White says. "Sometimes there's a belief that you can get over it yourself, or it's something that is caused by a personal weakness. That runs counter to what we know." What doctors do know is that biological and environmental factors cause mental health conditions, and the problem can be treated.

■ People with mental illness are "regular" people

"It's not always the homeless person, the violent person, the disruptor," Harrington says. More likely, it's "the person sitting next to you for years, and you had no idea they were dealing successfully with a mental illness."

A diagnosis of mental illness can be very frightening, especially for families. [Imagine you are] "a parent dealing with a child who has psychosis. You wonder what their life is going to be," suggests Woods. "Then you hear these great stories of people who become very successful in life, and you wouldn't know they had anything going on if they didn't tell you."

■ We're safe

One of the false beliefs surrounding mental illness is the idea that we're in danger from someone facing a mental health condition. "We know that's a myth," White says. According to the U.S. Department of Health and Human Services, "most people with mental illness are not violent and only 3 to 5 percent of violent acts can be attributed to individuals living with a serious mental illness." People with mental health conditions are 10 times more likely to be victims of violence than people in the general population.

What is the impact of stigma?

For many people, the stigma associated with mental illness can be just as bad — or worse — than the illness itself.

Colleen McCallum is a Rochester-area native and COO of the Laureate Institute for Brain Research, a clinical research organization working to discover the causes of and cures for disorders of mood, anxiety, eating and memory. From McCallum's perspective, "stigma increases isolation in people who are already isolated due to the symptoms of their illness. It creates more shame and embarrassment in some people who are already feeling that way due to how the symptoms impact their life trajectory."

Very often, stigma also prevents people from seeking the help that's available. For example, Harrington shares an alarming statistic: "Three-quarters of men living with a mental health condition will never see a doctor."

Why? One reason may be fear of being feared. "Men are afraid they will be thought of as dangerous or violent," Leigh-Estes says, "when the truth is that people with mental illness are no more violent than the general population."

Many elderly people may not be seeking the medical attention they

need, either, because of the biased idea that "when you're older, everyone's depressed," says White. "If depression is treated like it's just part of becoming older, that leads to people accepting a lower quality of life."

To combat this pattern, "people are working with health and human service workers who work with elders, educating them that depression is treatable," she says, "and really challenging their biases about what it means to be an older adult."

According to Harrington, stigma can also follow a patient into the emergency room. "Once [medical personnel] see that you've got a mental illness, they may not be listening to the fact that you think you're having a heart attack," she says. "It's not a panic attack, and it could be a heart attack. We have too many stories of people who have been dismissed from emergency care situations."

Stigma is a barrier to support

Some people "think that mental illness is something to be feared and not something people need help with," says Sine.

Leigh-Estes explains: "Typically, if someone goes to the hospital, people rally together and bring food to the family, send cards. But when someone is hospitalized because of mental illness, it doesn't happen."

Deep-rooted misunderstanding of mental illness can also be a barrier to compassion. "When you look at cancer or heart disease, depression is typically associated with these diagnoses but it's viewed as a side effect of another illness, which is not as stigmatized," says Harrington.

Similarly, "everyone really understands that you might have signs of depression after a heart attack — you can wrap your head around that. It's the same with cancer," she says. "But if you're living a beautiful life with lovely children and a roof over your head and you have depression, somehow that's where the stigma lies; people think, 'What's wrong with you — you have everything you could possibly want. Snap out of it.'"

She adds: "That's the kind of stigma were trying to crack."

The loneliness problem

Isolation is the worst outcome of stigma. "There are a lot of people who have given up on being part of the world because of the mental illness and because of the experience of not having fit in over the years. Eventually, you stop trying," Woods says. "So the more we can do earlier in the progression of the illness, the better."

According to Leigh-Estes, the isolation that results from stigma can lead to "depression, helplessness and suicide ideation." She adds, "It's a known fact that people with mental illness die younger than the rest of the population." That's due to illnesses such as diabetes and heart conditions, and the effects from eating poorly, a lack of exercise and generally not taking care of themselves.

