



Overcoming the Stigma of Mental Illness to Ensure Compassionate Care for Patients and Families

“When we use the word stigma, we’re usually referring to the burden of coping with psychiatric symptoms, doing the hard work of recovery, and being met by prejudice all around. As healthcare providers, we often carry the same baggage as everyone else. But on top of that, we have an amplified sense of responsibility to the patient.”

- Joseph Gold, MD, Chief Medical Officer, McLean Hospital



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INTRODUCTION

An estimated 43.7 million men and women in the United States live with a mental illness—[nearly one in five adults](#). The stigma associated with mental illness follows patients wherever they find themselves: at home, in the workplace and even in healthcare settings, where study after study has shown that people suffering from serious mental illnesses receive worse medical care.

At a recent Health Policy Breakfast in Boston, the Schwartz Center for Compassionate Healthcare convened a panel of experts to examine the impact of stigma and discrimination on patients and the patient-caregiver relationship. Each panel member had spent a substantial portion of his or her professional life in the world of behavioral health, and three out of the four said they also had a personal connection to mental illness—either as a patient or family member.

Among the major themes that emerged from the discussion were:

- The power of language and how the words we use to describe people with mental illness shape our attitudes
- The false separation between physical and behavioral healthcare and the often inferior care that people with mental illness receive for medical problems
- The importance of healthcare providers partnering with family members and those who patients view as family
- The need for professional competence and training in evidence-based therapies as well as compassionate care
- The harmful effects of stigma in the workplace
- Education as one of the most important ways to fight stigmatization

THE POWER OF LANGUAGE

Lisa Halpern, director of recovery services at Vinfen, a Massachusetts nonprofit that provides community-based support services to people with psychiatric conditions, began the session with a critique of the word “stigma,” which she said implies that there is something wrong with the person who is experiencing it. Halpern said she prefers to use the word “prejudice” or “discrimination,” which redirects attention to the person engaged in the discriminatory behavior. “Language has the power to shape attitudes,” said Halpern, who herself suffers from schizophrenia. “The words we choose and use are important.”

OPENING REMARKS:

Julie Rosen

Executive Director, The Schwartz Center for Compassionate Healthcare

Timothy McCrystal

Co-Chair, Health Care Practice Group, Ropes & Gray

MODERATOR:

Carey Goldberg

Co-Host, CommonHealth Blog, WBUR Radio

PANELISTS:

Joseph Gold, MD

Chief Medical Officer, McLean Hospital

Lisa Halpern

Director of Recovery Services, Vinfen

Steve Rosenfeld

President, National Alliance on Mental Illness (NAMI) - Massachusetts

Marylou Sudders

Massachusetts Secretary of Health and Human Services

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Massachusetts Secretary of Health and Human Services Marylou Sudders said that she dislikes hearing people refer to “the mentally ill,” and considers it dehumanizing. “We would never talk about ‘the cancers,’” Sudders commented. “These are people who have a variety of symptoms and diagnoses and need to be treated with the dignity we all want to be treated with when we have an illness.”

Sudders said that her own mother suffered from severe depression and alcoholism, which resulted in her early death at age 40. For years, Sudders spoke of mental illness in the third person, she said, refusing to acknowledge that it runs in three generations of her family. She said that many people talk about mental illness in the third person, when in fact mental illness is common and affects many families.

THE IMPACT OF STIGMA IN HEALTHCARE SETTINGS

Halpern said that one of the most pernicious ways people suffering from mental illness are discriminated against in healthcare settings is through what she called diagnostic overshadowing—when patients’ symptoms are over-attributed to a particular condition, in this case their mental illness. The result is that their other health problems can go undiagnosed and untreated.

Halpern told the story of showing up at the emergency department of an academic teaching hospital in Boston with a painful medical condition. “Upon revealing that I was on an antipsychotic medication and had psychosis, I was triaged to the psychiatric ER. All of my belongings were taken away, I was tested for illegal narcotics, I was put in a glass-walled room and given a sitter until the doctor came,” she recalled. “Having a psychiatric condition negated the possibility of having a medical condition.”

