Tackling Structural Discrimination in Healthcare Policy is Necessary to Achieve Parity for People with Substance Use Disorders and Mental Health Conditions

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ARTICLE

TACKLING STRUCTURAL DISCRIMINATION IN HEALTHCARE POLICY IS NECESSARY TO ACHIEVE PARITY FOR PEOPLE WITH SUBSTANCE USE DISORDERS AND MENTAL HEALTH CONDITIONS

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As the head of government affairs for Hazelden Betty Ford Foundation, the largest nonprofit substance use and co-occurring mental health treatment provider in the country, my job includes spending a considerable amount of time educating public policymakers on the disease of addiction and its prevalence in society. The truth is, substance use disorders and other mental health conditions are and have been very common, although society’s approach to prevention, treatment, and recovery has shifted dramatically over the last one hundred years. According to the National Survey on Drug Use and Health conducted by the federal Substance Abuse Mental Health Services Administration (SAMHSA), in 2014, 21.5 million people ages twelve or older had a substance use disorder (SUD) and about one in five adults ages eighteen or older suffered from mental illness.¹

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Ask any attorney or other legal professional in this country whether they have encountered someone at work who is suffering from a mental health condition or substance use disorder, and I would venture to guess the answer you would receive is a resounding—yes, of course! In fact, not only do we provide legal services to people with these diseases on a daily basis, we as a profession suffer ourselves from dangerously higher rates of behavioral health conditions than others in society. A 2016 study on this topic, published in the Journal of Addiction Medicine, identified both higher than average rates of alcohol-dependent drinking and levels of depression, anxiety, and stress within our profession than that of the general populous.2

Even with their prevalence, people with substance use disorders and mental health conditions have historically faced and continue to face extraordinary misunderstanding and discrimination in virtually every facet of public and private life. This is collectively referred to as stigma, and includes barriers to equity that are structural—through laws, regulations and policies—and public—including beliefs and attitudes of people in the community.3 Stigma can also exist towards one’s self, wherein a person internalizes beliefs and attitudes rooted in the stigma.4 In America, the stigma associated with behavioral health conditions throughout recent history has fostered an environment that restricts a person’s ability to access integrated, person-centered healthcare, safe stable housing, employment, and to otherwise fully participate in society.5 It has resulted in severe institutional barriers people have historically experienced and still experience today.6 Although the last sixty years have, through changes to public policy and enforcement of the law, brought about extraordinary structural and public change for the benefit of people with behavioral health conditions, so much more needs to be done.

I. America’s Evolving Understanding of Addiction and Mental Illness as Disease Conditions Have Shifted Public Policy to Support Community Integration and Better Behavioral Healthcare.

There are several ways in which the stigma has been reduced over the years. One way is through efforts to increase public awareness, including putting a face to the illness. For example, national advocacy campaigns have been created over the years, sometimes featuring celebrities and ath-

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4. Id.
5. See id.
6. Id.
letes, to bring the voice of mental health and addiction to people across the country.7 Similar forms of advocacy are also growing in grassroots efforts by everyday people whose lives have been touched by addiction and mental illness. Grassroots efforts have been happening in state capitals across the country during the Opioid Epidemic.8 In recent years, addiction to opioids has ravaged all corners of the country, and with it, has brought to life the face and disease of addiction in new and impactful ways. In West Virginia for example, where a colleague and I had the privilege of testifying before the state legislature in Charleston about the state’s opioid response, people have experienced the highest overdose death rate in the nation.9 It is difficult to find someone who has not been touched personally by this public health crisis in West Virginia. In 2016 alone, fifty-two West Virginians died per one hundred thousand people, surpassing the next closest state, Ohio, by over 20 percent that year.10 Parents and others who lost loved ones lined the walls of the hearing room as my colleague and I testified to lawmakers shaping public policy on the state’s opioid response. They held banners with pictures of hundreds of people that had been lost to the Opioid Epidemic for all of the lawmakers to see. Actions like this, where people are telling their stories and sharing their losses, help to systematically break down the stigma associated with substance use and mental health, and effectively and powerfully influence public policymakers for better access to behavioral healthcare across the country.

Another way the stigma has been lessened over time is through the integration of people, policies, and practices in our society and communities. Prior to my current role at Hazelden Betty Ford Foundation, I ran what remained of Minnesota’s state-based institutions and safety-net hospitals, which now care for some of the people in our society whose brain diseases are some of the most severe—with disease related behaviors that pose a harm to themselves or others. Ahead of the deinstitutionalization movement in the first half of the twentieth century, these types of state hospitals or treatment centers across the country housed and cared for people with disa-

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10. Id.
bilities, including mental health conditions and substance use disorders, iso-
lated and separated from the rest of society. The institutions were filled and maintained through segregationist approaches to public policy for people with disabilities until reforms began in the 1950s and 1960s. More than fifty years later, policymakers are still challenged to navigate the difficulties of unwinding from the one hundred years prior. For example, although Minnesota now serves far fewer people in its state hospitals than it did in the earlier 1900s, with more people living in the community with tailored supports, many of the state’s regional treatment centers remained open until the late 1990s.

