Policy Debate

DECLARING WAR ON STIGMA

by
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NAMI
The Nation's Voice on Mental Illness

It is impossible to talk about mental health policy without also addressing stigma. Stigma literally means "a mark of infamy or disgrace," but that definition is inappropriate to apply to people who struggle with chronic medical conditions, i.e., brain disorders, through no fault of their own.

> **...stigma "caused by a history of misunderstanding, fear, and embarrassment..."**

Instead, stigma represents ignorance, prejudice, or unfair discrimination on the part of others. It is part of American society and culture. We all know people who refer to some people as "mental" or "psycho."

So what's the big deal? We have freedom of speech in this country. Is concern about stigma simply "political correctness" run amok? Do people with mental illnesses and their families simply need to develop a thick skin or a sense of humor?

In the recently released movie, *Agent Cody Banks*, for example, Frankie Munoz of "Malcolm in the Middle" fame, plays a high school teenager recruited by the Central Intelligence Agency (CIA) to take on missions that adult secret agents can't. He loves to skateboard, hates math, and freezes up around girls. In two scenes, he gets so nervous around girls that they taunt: "What are you, in special ed. classes?" One parent who took a young son with Attention Deficit Hyperactivity Disorder (ADHD) to the movie was outraged: "At a time when we are working so hard to remove the stigma of disabilities and special needs, those lines were a slap in the face and a giant step backwards. I can't imagine what went through my son's head as he sat there listening to the actors make fun of him and his disability."

At one level, the movie lines were realistic: that's how teenagers may talk. On another, however, they represent the power of a movie—or other media—to reinforce and perpetuate stigma. And that's only a mild example. What choices do Federal and State governments—or individual citizens—have in fighting stigma? Does it matter?

Does it make a difference if the son was under age eight and the movie was rated PG?

At what point does freedom of speech end and harmful discrimination begin? What kinds of costs result from stigma? Who should pay to remedy them? From a perspective of cultural change, these are important, emerging issues.

The Surgeon General's Report

In the landmark Report on Mental Health in 1999, the U.S. Surgeon General identified stigma as "the most formidable obstacle to future progress in the arena of mental illness and mental health."

Stigma causes people to "avoid living, or working with, renting to, or employing people with mental disorders, especially severe disorders such as schizophrenia…It reduces patients' access to resources and opportunities (e.g., housing, jobs) and leads to low self-esteem, isolation, and hopelessness. It deters the public from seeking and wanting to pay for care. In its most overt and egregious form, stigma results in outright discrimination and abuse. More tragically, it deprives people of their dignity and interferes with their full participation in society."

Stigma has real consequences—which include barriers to treatment and recovery, and even contribution to suicides.

The Surgeon General reported that two-thirds of all people with diagnosable mental disorders never seek treatment. Stigma is one reason. Especially among young people or residents of small communities, there is fear about what others may think. Many people are afraid of being taunted, shunned or discounted.

Stigma also results in decisions by society or its institutions not to invest in adequate levels of treatment or support, either through private insurance premiums or taxes. The result is that people with severe illnesses are neglected, abused, or abandoned.

Individual recovery also may hinge on a person "coming to terms" with a mental illness, such as bipolar disorder or schizophrenia. In order to manage a chronic illness, a person needs to accept it and to some degree assimilate it into their overall identity. When stigma is attached, it too is absorbed—with destructive, toxic effects, affecting a person's self-esteem and ambitions.

To the degree that recovery also means finding a job and a place to live, stigma creates additional barriers, making recovery all the more difficult. These are not just hypothetical issues. Young adults in their 20s are among those most at risk for the onset of a severe mental illness. One or more factors may trigger it: e.g., the breakup of romantic relationship and/or the sudden loss of a job. As the person becomes ill, they may be hospitalized or roommates may move out, leading to additional financial pressure and even loss of an apartment. Consequences "snowball." Recovery may require not only treatment with medication and therapy, but literally, rebuilding one's life and sense of identity within a community.

