Commentary:
Mental Illness, Society, Stigma, and Research

by James P. McNulty

The *Oxford English Dictionary* defines “stigma” this way:

2. fig. A mark of disgrace or infamy; a sign of severe censure or condemnation, regarded as impressed on a person or thing; a ‘brand’ . . .

b. A distinguishing mark or characteristic (of a bad or objectionable kind); in Path. a sign of some specific disorder, as hysteria.

I have lived with bipolar disorder for more than 35 years—all of my adult life. The first 15 years were relatively conventional, at least on the surface. I graduated from an Ivy League university, started my own business, and began a career in local politics. I was married, the father of two sons. I experienced mood swings during these years, and as I got older the swings worsened. Eventually, I became so ill that I was unable to work, my marriage ended, I lost my business, and I became homeless.

At this point I had my most powerful experience with stigma. I was 38 years old. I had recently been discharged after a psychiatric hospitalization for a suicide attempt, I had no place to live, my savings were exhausted, and my only possession was a 4-year-old car. I contacted the mental health authorities in the State where I then lived and asked for assistance in dealing with my mental illness. I was told that to qualify for assistance I would need to sell my car and spend down the proceeds. I asked how I was supposed to get to work when I recovered enough to find a job. I was told, “Don’t worry about going back to work. People like you don’t go back to work.”

In July 2002 I was offered an unusual opportunity to participate in a National Institute of Mental Health–sponsored workshop on stigma, mental illness, and the media. For the past 15 years I have labored in the front lines of the advocacy movement, fighting for better treatment and better treatments. I have spent countless hours with journalists, writers, television reporters, legislators, and bureaucrats, trying to overcome conceptions about mental illness that are wrong, often dangerously so. I have no doubt that stigma against those living with mental illness exists and that its effects are widespread, pernicious, and deleterious.

Over many years I have seen numerous antistigma efforts, both efforts that are national as well as local, and solely local efforts. In 1997 I began to participate in a national program offered by the National Alliance for the Mentally Ill (NAMI), a program initially known as Living With Schizophrenia and Other Mental Illnesses, and now known as In Our Own Voice: Living With Mental Illness. This was my introduction to formal antistigma activity. A person with mental illness presented, with the assistance of a video, the story of the illness and journey into recovery. It was effective, and the response was electrifying. We made presentations to Rotary Clubs, the Governor of Rhode Island and his cabinet, the chair of the Rhode Island House Finance Committee, teachers, students, hospital employees, and mental health center workers. I felt that this program was an effective answer to the humiliation I had experienced with the public mental health system.

There is a great deal happening in terms of antistigma efforts, far more than most would suspect (see Estroff et al., this issue), considering the apparent lack of impact these programs seem to have had on public awareness of the realities of mental illness. My view prior to the workshop was that “academic research” probably did not have much to offer in terms of stigma prevention but that “market research” in terms of honing the message and finding the right media “outlets” would be useful. Because the University of Pennsylvania’s Annenberg School of Communication was involved in the workshop, I was optimistic that some useful information would come from the meeting.

In the days just prior to the workshop, there was an extremely unfortunate headline in the *Daily Trentonian*:

Send reprint requests to NIMH, Schizophrenia Bulletin, 6001 Executive Blvd., Rm. 8184, MSC 9663, Bethesda, MD 20892–9663.
newspaper, on the occasion of a fire at Trenton Psychiatric Hospital (where Nobel Prize–winning mathematician John Nash was once a patient). In extremely large type, next to a picture of the burning hospital, was the headline “Roasted Nuts.”

This headline came shortly after the culmination of a feast of media attention lavished on the movie A Beautiful Mind, based on the biography of Professor Nash. This was hailed as one of the best movies on mental illness to ever come out of Hollywood, and it won four Oscars, including that for Best Motion Picture. The cognitive dissonance of extremely positive movie reviews and an appalling newspaper headline was disconcerting and disheartening to the advocacy community and professionals alike.

The workshop attendees were an impressive group. Among them were the principal authors of the articles presented in this issue. Other attendees were Otto Wahl, Kathleen Jamison of the Annenberg School of Communication, Susan Rogers of the Substance Abuse and Mental Health Services Administration–funded Resource Center To Address Discrimination and Stigma, and numerous others. The proceedings of the workshop made it evident that our understanding of stigma and how to redress it falls far short of what is needed for broad effectiveness. In particular, I was impressed by what academia has accomplished in research on stigma and mental illness, and I came away convinced that it is vitally important—an extremely urgent matter of public policy—that we focus more on research in this area.

The articles in this issue by Corrigan, Estroff, Link, Stout, and Watson (and assorted coauthors) are critical early steps in identifying the limits of our knowledge about stigma and its effects. They clearly build on the efforts of earlier research, including their own.

Watson et al. (this issue) describe an educational intervention for middle school students and offer some reason for optimism. Estroff et al. (this issue) describe community efforts to reduce the stigma of psychiatric disorders and discuss the constituent elements of these programs, as well as identifying exemplary programs. Corrigan et al. (this issue) describe intentional and unintentional structural discrimination and how these directly affect people with mental illness.

Of particular interest to me, and perhaps to other persons with mental illness, is the table that Corrigan uses to show how the civil rights of individuals with mental illness are restricted by State statute. Incompetence, which one might assume would be an absolute bar to voting or holding office, is far less of a restriction than mental illness. Nineteen States restrict the right to vote for those with mental illness, but only 12 restrict the right to vote of those found incompetent. Mental illness is a bar to holding elective office in 16 States, but those ruled incompetent are so restricted in only 6.

Link et al. (this issue) discuss issues in measuring stigma, identify measures in use and those that look promising, and point to gaps in knowledge. Stout et al. (this issue) review research on the media and mental illness. They point out that our assumption that the largely negative and inaccurate portrayals of mental illness in the media actually influence individual perceptions is based on circumstantial evidence. Before the media can be used as a vehicle to reduce stigma, it is essential that various mechanisms and interrelationships involved in the complex interplay between various media genres and the public be better understood.

The Surgeon General's Report on Mental Health (U.S. Department of Health and Human Services 1999) and the President's New Freedom Commission on Mental Health (2003) both feature reduction of stigma prominently as a desirable public health policy. In fact, the President himself identified stigma as "an obstacle . . . preventing Americans with mental illnesses from getting the excellent care they deserve." Most would intuitively agree with this premise, and research does indeed indicate that stigma is implicated in many issues that result in suboptimal treatments for mental illness, from employment and housing, to treatment adherence and emergency medical interventions, to law.

Research on stigma, its causes and effects, and how to reduce it is vital to public policy, but ultimately this research must be judged on its ability to improve the lives of persons with mental illness. Antistigma efforts occur on a daily basis in almost every part of our country, but clearly these efforts have not yet resulted in the desired changes in public attitudes and perceptions. As a rule, people with mental illness do not receive good treatment at the hands of nonpsychiatric medical professionals in emergency rooms or in general medical treatment. Mental health, as a field, often still stigmatizes consumers and families. Mental illness is routinely depicted inaccurately and in a stigmatizing way in the press, television programs, and movies. Insurance coverage for mental illness is inequitable, even in those States that have parity laws. It is difficult to overstate the drawbacks of going public or "coming out" as a person with mental illness. Well-designed, appropriate research is needed to inform and direct the limited resources available in mental health generally into antistigma efforts that will have the greatest impact on changing public attitudes.

References


Estroff, S.E.; Penn, D.L.; and Toporek, J.R. From stigma to discrimination: An analysis of community efforts to...


