



End the Denial: Achieving Mental Health Justice in Illinois

**Testimony of
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Good morning Chairwoman Conroy, Spokesperson Demmer, and Members of the Committee on Mental Health. Thank you for the opportunity to testify before you today.

We are living in denial in Illinois. With escalating overdose and suicide rates -- at a time when outcomes for nearly every other illness are improving -- we can no longer pretend that we are not in the middle of a public health crisis. In just the past four years in Illinois, overdose deaths from opioids have increased 76% (from 1,072 in 2013 to 1,887 in 2016).¹ These increases have occurred across counties in Illinois:

- Cook (94%), DeKalb (200%), DuPage (82%), Franklin (167%), Kane (80%), Kendall (144%), Madison (42%), McHenry (140%), Sangamon (57%), Tazewell (200%), Will (102%), and Winnebago (36%).

Make no mistake, tornadoes of addiction are ripping through our families and communities, leaving families destroyed and desperate for help. Yet only 1 in 10 people living with addiction gets treatment. We would simply not stand for only 1 in 10 Americans with diabetes getting treatment.

Suicide has also been tearing apart more and more families. Deaths in Illinois have increased more than 35% over the last 15 years (from 1,003 in 2000 to 1,363 in 2015).² Suicide is the 11th

¹ Illinois Department of Public Health, *Drug Overdose Deaths*, May 8, 2017, <http://www.dph.illinois.gov/sites/default/files/publications/Drug-Overdose-Deaths-May2017.pdf>

² Center for Disease Control and Prevention, National Suicide Statistics, <https://www.cdc.gov/violenceprevention/suicide/statistics/>

leading cause of death in Illinois and the 3rd leading cause for young adults aged 18-24.³

Too many individuals and their families are in crisis because of mental health conditions (which include substance use disorders). And, when our families are in crisis, so are our communities. Yet shame, stigma, and our separate and unequal system of care, which carves out mental health and refuses to reimburse for it in the same way as other types of care, stand in the way of treatment. Families from around Illinois increasingly recognize the extent of the problem, with nearly 9 in 10 people recently polled saying we must change the way we handle mental health conditions in Illinois.⁴

The mission of The Kennedy Forum Illinois is to end stigma and discrimination against those with mental health conditions. On a nonpartisan basis, we bring together persons with lived experiences, families, civic and business leaders, and providers to end our separate and unequal mental health system. We work to change the conversation around these issues *and* to create the system we need to provide care to the millions of Illinois residents living with mental health conditions. Families are leading the way kicking down the doors of shame and stigma of mental health conditions, and now we must work with them to kick down the doors of denial to advance justice and heal our communities.

The Kennedy Forum Illinois is uniquely positioned to shape debate and align stakeholders. By providing bold leadership, strategic partner alignment and concerted action, we are building and leveraging momentum and support to alter the way that mental health and addiction challenges are considered and addressed. Please use us as a resource to bring you the information, data, and expertise you need to end our separate and unequal system and create the system our state needs. Together, we have the opportunity to make Illinois *the national leader* in the treating and advancing justice for people living with mental health conditions.

I will center my testimony today around six key components of creating justice for people living with mental health disorders, their families, and our communities: ending stigma, increasing early detection/intervention, improving care quality, integrating mental health care into the primary care system, leveraging technology, and ensuring equal access to care.

Changing the Conversation to End Stigma and Discrimination

To create a system where illnesses of the brain are treated like illnesses of the body, we must end stigma and discrimination against individuals who have suffered from these illnesses. The consequences of stigma and discrimination are all around us. Despite the prevalence of mental

³ Illinois Department of Public Health, *Leading Causes of Death By Age Group, Illinois Residents, 2015*, <http://www.dph.illinois.gov/sites/default/files/publications/leading-causes-death-2015-3817.pdf>

⁴ The Kennedy Forum Illinois, *Illinois Statewide Survey: Key Findings*, April 2015, http://thekennedyforumillinois.org/wp-content/uploads/2015/04/KFI-Infographics_Sheet_r3.pdf

health disorders (an estimated 1.3 million Illinoisans experienced serious psychological distress each year⁵), individuals with mental health conditions frequently do not seek help and, even if they do, often do not receive the same levels of treatment or support they would if they had any other health condition. Families, too, often feel isolated and struggle to help loved ones without needed support.

