

Perspectives on Stigma and Families with Mental Illness

Summarized by Thomas T. Thomas

Our January speaker, Dr. Stephen Hinshaw, is Professor of Psychology at the University of California, Berkeley, and chairs that department. He is also the author of *The Years of Silence Are Past: My Father's Life with Bipolar Disorder* (2002) and *Mark of Shame: Stigma of Mental Illness and an Agenda for Change* (2007). A sought-after speaker, Dr. Hinshaw is able to combine the academic and personal aspects of mental illness.

“The word ‘stigma’ in Greek means a mark or brand to signify difference,” he said. “In Athens, in the agora, you could identify a traitor or an enemy alien by a brand on his shoulder or face.” While our society today doesn’t use physical branding, there are still marks of difference. Some, like skin color, are openly visible while others, like being left handed, having suffered a major depression, or having a relative with schizophrenia can be concealed—and there the brand is psychological.

“Concealed stigma creates a mystery,” Hinshaw said. “You have to watch how you talk for what you might reveal. This creates a layer of anxiety, and you are not sure of belonging in the group.”

He described a test given in the 1930s to measure people’s attitudes toward racial difference on a “social distance scale”: would you be comfortable with a member of the group living in your city? ... on your block? ... attending your child’s school? ... marrying your daughter? In the years between the national census (1955, ’65, etc.), tests of impressions about the behavior of people with mental illness and social distance relative to them have shown that we now understand more about the subject than in the ’50s, because we now teach psychology in high schools, but we have less tolerance in terms of social distance.

“Facts alone don’t lessen distance, but knowing and interacting with someone reduces prejudice and stigma,” Hinshaw said. “Contact is more important than knowledge.”

The origins of stigma include:

1. **Stereotyping**, or cognitively perceived assumptions about others. Making some assumptions about new people is necessary for us to survive, because otherwise we would be overwhelmed. But stereotyping is damaging when it turns to ...



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2. **Prejudice**, or “prejudgment,” of the members of a group, which leads to ...
3. **Discrimination** against those members.

Some discrimination is necessary in society. For example, people with 20/200 eyesight shouldn't be allowed to drive without correction. But some states have laws prohibiting people with a history of mental illness from driving, voting, serving on a jury, having custody of their children, or running for public office. That last item would have prevented an Abraham Lincoln, with his history of depression, or a Winston Churchill, with his alcoholism and probable episodes of mania, from holding office.

The Americans with Disabilities Act passed in 1990 made it illegal to discriminate on the basis of physical or mental disorders, but only 5% of suits under the act are brought on the basis of mental illness. “Why? Because you have to tell the boss!” Hinshaw said. Yet making accommodations for mental illness—such as changes in work schedule, work situation, or duties—are usually less costly than accommodations for physical disabilities.

“What we'd really like to do,” he said, “is measure unconscious or implicit bias.” This can be done with a simple implicit association test (IAT), usually performed online, showing pictures of, for example, a young person and an old person along with the words “good” and “bad,” and asking the test subject to make rapid associations. These tests show stigma associated with mental illness is not only conscious but also implicit. Hinshaw noted this is also shown in the way young children quickly pick up derogatory terms like “spaz” and “psycho.”

Stigma affects people in various ways:

- **“Self-stigma”** arises when group members internalize the stigma and start to feel negatively about themselves. Groups such as racial minorities can fight this through peer identification and group solidarity. But with mental illness, no one wants to identify with the group. Internalization is high and can keep patients from getting treatment or influence the decision to stop taking medication.
- **“Courtesy stigma”** affects anyone associated with the stigmatized group, such as friends, family members, psychiatrists, and therapists—who are often considered the lowest ranks of the medical profession. (Therapists themselves may reflect stigma because they are trained in an us-vs.-them, healthy-vs.-sick dichotomy and have lower expectations about their patients.)

Hinshaw traced the history of treating people with mental illness and how treatment has contributed to stigma. The first mental hospitals in the U.S. were built in the 1860s, usually out in the country, away from population centers. These places gained a reputation as “snake pits”; so in 1963, to bring care back into the community, John F. Kennedy signed the Community Mental Health Act. It was intended to construct local centers that would care for people with mental illness and retardation. Unfortunately, the funding did not exist to actually build such centers. In 1955, the population in state hospitals was 600,000, while today it is 35,000—a 95% reduction—and those people are on the streets.

Three groups rate the highest on the social distance scale: the homeless, drug abusers, and those with mental illness. As NAMI members know, these conditions are somewhat linked.

People with mental illness are now even more isolated. “If you develop schizophrenia,” Hinshaw said, “move to Africa or India. Those cultures allow and even expect people to go a bit off track in their teens and still have a role in society. In the U.S., if you go off the growth curve, you have no place to come back.”

The U.S. has also made it too hard to get treatment. In the 1950s, all it took to commit a person to the state hospital was a paragraph from a doctor, and too often the term was essentially for life. Now, a person must be shown to be a “danger to self or others,” or—in California—gravely disabled, and the term is for 72 hours or, with extensions that require a judge’s order or the patient’s consent, up to 30 days. “I think there’s room for a middle ground,” Hinshaw said. Ironically, however, prosecutors often favor the insanity plea for some crimes, because that usually allows the person to be locked up for a longer period and get needed treatment.

The stereotype these days—especially after the current wave of mass shootings—is that mentally ill people are violent. “But actually that’s a small group,” he said. “Certain people with delusions and psychosis, antisocial personality disorder, or a sociopathic personality may be violent. In reality, most people with mental illness are the victims of violence.”

When asked about options for recovery, Hinshaw said: “That’s the big word today. The stereotype is the patient will always be sick. But we’ve learned it’s not enough to house and care for patients. We want them to get better, but having the right community services is key.” He also noted the term is loaded, because some mental health professionals are aware that not everyone can recover.

Families can help fight stigma by realizing they have two burdens: the *objective* burden of taking the time and enduring the cost of caring for an ill loved one, and the *subjective* burden of isolation through keeping the illness a secret. When families can self-identify as having a stake in mental illness and demand treatment, they become empowered. They can then participate in the peer identity and group solidarity that lets other groups subject to discrimination fight their stigma.

Hinshaw described a new program he’s involved with called LETS, which stands for “Let’s Erase The Stigma” (www.lets.org). It’s aimed at middle and high schools and is currently in practice at five schools on the San Francisco Peninsula. The program provides a guidebook for teachers to set up LETS Clubs at the school, similar to the Chess Club or the French Club. The program has no defined curriculum, because the point is not to teach about mental illness.¹ Instead, students are encouraged to share and discuss their thoughts and engage in activities designed to reduce stigma and bullying. “Kids are sensitive to differences and injustice,” he said, “and have a hunger to fight stigma. This program can lead to a new generation of adults without stigma.” After just a semester in a LETS Club, students don’t necessarily show an increase in knowledge about mental illness, but their social distancing response has vastly changed.

“Stigma is the most important issue,” he said.

¹ However, if the teacher spots a child with problems, there’s a protocol for referring him or her to the school counselor.