Even with protections under the Americans with Disabilities Act (ADA) or other laws, recovery is not easy. At a practical level, it means going to job interviews prepared to explain gaps in your resume or submitting an application for an apartment with previous landlord references and enough money to cover a first month's rent and a security deposit. What a person once took for granted can take years to rebuild. Stigma makes the process harder. People are devalued. Their needs are suppressed or ignored. Besides the individual suffering that results, society loses, in terms of net human creativity and productivity.

"Stigma must be overcome," the U.S. Surgeon General declared. "People should be eager to seek care. They must be more willing to absorb its cost. They should become far more receptive to the messages that…mental health and mental illness are part of the mainstream of health, and they are a concern for all people."

Violence and Stigma

A key reason for the stigma that surrounds mental illness is the public perception that mental illness usually involves violent behavior—and people fear violence. Ironically, however, the reality is very different.

"The likelihood of violence is low," the Surgeon General reported. The greatest risk involves individuals who have both a mental disorder and a substance abuse disorder; people experiencing severe psychosis also may pose risks if they are not taking medication. Even so, the overall risk is no greater than that for the rest of the general population; the contribution of mental illness to the total level of violence in American society is "exceptionally small." In fact, people with mental illness are two to three times more likely to be *victims* of violence.

So why is stigma so pervasive? Because perception trumps reality. People react to stereotypes.

What shapes perceptions? Our cultural environment, which includes news, entertainment, advertising, and other media. Every time a newspaper headline describes a person or proposal as "schizophrenic," meaning (pejoratively) a "split" or "multiple" personality, stigma is perpetuated through misinformation and ignorance. Every time a television show portrays a character with bipolar disorder killing someone in a fit of mania, stigma is generated.

Think about it. When was the last time you saw a movie or television show that portrayed a person with a severe mental illness as a sympathetic character as a hero? Fortunately, there have been a few, but only in recent years. One was *A Caveman's Valentine* (2001) starring Samuel Jackson, in which a homeless, former concert pianist with schizophrenia solves a murder. Another was the Oscar-winning *A Beautiful Mind* (2002), based on the life of John Nash, the Nobel Prize winning mathematician (and NAMI member) who has battled schizophrenia.

NAMI awarded each of them an "Outstanding Media Award" for accuracy, balance and compassion: which represents one strategy in the fight against stigma. When newspapers, movies, or other media get it right, we praise them. Give honor where honor is due. Public praise is important, because in many cases, reporters or movie producers have found that they face personal career risks by going against the grain of stereotypes.

Another positive strategy is NAMI's *In Our Own Voice: Living With Mental Illnesses* program, which currently is available in approximately 25 states. Individuals with mental illnesses make presentations to different audiences (including high school students) in order to provide the "human face" of mental illness—to help break down stereotypes and "social distance." See http://www.nami.org/education/ioov.html. To inquire about arranging for a presentation to your debate team, school or other civic organizations, contact sara@nami.org.

NAMI also pursues strategies of protest. See, for example, NAMI's "StigmaBuster" archives at http://www.nami.org/campaign/stigmabust.html#AlertList. Perhaps one of the worst examples of stigma in the news media in recent memory involved the New Jersey daily newspaper, *The Trentonian,* which in 2002 reported a fire at the state psychiatric hospital under the headline "Roasted Nuts." Fortunately, no one was killed or injured in the fire.

NAMI submitted the headline in testimony before President Bush's "New Freedom" Commission on Mental Health to illustrate how people with mental illness can be publicly devalued, and how through failures of internal leadership and institutional irresponsibility, such attitudes become embedded structurally in society. Who should be accountable? The headline writer? The editor? The publisher? No one? Although newspapers and other media enjoy freedom of the press, but with rights come responsibilities. NAMI argued the headline could be considered under the ADA as ***prima facie* evidence of a hostile work environment** for people with mental illnesses or their family members. Statistically that might be as many as 20 percent of Trentonian employees.