Our separate and unequal system of care is pervasive, with the tentacles of stigma and discrimination reaching into all aspects of mental health. One simple way to identify deep-seated discrimination is, when talking about mental health, substitute another type of medical condition for a mental health disorder. For example, every time you hear the word “mental health” or “addiction” replace it with the word “diabetes,” “heart disease,” or “cancer.” No one would ever be told, “You’re entitled to 10 treatments and then your cancer coverage stops.” Or, “Your high blood pressure relapsed, therefore your treatment is a failure and won’t be reimbursed anymore.”

The effects of stigma and discrimination are also evident in policy making, which often treats illnesses of the brain as individual moral failings and as separate from other health conditions. Working towards justice for people living with mental health conditions should be a societal moral imperative. ***The Kennedy Forum Illinois urges you to continue to listen to people living with mental health conditions and to use your position to educate others about the urgent need to change how we treat illnesses of the brain.***

Increasing Early Detection and Intervention of Mental Health Problems

Each year, more than 17 million children and youth in the U.S. -- nearly 1 in 5 -- will have a mental health condition. Yet, a systemic lack of identification and intervention means few receive the help that they need. For instance, trauma and toxic stress can derail a child’s healthy development, damaging a child’s underlying brain architecture and resulting in increased incidence of physical and behavioral health issues ranging from diabetes and heart disease to depression and substance use disorder. The early intervention of caring adults who build supportive, responsive relationships with children can prevent – and even reverse – the damaging effects of trauma and toxic stress.

Our education system is in an optimal position to address youth challenges and promote wellness and resilience. However, this doesn’t mean that schools should be solely responsible. By working together, schools and communities can integrate services, support students, and create environments both inside and outside of the classroom that support positive mental health and effectively address any mental health challenges.

⁵ Hanke Heun-Johnson, Michael Menchine, Dana Goldman, and Seth Seabury, University of Southern California Leonard D. Schaeffer Center for Health Policy & Economics, “The Cost of Mental Illness: Illinois Facts and Figures,” <http://healthpolicy.usc.edu/documents/IL%20chartbook%202017.pdf>.

Unlike other health conditions that emerge as people near retirement, mental health disorders emerge primarily during youth -- 50% of mental health conditions present before the age of 14 and 75% before the age of 24. Because these illnesses frequently hit as people enter their prime working years, the estimated economic burden of serious mental illness in Illinois exceeds \$5 billion a year.⁶

For too long, our young people who develop mental health disorders have been hidden in plain sight, misunderstood and mistreated, with few places to turn. ***The Kennedy Forum Illinois urges you work to create a robust system of early detection and intervention within our schools and communities that identifies and treats mental health problems before they become more difficult and costly to treat.***

Improving the Quality of Care

Poor mental health denies people the chance to lead healthy and productive lives. Inadequately treated mental health disorders are also an enormous driver of cost in our healthcare system as patients with a mental health diagnosis have nearly triple the average physical health care costs of enrollees without a mental health diagnosis. And, nationwide, 27% of all disability is due to inadequately treated mental health disorders.

Outcomes of mental health care provided in real world settings lag far behind the outcomes achieved in large trials of evidence-based treatments. All primary care and behavioral health providers treating mental health disorders should implement a system of measurement-based care whereby validated symptom rating scales are completed by patients and reviewed by clinicians during encounters. Measurement-based care will help providers determine whether the treatment is working and facilitate treatment adjustments, consultations, or referrals for higher intensity services when patients are not improving as expected.

Measurement-based care optimizes the accuracy and efficiency of symptom assessment, improves the detection of non-response (prompting revisions to the treatment plan), and maximizes the likelihood that patients receive the most effective treatment. ***The Kennedy Forum Illinois urges you to advance the quality of mental health care by promoting the adoption of evidence-based measures by all behavioral health and primary care providers.***

Increasing Evidence-Based Integration of Mental Health Care Into the Primary Care System

Increasing access to quality mental health care not only means increasing the number of mental health specialists, but also integrating mental health care into our primary care system, where most people receive care. Only 40% of people living with mental health disorders receive

⁶ "The Cost of Mental Illness: Illinois Facts and Figures."

treatment in any given year, meaning that 60% get no treatment at all. Only 12% receive care from a psychiatrist, and only 22% receive care from any mental health specialists. Because our specialty mental health care system does not have the capacity to serve all those who need treatment, we must have a comprehensive strategy that fosters integration of behavioral health into our primary care system. We must work to end the silos where behavioral health care is treated completely separately from other type of health care.

