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*Op-Ed*

## A Tale of Two Diseases: Mental Illness and HIV/AIDS

LAWRENCE O. GOSTIN

**I**N 2011, I WAS SPEAKING AT AN INTERNATIONAL AIDS conference where the first two speakers were from UNAIDS and Harvard. UNAIDS announced a new campaign: Getting to Zero: Zero New HIV Infections, Zero AIDS-Related Deaths, and Zero Discrimination. (A year later, Secretary of State Hillary Clinton called for an AIDS-Free Generation.) The Harvard researcher reported the results of a groundbreaking study demonstrating that individuals living with HIV/AIDS who were receiving effective treatment posed virtually no risk of transmitting the infection. A newly diagnosed 20-year-old today can expect to live another 50 years on treatment.

I was astounded by the scientific progress that could allow UNAIDS to envisage an end to AIDS. Knowing how intractable the AIDS pandemic once seemed, I asked how this could happen. And why, I inquired, had the same not occurred with mental illness, the field in which I began my career?

I was the legal director of the National Association of Mental Health in the United Kingdom in the 1980s.<sup>1</sup> At that time, major mental illnesses were treated primarily with powerful antipsychotics, such as haloperidol, that carried the debilitating side effects of tardive dyskinesia—involuntary movements of the tongue, lips, face, trunk, and extremities. When I first saw mental patients shuffling, tongues protruding, and physically shaking, I thought they exhibited symptoms of mental illness, but soon realized it was the treatment itself. Newer second-generation medicines cause metabolic syndrome, obesity, and cardiovascular disease. In other words, the therapeutic science of mental health has not come nearly far enough.

Another indicator of the lamentable failure to meet the needs of persons with mental disabilities is the large number of vulnerable individuals warehoused in large, inhumane institutions, often for decades.

While the deinstitutionalization movement (a strained alliance between civil libertarians and fiscal conservatives) tore down sterile hospitals, today many individuals with mental illness are in prisons or nursing homes or are homeless.

More than a quarter of the homeless in America have a severe mental illness. The US Bureau of Justice estimated that in 2005, 705,600 mentally ill adults were incarcerated in state prisons, 78,800 in federal prisons, and 479,900 in local jails<sup>2</sup> and that they were up to 4 times more likely to be on probation or parole. A disproportionate number of prisoners in isolation suffer from mental illness. If the imprisonment of the mentally ill is one of society's deepest pathologies, then the isolation of a vividly psychotic prisoner is cruel beyond imagination.

Inadequacies of science and failures in policy might be overlooked if mental illness were not so prevalent, with its enormous individual, family, community, and economic costs. Persons with mental disabilities account for more than 7% of all disability-adjusted life years (DALY) globally, with the highest proportion among young people aged 10 to 29.<sup>3</sup> This figure excludes suicide, which results in a death every 40 seconds, every hour, every day.<sup>4</sup> Escalating humanitarian disasters—from the earthquakes in Nepal and Haiti to the Syrian refugee crisis—have created untold mental stresses and depression. The World Economic Forum concluded that mental illnesses have the greatest impact on economic costs of any class of noncommunicable diseases, typically affecting the young and extending across the prime productive years—\$2.5 trillion/year in 2010, on track to reach \$6.0 trillion/year in 2030. In the United States, roughly half of the 1.3 million children receiving Supplemental Security Income (SSI) disability benefits qualified primarily because of a mental disorder.<sup>5</sup>

Mental illness accounts for about 13% of health care costs globally but only 3% of health care funding; many countries have no dedicated mental health budget. Despite their higher death rate, mental illnesses receive a fraction of the charitable donations made to combat cancer or HIV/AIDS. Moreover, the trained mental health workforce is pitifully small, given the need. Mental health professionals account for just 1% of the global health workforce. On average, low-income countries have fewer than 1 mental health worker for every 100,000 population. In fact, treatment has become a privilege of the wealthy, who have 50 times greater access to mental health care in higher-income countries.

HIV/AIDS and mental illness have common features. Both are complex, intractable diseases affecting marginalized communities throughout the life span, and both are shrouded in stigma and discrimination. Certainly the human suffering and social alienation caused by HIV/AIDS remain an urgent global threat. Yet AIDS has changed the world. How did all these technological advances come about, and why did a particular disease, AIDS, forge a pathway toward unprecedented scientific discoveries while mental illness remains largely ignored?

When states and philanthropists pour resources and political commitment into scientific research, it can make a huge difference. We know there is an entirely incommensurate response to mental illness when compared with HIV/AIDS. But why was there concerted action for one disease but not the other? The answer is social mobilization. Civil society organizations in the United States (ACT UP, Lambda Legal Defense), South Africa (Treatment Action Campaign, AIDS Legal Project), Uganda (AIDS Support Organization), and elsewhere forced governments to pay attention to the suffering and deaths. Advocates acted with passion, even aggression (“AIDS = Death”), they painted a human face on the disease (Ryan White), and they were supremely knowledgeable and articulate. Their voice was omnipresent in the halls of power: scientific expert panels, parliamentary hearings, and the media.

To be sure, there is an active mental health movement: the National Alliance on Mental Illness (NAMI) is the nation’s largest grassroots mental health organization. Persons with mental disabilities, however, tend to be more vulnerable and less educated, largely because their illnesses struck when they were so young and were so debilitating. Even though mental illness is one of the most ancient and enduring sociomedical conditions, the mental disabilities movement is still, even in 2015, in desperate need of more support. Witness the Movement for Global Mental Health’s Call for Action, pleading for resources commensurate with the global burdens of these devastating mental health problems. Nonetheless, global health organizations, such as the World Health Organization, devote only a tiny fraction of their budgets to mental illness; Ebola and global health security now dominate the world stage. Mental illness remains virtually invisible in modern global health discourse. Major international organizations and partnerships have sprung up around infectious diseases—UNAIDS, Global Fund, Stop Tuberculosis, Malaria No More, UNITAID, Global Polio Eradication, and the

GAVI Alliance. Yet I challenge you to name a single equivalent international agency or public/private partnership devoted to ending mental illness.

So much has happened in the years since AIDS first emerged. Whereas once an HIV diagnosis was a death sentence, today individuals can live long and full lives. But look back to the plight of persons with mental disabilities in the 1980s. Today, persons with serious mental illnesses, particularly those in lower socioeconomic classes, are no better off than they would have been if they had been born decades ago. Their treatment, if indeed they have access to any, will be nearly as debilitating as the disease. They are likely to be in a prison or nursing home or, just as problematic, living on the streets. Sadly, in 2015, the mentally ill remain the most stigmatized and isolated among us.

How is that for scientific and social progress?

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