Halpern said that her experience in the emergency department explains why people with serious mental illnesses die on average 25 years earlier than the general population; [their increased morbidity and mortality are largely attributable to treatable medical conditions and inadequate access to medical care.](#)

INTEGRATING BEHAVIORAL AND MEDICAL HEALTHCARE

“Nothing about having a developmental or psychiatric disorder makes you immune to what other people get,” stated McLean Hospital Chief Medical Officer Joseph Gold, MD, adding that the best care integrates behavioral and medical healthcare. Sudders said that Massachusetts is moving toward greater integration of the two through its Medicaid program and that the patient-centered medical home model also ensures better coordination.

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- Massachusetts Secretary of Health and Human Services Marylou Sudders





An audience member remarked that some people have suggested that behavioral and medical health records be separated as a way to manage stigma, an idea that all of the panelists rejected. “If I’m going to prescribe a medication, I need to know what else you’re on,” said Gold. Halpern added that separating the two types of records only serves to perpetuate the stigmatization of mental illness.

COMPASSION AND COMPETENCE

Steve Rosenfeld, president of the Massachusetts chapter of the National Alliance on Mental Illness (NAMI), described the most compassionate clinicians as possessing the following qualities:

- They have professional humility and lead with how little they know—because so little is still known about mental illness.
- They see the family as crucial to the patient’s recovery. “An engaged, educated, guided family is as important to recovery as medication,” he said.
- They’re anxious to listen to the family’s point-of-view and understand that “family” extends beyond the patient’s biological family to include the “spiritual” family.
- They have high expectations for their patients.

Halpern said it was her family’s high expectations that helped her climb out of the abyss of mental illness that consumed her in her 20s. She was a graduate student at Harvard’s Kennedy School when she began suffering from delusions and a dramatic loss of cognitive function—forgetting how to read and write and being unable to do the simplest tasks like using a coin-operated washing machine.

According to Halpern, her mother read children’s books to her, encouraged her to color and do puzzles, and always believed she would return to grad school. “Anyone can recover, but it takes high expectations. It’s about holding the bar high for someone and expecting them to get over it, even if they have to take baby steps along the way,” she said.

Rosenfeld, whose son has bipolar disorder, underscored the importance of professional competence as well as compassion, quoting nationally renowned psychologist Kay Redfield Jamison, who has been very public about her own struggle with bipolar disorder. “I am often asked what the most important factor in treating bipolar disorder is,” Jamison wrote. “My answer is competence. Empathy is important, but competence is essential.”



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- Joseph Gold, MD, Chief Medical Officer, McLean Hospital



Gold said that many clinicians want to help patients suffering from mental illness, but lack the tools and knowledge to do so. For example, few pediatricians are trained to deal with the teenage girl who is cutting herself or the boy who reveals that he crashed the family car because he was drunk, explained Gold.

Through the [Massachusetts Child Psychiatry Access Project \(MCPAP\)](#), for which Gold serves as medical co-director, pediatricians and family practice physicians receive consultative services over the telephone from experienced child psychiatrists. “MCPAP has changed the landscape for pediatricians by training them to do mental health screenings at every well child visit, diagnose mental health conditions earlier, and make timely referrals,” explained Gold. “The bottom line is that pediatricians have more confidence in their competence and treat people with more respect and warmth rather than dread and fear.”

A dearth of experienced mental health clinicians is a problem that goes far beyond pediatrics, added Gold. While there are now evidence-based, non-pharmacological treatments for a wide range of mental disorders—from autism spectrum disorder to anxiety and depression to obsessive compulsive disorder—too few clinicians are trained in these treatment methods. Gold said there are some encouraging signs that access may be less of an issue in the future, including health plan reimbursement for telepsychiatry, in which psychiatric assessments and care are delivered through telecommunications technologies like videoconferencing.

WORKPLACE STIGMA

Stigma in the workplace is another huge problem for people with mental illness, the panelists agreed. Sudders described an experience her niece, who suffers from schizoaffective disorder, had at her job. After struggling with the effects of her illness, she had finally reached a place of equilibrium and was working at a job she liked where she had a good relationship with a particular co-worker. One day the colleague asked her what sort of medication she took every day, and she felt safe enough to share her diagnosis with her. “It was as if she had the plague,” recounted Sudders. “The person literally recoiled. She stepped back and never made eye contact with or talked to my niece again.”