Sine acknowledges another dimension to the isolation of people with mental illness. "Some people with mental illness isolate themselves because they are afraid — those who have delusions

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and paranoia,” she explains. “So not everyone who is isolated is there because of stigma.”

Researchers at Harvard University assert that our relationships have a powerful, positive impact on our health. “Loneliness kills,” according to Robert Waldinger, director of the study. “It’s as powerful as smoking or alcoholism.”

Stigma and isolation can have terrible consequences. “The most harmful, most devastating,” Harrington says, “is if someone does not reach out for help, they don’t believe anyone is there to support them, and they believe the best way out is to leave, to take their own life. And as we all know, those rates are increasing.”

What can we do?

The mental health community has worked for a long time, trying to fight the stigma associated with mental illness. “A large part of the solution is educating people,” McCallum says. “I think most of the stigma is generated by fear and lack of compassion.”

The advocates fighting stigma are coming at the problem from several directions.

Sine explains that “NAMI is dedicated to educating the public about mental illness — what it is and what it isn’t — and to decreasing the stigma. It’s about understanding mental illnesses that are biologically based, diagnosable, recognizable and treatable.”

Harrington describes Bring Change to Mind’s efforts in high schools and on college campuses. “To put an end to stigma, it comes down to educating everyone that mental health is something we all contend with. As Glenn [Close] always says, ‘it’s part of the human condition.’”

Even the lexicon around mental illness is stigmatizing. At a suicide conference that White attended, organizers sent an email asking presenters to consider some of the language used in discussion. “They asked that we not use phrases such as commit suicide.”

The Bring Change to Mind website recommends replacing the phrase “suffering from mental illness” with something less stigmatizing, such as “living with mental illness” or “affected by



Actor Glenn Close co-founded Bring Change to Mind to encourage dialogue about mental health. BRING CHANGE TO MIND

mental illness.” The site also recommends avoiding damaging terms such as “crazy,” “psycho” and others.

Sine is frustrated with comments such as “he’s bipolar,” implying the diagnosis is the entire person. “Bipolar is a condition,” she says. “Would we say, ‘He is cancer?’ Of course not!”

White adds: “It speaks to how everybody needs to be very intentional in this space. It is both our hope and our challenge.”

But talk about it

Talking about mental illness is surprisingly difficult, considering how

many of us experience it.

“Part of it is the more people you know who have mental illness, the more people who come out and say, ‘I have depression,’ ‘I have anxiety,’ ‘I have obsessive compulsive disorder, the more that [the condition] becomes just another part of a person,” says Woods. “Mental illness doesn’t define a person. It’s just something that’s a part of them.”

Harrington says, “One of our taglines has been, ‘Start the conversation,’ and it’s really important that we reach out to one another. If you see someone who appears to be struggling, ask what’s going on. Try to start the conversation in some way that seems safe and loving,

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because sometimes that’s all it takes to unburden someone from the silence they’ve spent months or years building.”

Everyone has a role. Harrington adds, “Parents need to talk to their kids. Teens need to keep an eye out for their friends. We all just need to do better watching out for one another.”

Talk and connect

The Compeer program leverages the power of friendship to improve the health of its participants. McCallum points out that Rochester is the birthplace of the Compeer program, which pairs a companion with a person who has a mental illness. “Typically,” she says, “they meet one to two times per month for coffee, lunch, etc., and it has been incredibly successful.”

Relationships may be the best medicine. “The reality is, people need people,” Woods says. “We make mental illness just a part of your life, like anything else.”

White says preventing suicide involves bolstering “strong peer relationships, integration with community, and a sense of belonging.”

Stigma erodes these vital connections, so by working against the stigma associated with mental illness “we are increasing the protective factors [of relationships, community and belonging] and decreasing the things that are a threat to long-term health,” White says.

According to Leigh-Estes, “The opposite of stigma is acceptance.” For those people unsure about turning for help, “People always come to us feeling that they are alone. Then, they form life-long alliances. That’s how we help to erase stigma.”

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