Many behavioral health conditions can be treated effectively in primary care offices using a Collaborative Care Model, which is a specific type of integrated care that treats common mental health disorders in primary care settings. Studies have shown that for every dollar spent on collaborative care, there is a \$6.50 decrease in health care costs.⁷ In addition to the primary care provider and the patient, this models usually adds a care manager (typically embedded) and a psychiatric consultant (typically remote). More than 80 randomized controlled trials have shown Collaborative Care to be more effective than usual care for common mental health conditions such as depression or anxiety. The Centers for Medicare and Medicaid Services (CMS) recently changed the Medicare Physician Fee Schedule to improve reimbursement for Collaborative Care. ***The Kennedy Forum Illinois urges you to advance Collaborative Care in Illinois by adopting these new codes in the state's Medicaid program to encourage the adoption of Collaborative Care.***

Leveraging Technology to Improve MH/SUD Care

Individuals living with mental health disorders often experience comorbid illnesses, disability, and even death. Yet treatment for these individuals is limited by the need for more effective treatment regimens, and the lack of technology-based solutions that deliver new treatments and improve access to care. A basic example is that fewer than 30 percent of behavioral health providers have implemented electronic health records. Given that more than 68% of adults a mental health disorder had at least one medical condition, not having interoperable electronic health records significantly inhibits behavioral healthcare integration and fails to capture the needs of patients across clinical settings.

A wide variety of hardware, services, and software have shown a demonstrated benefit in improving behavioral health, yet they are not in widespread use. While we need to address a range of social, ethical and legal issues associated with the deployment of these emerging technology and software solutions, promoting technology-based approaches to behavioral health will have numerous direct and indirect benefits for Illinois residents. Moving into a digital future will involve a combination of payer support, clinician education, professional society engagement, patient acceptance, and more effective public/private oversight.

⁷ Center for Health Care Strategies and Mathematica Policy Research, *The Collaborative Care Model: An Approach for Integrating Physical and Mental Health Care in Medicaid Health Homes*, May 2013, http://www.chcs.org/media/HH_IRC_Collaborative_Care_Model_052113_2.pdf.

The Kennedy Forum Illinois urges you to treat this lack of adoption with the same degree of alarm that would be given if there was slow adoption of assessment, treatment, or infrastructure technologies in other health care settings.

Ensuring Equal Access to Care

People seeking payment for mental health services from private insurers are denied payment at a rate double of those seeking other medical services.⁸ While there are strong federal and state laws on the books that require health insurance plans that cover mental health conditions to do so on an equal basis with other medical care, these laws are yet to be effectively enforced. Without enforcement, insurance plans continue to place restrictions on mental health benefits that simply do not exist for other types of care. Examples of common restrictions that are often illegal include⁹:

- Limits on how many days a person can stay in a facility for mental health treatment when such limits are not in place for other types of medical conditions.
- Limits on how many times a person can see a behavioral health provider when such limits do not exist for other types of providers.
- Higher costs for prescription medication to treat mental health conditions than for prescriptions for other treatments.
- Prior authorization requirements for mental health conditions that are more stringent than for other types of conditions.
- Medical necessity reviews to continue treatment that are done more frequently for mental health conditions.
- Requirements that a less expensive mental health treatment be tried before the treatment recommended by a doctor that are applied more stringently than for other types of conditions.
- Denial of coverage for mental health treatment outside of a specific region or state when such restrictions do not exist for other types of medical treatment.

Patients and providers report that these barriers continue to be significant barriers to care. For instance, in a recent survey of Illinois providers, more than half said that commercial insurers “sometimes,” “often,” or “always” refused to cover behavioral health treatment services requested because they were not medically necessary. Nearly 60% of providers were told by commercial insurers with the same frequency that patients must “fail-first” with less expensive treatment before the insurer would pay for the requested level of care.

⁸ NAMI, *A Long Road Ahead: Achieving True Parity in Mental Health and Substance Use Care*, 2015, <https://www.nami.org/About-NAMI/Publications-Reports/Public-Policy-Reports/A-Long-Road-Ahead/2015-ALongRoadAhead.pdf>.