As it turned out, Sudders’ niece was in the minority in sharing her diagnosis with her co-worker. Rosenfeld said that a NAMI survey in Massachusetts found that while the majority of people said they would advise someone with mental illness to tell their friends and family, [only 27 percent said they would advise them to tell a co-worker.](#)

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- Lisa Halpern, Director of Recovery Services, Vinfen





The overall employment picture can also be bleak for people with mental illness. It's estimated that the unemployment rate among people with mental disorders is [three to five times higher than it is for people without mental illness](#). Meanwhile, studies show that most adults with mental illness want to work and approximately [six out of 10 can succeed with appropriate support](#).

Among the employed, mental illness is the number one cause of workplace disability, Rosenfeld pointed out. "People who are ill stay on the job because they worry about disclosing their illness. They try to tough it out — a phenomenon called 'presenteeism.' We need to make sure that workplaces are safe, welcoming, and as therapeutic as a workplace can be," urged Rosenfeld.

NAMI Massachusetts' campaign, [CEOs Against Stigma](#), focuses on bringing the reality of mental illness out of the shadows. "I have been amazed at how interested CEOs are," said Rosenfeld, adding that employee assistance programs should not simply be reactive, but also need to reach out proactively to employees. "It's a culture shift," remarked Halpern. "It's a stronger company when people are comfortable being open about having sought help."

EDUCATION AS STIGMA BUSTER

Despite Sudders' niece's experience, research shows that direct contact with people in recovery from mental illness is the biggest stigma buster, according to Rosenfeld. Halpern too believes education is a "game changer." That's why she is involved in [NAMI's "In Our Own Voice" program](#), through which she has an opportunity to educate a wide range of people about schizophrenia from her first-person perspective.

"You don't know who our future doctors and nurses will be," she said, adding that she has also written about her experience in the emergency department for a medical textbook. "A warning to hospitals: I write articles," she quipped.

All schools that train healthcare professionals need to do a better job of exposing their students to people with mental illnesses and emphasizing the importance of "partnering compassionately" with *all* patients and families, according to Sudders.

Rosenfeld said he believes society is at a "tipping point" when it comes to the stigma of mental illness. He recounted the story of a young man with schizophrenia who sought his advice about applying to law school. Rosenfeld assumed the applicant would ask him if it was OK *not* to reveal his diagnosis. "As it turned out, he wanted to disclose his illness to schools because he considered his recovery process part of what distinguished him," Rosenfeld said. "I don't know how the law schools reacted, but things are changing and he is helping to change them."



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- Steve Rosenfeld, President, National Alliance on Mental Illness (NAMI)-Massachusetts



An audience member commented that conversations about mental illness are now occurring in places they never have before—in churches, synagogues and at forums in the suburban town where he lives. “There was a time when the word cancer wasn’t used,” he said. “Now, the minute you talk about mental illness in a public forum, you are surrounded by people who have firsthand knowledge of it.”

Schwartz Center Medical Director Beth Lown, MD, concluded the discussion by offering her perspective as a caregiver. While healthcare professionals are not immune to the fear and anxiety that surround mental illness, “we can’t indulge this,” she said. Instead, caregivers are obligated to understand the complexities of their patients, their network of relationships, and their anguish in order to truly care for them. “If you’re equipped to walk alongside the person who is suffering, you’ll experience an incredible sense of purpose and meaning,” she said. “This is why people go into healthcare. Compassion is the answer.”



From left, NAMI President Steve Rosenfeld; Vinfen Director of Recovery Services Lisa Halpern; Carey Goldberg of WBUR; Schwartz Center Executive Director Julie Rosen; Mass. Secretary of Health and Human Services Marylou Sudders; Event Committee member Ellen Epstein Cohen of Adler, Cohen, Harvey, Wakeman and Guekguezian; Tim McCrystal of Ropes & Gray; and McLean Hospital Chief Medical Officer Joe Gold.

“It’s important to remember to always move toward people who are suffering, rather than away from them, and remember that people with mental illness can and do recover.”

- Carey Goldberg, Co-Host, CommonHealth blog, WBUR

The Schwartz Center for Compassionate Healthcare is a national nonprofit leading the movement to bring compassion to every patient-caregiver interaction. Research shows that when caregivers are compassionate, patients do better and caregivers rediscover their passion for healing. The Center believes that a strong patient-caregiver relationship characterized by effective communication, emotional support, mutual trust and respect, and the involvement of patients and families in healthcare decisions is fundamental to high-quality healthcare. Visit us at theschwartzcenter.org and follow us on **Twitter and **Facebook**.**