During the 1960s, President John F. Kennedy was widely known for his leadership in behavioral health and disability advocacy, with many crediting his close relationship with his sister Rosemary, who suffered from profound disabilities, as inspiration for his focus, which included those with brain diseases. In 1963, President Kennedy signed into law the Community Mental Health Act which directed the establishment of community mental health centers to treat people in communities across the country instead of in institutions, fundamentally changing how people could access care. Additionally, the care itself was transformed. Funding for development of new and innovative approaches and medicines was appropriated, which supported people’s recovery from mental illness and resulted in different approaches to addiction in the years that followed.

Not only were policymakers evolving their view and approach to behavioral health through structural changes in care and housing services provided, courts were as well. For example, in 1962, the United States Supreme Court issued a lesser known but important opinion, Robinson v. California, where the Court held that a California law criminalizing addiction itself was an unconstitutional violation of the Eighth Amendment. This opinion paved the way for people with substance use disorders to be treated fairly by our justice system. In Robinson, a police officer, noticing what appeared to be track marks on a man’s arm, charged him with misdemeanor drug addiction. Mr. Robinson was convicted and served ninety days in jail. He appealed the decision and won—the Supreme Court sided

12. See id.
13. See id.
15. Id.
17. Id. at 661–62, 666.
18. See generally id.
with him, agreeing that addiction is a disease condition, and not a crime.\(^\text{19}\) Although scholars generally minimize the importance or relevance of Robinson from the perspective of legal precedent in the years that passed since the decision, it in some ways marked a transformation at the highest level of our legal system by recognizing that addiction is not a crime, but an illness.\(^\text{20}\) The United States Supreme Court smashed stigma that day, whether it realized it at the time or not.

The public policies that have shaped and made possible the progress of the 1960s through today for people with disabilities have been successful in large part due to the efforts of decades prior—including pioneering legislative efforts like the 1946 National Mental Health Act which, among other things, provided more funding toward mental health and created a National Institute of Mental Health to research brain disease.\(^\text{21}\) For alcoholism, philanthropy and lived experiences of people with the disease played pivotal roles, including the founding of Alcoholics Anonymous in the 1930s and the “Minnesota Model” of treatment for substance use disorders at Hazelden, both landmark moments in the evolution of treatment and recovery for those with substance use disorders.\(^\text{22}\)

II. Public Policymakers’ Recent Focus on Eliminating Historical Discriminatory Exclusions in Health Benefits Is a Necessary Pivot Intended to Improve Access and Parity in Behavioral Health.

Even with these progressive legislative, court, and community-based changes, lawmakers in the United States are continuing in the fight to bring full parity in care for people with mental illness and substance use disorders, but sometimes their policy approaches have had the opposite effect. One stark example of this came just two years after the Community Health Act, as part of the landmark Social Security Amendments of 1965, which created what are now the Medicaid and Medicare programs in America.\(^\text{23}\) In order to incent community-based treatment for people with mental illness, the Social Security Amendments contained an exclusion for federal Medicaid payments called the Institute for Mental Diseases Exclusion (IMD Exclusion). Essentially, the IMD Exclusion had the effect of preventing federal payment of Medicaid dollars for inpatient care of adults under sixty-five in psychiatric facilities, which, in a 1988 amendment to the law was

\(^{19}\) See id. at 666–67.


\(^{21}\) National Mental Health Act, Pub. L. No. 79–487 (1946).


defined as “a hospital, nursing facility or other institution of more than sixteen beds, that is primarily engaged in providing diagnosis, treatment or care of persons with mental diseases.”24 The policy behind the IMD Exclusion originally aligned with the Community Mental Health Act’s intent of decreasing the institutionalization of people with mental illness, by refusing to provide payment for necessary care for people in need of the most intensive mental health services in specialty care settings, and instead investing in and focusing payment on lower-intensity outpatient care.25 Even with that good intent, the practical effect of the IMD Exclusion has been the creation of an institutional and discriminatory barrier to treatment for people across the country since its inception.26