⁹ ParityTrack, Common Violations, <https://paritytrack.org/know-your-rights/common-violations/>

Equal access to mental health treatment requires equal payment for services. We do not force other health care providers to fund care they provide through grant applications. Patients and their families should not be forced to jump through hoops and navigate a bewildering appeals process to have treatment reimbursed as the law requires. **The Kennedy Forum Illinois urges you to mandate insurers report critical information necessary to end payment discrimination and to conduct vigorous oversight of state regulatory agencies to make equal payment a reality.**

Investing in a Healthier, Less Costly Future

We are grateful for all of your commitment to creating the system our state needs to achieve justice on behalf of people living with mental health and addiction. Investing in behavioral health is one of the smartest investments our state can make in improving the health of individuals, their families, and their communities. Unfortunately, Illinois' prolonged budget impasse is having a devastating affect on behavioral health in our state, leaving providers on the brink of collapse and cutting off people living with mental health conditions from treatment. Lawmakers should commit to doing no further harm, which means finally enacting a budget that supports – and pays for on a timely basis – behavioral health services.

Proposed federal changes to Medicaid and the Affordable Care Act would also have devastating effects on behavioral health care. Changes to the Affordable Care Act's required essential health benefits would undermine access to mental health benefits for millions of Americans by allowing plans to simply not cover these benefits at all. Undoing the federal government's commitment to Medicaid expansion and converting Medicaid to a block grant system would drain billions of dollars from Illinois and put mental health treatment at grave risk. State lawmakers are uniquely positioned to make it clear what is at stake for Illinois if these proposed changes were enacted.

With Illinois' significant financial challenges, making the *right* investments is all the more important. Each year, the State of Illinois spends more than \$250 million incarcerating people with serious mental illness in state prisons. Adults with serious mental illness in Illinois are 1.5 times more likely to be hospitalized than the nationwide average. And adults with schizophrenia, bipolar disorder, and major depressive disorder spent nearly 480,000 days hospitalized in 2014, with total hospitalization charges exceeding \$1.1 billion. Illinois is paying on the back end many times over what it "saves" on the front end: Per capita state mental health agency expenditures in Illinois 13th lowest in the U.S. at \$72, compared to the national average of \$127.¹⁰ The high costs, comorbidity, and prevalence of untreated mental health disorders mean that building the mental health system our state needs can be a force multiplier in reducing overall health care costs.

¹⁰ All data above from "The Cost of Mental Illness: Illinois Facts and Figures."

As U.S. Senator John McCain said at a recent Kennedy Forum event in Washington, “This is a cause worth pursuing. This is a cause worth believing in. We have a divided America, but we must unite on this issue.”

The Kennedy Forum Illinois looks forward to working with you in making Illinois a national leader in achieving justice for people living with mental health and addictions by creating a system that meets their needs and enables them to achieve their goals.

RESOURCES FROM THE KENNEDY FORUM

ParityTrack Website: www.paritytrack.org

ParityRegistry Website: www.parityregistry.org

New Technologies for Improving Behavioral Health, https://thekennedyforum-dot-org.s3.amazonaws.com/documents/10/attachments/02_cura06_issue-brief-Technology_digital.pdf?1492531689

Navigating The New Frontier of Mental Health and Addiction: A Guide for the 115th Congress, https://thekennedyforum-dot-org.s3.amazonaws.com/documents/9/attachments/The_New_Frontier_CongressGuide.pdf?1485267841

5 Pillars: The Pathway to Improving the Delivery of Mental Health Services in Education, https://thekennedyforum-dot-org.s3.amazonaws.com/documents/7/attachments/Education_Five_Pillars.pdf?1472449871

Promoting Brain Health and Brain Fitness: A National Call for Action, https://thekennedyforum-dot-org.s3.amazonaws.com/documents/2/attachments/issue-brief-Brain_Fitness_160725.pdf?1469465072

A Core Set of Outcome Measures for Behavioral Health Across Service Settings, http://thekennedyforum-dot-org.s3.amazonaws.com/documents/MBC_supplement.pdf

Fixing Behavioral Health Care in America: A National Call for Measurement-Based Care in the Delivery of Behavioral Health Services, https://thekennedyforum-dot-org.s3.amazonaws.com/documents/KennedyForum-MeasurementBasedCare_2.pdf

Parity Resource Guide for Addiction and Mental Health Consumers, Providers and Advocates, https://paritydata-prod.s3.amazonaws.com/documents/8/attachments/KennedyForum-ResourceGuide_FINAL_2.pdf?1433883787