In the face of broad protest, *The Trentonian* apologized. To its credit, the paper also has worked over the past year to focus

serious coverage on issues affecting people with mental illnesses.

Increasingly, however, apologies are not enough. Nor is it enough when a company running an offensive TV commercial or newspaper advertisement pulls it in response to public complaints. Public education and stronger measures are needed to discourage stigma *before* it is generated.

President Bush and Recent Initiatives

In establishing the New Freedom Commission on April 29, 2002, President Bush, like the Surgeon General, identified stigma "caused by a history of misunderstanding, fear, and embarrassment" as one of the principal obstacles to improving the mental healthcare system. "Stigma leads to isolation, and discourages people from seeking the treatment they need. Political leaders, health care professionals, and all Americans must understand and send this message: mental disability is not a scandal—it is an illness. And like physical illness, it is treatable, especially when the treatment comes early."

As part of the President's New Freedom initiative, the federal Substance Abuse and Mental Health Services Administration (SAMHSA) has launched a three-year, eight-state pilot program known as the Elimination of Barriers Initiative (EBI) to test model strategies and public education materials to reduce stigma and discrimination. The eight states are California, Florida, Massachusetts, North Carolina, Ohio, Pennsylvania, Texas and Wisconsin. In conjunction with State Departments of Mental Health—which are facing budget crises in treatment and support services—federal dollars will be leveraged to provide television, radio, and print public service announcements Private "partnership" dollars also may play a role. Politically, however, public education programs may be limited in their messages.

A challenge still exists to lower the volume of stigma being generated by private media. The solution does not require external censorship, but institutions should be encouraged to exercise editorial judgment and act in socially responsibly—if not through "moral suasion" by the President, Surgeon General, and other leaders, then by requiring companies that profit from the generation of stigma to help bear the cost of eliminating it.

Over the last year, NAMI has begun exploring new strategies to do exactly that. Most recently, a NAMI advocate filed a formal complaint with New York City's Commission on Human Rights over an especially outrageous skit broadcast on January 9, 2003 by NBC's "Saturday Night Live" (SNL). The skit used mental illness and references to psychiatric medications to lampoon, vilify, and dehumanize North Korea dictator Kim Jong Il. See http://snltranscripts.jt.org/02/02ikim.phtml.

In supporting the complaint, NAMI did not challenge NBC or SNL's freedom of speech, particularly the right to remain free from prior restraint. "Rights, however," declared NAMI Legal Director Ron Honberg, "include responsibilities to the broader community, particularly in the case of corporations created by and operating under the benefits of law. Just as a person cannot shout 'Fire!' falsely in a crowded theater, a broadcast company should be held accountable for public injuries created by or perpetuated by it actions. It also must be accountable for the unfair discrimination that may result against individuals, including current or potential employees." The SNL skit was more than political satire. It represented a reckless disregard of national public health concern and constituted the kind of stigma "in its most overt and egregious form" that the Surgeon General identified as leading to "outright discrimination and abuse."

NAMI asked the Commission to investigate NBC's internal anti-discrimination policies and broadcast "standards and conduct" policy. To remedy the internal and external stigma generated by the broadcast, NAMI asked that NBC be required to conduct antistigma education programs for employees and to produce an antistigma public service announcement to be broadcast during future episodes of SNL and other primetime shows. The case is pending, subject to an offer of mediation made by the Commission to NBC.

Additional mechanisms to fight stigma may include the Federal Communications Commission (FCC), Department of Labor (DOL) and other agencies—as well as private lawsuits in the courts. As a matter of federal policy, however, specific tools and strategies are still emerging. We still have a long way to go.

What's most important is not to underestimate the importance—and power—of an individual, articulate letter or telephone call. Long after the NAMI Policy Debate has ended in Atlanta, we hope that many NFL debaters will subscribe by e-mail to NAMI's free monthly StigmaBuster Alerts and exercise *their own* rights by speaking out. We welcome your ideas and your help.

Other Sources

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