Op-Ed

The Long and Winding Road of Mental Illness Stigma

JONATHAN COHN

SOMETIMES RESEARCH GETS YOUR ATTENTION BECAUSE IT teaches you about a new problem. And sometimes research gets your attention because it teaches you about an old problem that hasn't gone away.

A report (<http://www.cdc.gov/nchs/data/databriefs/db203.htm>) that the US Centers for Disease Control and Prevention (CDC) issued in May 2015 fits the latter category.¹ The subject was mental health, specifically, how the prevalence of “serious psychological distress” varies by income and insurance coverage. According to the report, such distress affects about 1.2% of people in households with incomes of at least 4 times the poverty line. For people in households with annual incomes below the poverty line, the incidence of such distress is 8.7%, or more than 7 times higher. (The federal poverty line this year is an annual household income of \$11,770 for an individual and \$20,090 for a family of 3.) The CDC report also found that people with serious distress were less likely to have health insurance than those without serious distress.

The CDC report's data set ends in 2013, too early to pick up most of the effects of the Affordable Care Act, which has made insurance coverage available to millions and bolstered the requirement that private insurance cover mental health care. There's good reason to think these reforms will reduce disparities in mental health care, just as previous initiatives (<http://www.nber.org/oregon/>) appear to have done.² Once people have insurance, they are more likely to seek treatment for psychiatric problems and to be financially secure, both of which tend to improve mental health.

But barriers to mental health care remain, even with the Affordable Care Act in place. Many people with insurance still find that their benefits don't include adequate coverage of psychiatric treatment because, for example, they can't find professionals who will take their insurance or because they can't cover the copayments and deductibles they owe

every time they fill a prescription, see a therapist, or get in-patient treatment. The relatively affluent can pay for what they need out of their own pockets. The rest cannot.

This problem is endemic to US health care. Limited networks or providers, scrutiny of referrals and treatment requests, high out-of-pocket costs—these tools, misapplied, can cause hardship for a diabetic as easily as they can for somebody struggling with bipolar disorder. But the toll they can take on people who suffer from psychiatric illness seems particularly harsh. In a recent survey (<http://www.nami.org/About-NAMI/Publications-Reports/Public-Policy-Reports/A-Long-Road-Ahead/2015-A-Long-Road-Ahead.pdf>) conducted by the National Alliance on Mental Illness, reports of difficulty finding psychiatrists, therapists, and substance counselors were 3 times more common than reports of difficulty finding physical health specialists.³ Research has shown that mental illness and substance abuse are closely linked, even at the genetic level, and can reinforce or lead to one another.⁴ Moreover, 50% of all people diagnosed with severe mental health disorders also suffer from substance abuse problems.

Here the story about mental health care becomes a story about society's attitude toward mental illness in general—specifically, the stigma that reformers have been trying to stamp out at least as far back as the 19th century when Dorothea Dix exposed widespread mistreatment of the mentally ill. Efforts by her and other reformers made a difference, persuading many Americans that people dealing with psychiatric problems deserved the same compassion, sympathy, and assistance as people dealing with any other disease. Sadly, when it comes to mental health disorders, a great deal of stigma endures. One place where this stigma left a lasting mark was on the design of health insurance policies, which in the United States began to take shape in the early and mid-20th century.

Originally, insurance companies didn't want to cover mental health at all, in part because it seemed so susceptible to opportunities for abuse, given the relatively subjective nature of many diagnoses. Eventually, insurers started adding mental health coverage, partly at the behest of employers who realized that better mental health care for employees might boost productivity and retention. Insurers were still wary, however, and they typically put limits on what they would spend, even though they had no similar limits for the treatment of other kinds of illnesses.

The insurers' anxiety was legitimate, as for-profit companies frequently exploited their generous coverage of mental illness. By the 1980s and 1990s, spending on mental health had exploded, and insurers responded by introducing managed care (<http://www.nejm.org/doi/full/10.1056/NEJM199601113340221>). They subjected referrals and treatment decisions to the insurers' approval while setting low reimbursements that few providers were willing to take and applying these methods far more aggressively than they did for the treatment of other illnesses. Costs came down, but—sometimes—in ways that even some insurance industry officials worried might compromise access to and quality of care.⁵

Ever since that time, advocates for mental health care have been calling for true “parity” between mental and physical health benefits. They have won some important victories, thanks in part to efforts by 2 former senators, Pete Domenici, a Republican from New Mexico, and the late Paul Wellstone, a Democrat from Minnesota. These victories were proof that the cause of bolstering mental health care had broad ideological appeal. All it took was awareness of the problem, something that both men had because both had close relatives who suffered from psychiatric problems.

But many of the state and federal parity bills that became law during the 1990s and 2000s had loopholes, like allowing insurers to limit the number of days of in-patient psychiatric care, something insurers could not do for other conditions. Even though subsequent legislation, including the Affordable Care Act, has attempted to close many of those loopholes, treatment remains far from equal. In the aforementioned report from the National Alliance on Mental Illness, 29% of survey respondents said that insurers had refused to approve recommended mental health treatment—more than twice the percentage of respondents for whom the same insurers had refused to approve recommended physical health treatments.

Today, advocates seek stricter enforcement of existing regulations (like those promising “adequate” networks of providers), as well as new regulations or laws that would protect lower-income people from higher out-of-pocket spending. Both efforts face stiff political opposition, not least because they would impose new costs up front, even if they yielded bigger returns later. But advocates also have science on their side. Sophisticated brain scans and other diagnostic techniques have made clear that serious mental illness is a physiological and pathological phenomenon.

Research has tied its development to genetics as well as to environment while establishing ties to proclivity for substance abuse. A patient suffering from depression, bipolar disorder, or schizophrenia has a disease that is every bit as real as cancer, diabetes, or a heart attack.

Reformers, doctors, and mental health professionals have been trying to make that case for a long time. Alas, they have much more work to do.

References

1. Weissman J, Pratt LA, Miller EA, Parker JD. Serious psychological distress among adults: United States, 2009–2013. NCHS data brief 203. Hyattsville, MD: National Center for Health Statistics; 2015.
2. Baicker K, Taubman SL, Allen HL, et al. The Oregon experiment—Medicaid’s effects on clinical outcomes. *N Engl J Med*. 2013;366:1713–1722.
3. National Alliance on Mental Illness. A long road ahead: achieving true parity in mental health and substance use care. Arlington, VA: National Alliance on Mental Illness; 2015.
4. National Institute on Drug Abuse. Drugs, brains, and behavior: the science of addiction. Bethesda, MD: National Institute on Drug Abuse; 2007, 2014. <http://www.drugabuse.gov/publications/drugs-brains-behavior-science-addiction/preface>. Accessed June 1, 2015.
5. See Iglehart J. Managed care and mental health. *N Engl J Med*. 1996(334):131–136; and Freudenheim M. The squeeze on psychiatric chains. *New York Times*. October 26, 1991.

Address correspondence to: Jonathan Cohn, The Huffington Post, 77 Broadway, New York, NY 10003 (email: CitizenCohn@gmail.com).