The IMD Exclusion exists as one of the few prohibitions on Medicaid payment for care, regardless of medical necessity. It is hard to overstate the importance of Medicaid in covering and paying for behavioral health care. Medicaid is the single largest payer for mental health and substance use services in the United States, accounting for twenty-six percent of all behavioral health spending in 2009, according to a 2015 report from the Medicaid and CHIP Payment Access Commission (MACPAC).27 While one in five individuals enrolled in Medicaid has a behavioral health diagnosis, they account for almost half of all Medicaid expenditures, totaling more than $131 billion (spent on medical, behavioral health, and other covered services).28 Although many states have over time supplemented the gap in federal contributions for inpatient treatment programs caused by the IMD Exclusion, the lack of national investment has been a long lasting barrier to building inpatient provider capacity across the country, and is widely attributed as a significant cause of the behavioral workforce shortages experienced in rural and low-income communities.29

Public policymakers in recent years have turned their attention to the IMD Exclusion’s ongoing consequences to people, particularly as the need for inpatient substance use treatment grew due to the Opioid Epidemic. Just as in West Virginia, 2016 was a record year nationally for the Opioid Epidemic, with approximately 63,000 Americans dying from drug overdoses, three times greater than in 1999, and an 88 percent increase in deaths from synthetic opioids from 2013 to 2016.30 That year, the Obama administration

25. MedicaId and CHIP Payment Access Comm’n, Report to Congress on Oversight of Institutions for Mental Diseases 1, 4 (2019).
27. MedicaId and CHIP Payment Access Comm’n, Report to Congress on Medicaid and CHIP Payment 1, 90 (2019).
28. Id.
29. See MedicaId and CHIP Payment Access Comm’n, supra note 25.
put into motion significant reforms with the policy intent to increase access to residential treatment for people insured through Medicaid managed care plans.31 These reforms included the final rules issued by the Department of Health and Human Services which expanded coverage for Medicaid plans payment of care in IMD Exclusions for up to fifteen days of care.32

The following year, President Trump established his 2017 Commission on Combating Drug Addiction and the Opioid Crisis which recommended, among other actions, granting waivers to the IMD Exclusion to all fifty states in order to increase access to inpatient services for people with substance use disorders.33 Although not all fifty states have been approved for administrative waivers, in 2018 Congress’s passage of the SUPPORT Act included express statutory authority for states to apply for a waiver allowing for payment for care in IMD Exclusion facilities up to thirty days within a year.34 To date, through one of several mechanisms, the Centers for Medicare and Medicaid Services has approved thirty-four waivers to expand behavioral health services, many of which modify the IMD Exclusion requirements.35

III. POLICYMAKERS’ UTILIZATION OF MANDATES AS REFORM TOOLS ARE ATTEMPTING TO ADDRESS SYSTEMIC DISCRIMINATORY PRACTICES ROOTED IN STIGMA AND MISUNDERSTANDING.

Like exclusions, the practical impacts of stigma surrounding addiction and mental health issues have shaped our country’s approach to health insurance coverage and the decisions about what are included as mandatory benefits. In recent years, coverages have expanded through changes to healthcare public policy, as lawmakers have seen and experienced the far-reaching consequences that lack of insurance has had on people with behavioral health conditions. Changes that have and continue to be made are already shaping a brighter future for people who need help. As common as mental health conditions and substance use disorders have been and continue to be in our society, the journey to having comprehensive insurance

32. Id.
coverage to treat a person’s disease condition has been long and is yet to be complete. The barriers are tangible, and all too often deadly.

I was first exposed to this issue as a young attorney representing ERISA-regulated health benefit plans in 2008, the year that the Congress passed the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act (MHPAEA), more commonly known as Federal Parity. With this legislation, Congress attempted to systemically address the inequities people faced in access to behavioral healthcare by requiring that any limitations on offered mental health and substance use benefits for group health insurance could be no more restrictive than other medical/surgical benefits offered to enrollees, including co-pays and deductibles. The MHPAEA applied to both the fully-insured and self-insured markets and was an extraordinary step toward covering behavioral health benefits similarly to those offered for other disease conditions.

Hard fought for many years, the MHPAEA did not pass alone, but as part of Congress’s Troubled Asset Relief Program (TARP), which appropriated $700 million stabilizing the banking, auto and real estate industries, the credit markets, and provided foreclosure relief to people suffering across the country. Although on its face it may seem that these provisions were an afterthought, inclusion of Federal Parity was instrumental in TARP’s passage, and many attribute the inclusion of the MHPAEA as part of negotiations for members of Congress who were reluctant to vote for the very controversial TARP “bailout.” It also opened the eyes of benefits attorneys, like myself and others, to the new opportunity the MHPAEA afforded to employees—that they did not have to experience barriers such as fear or shame to ask their employers for more comprehensive behavioral health benefits for themselves and their families.

In 2011, following the MHPAEA passing, but before final rules were promulgated, the Patient Protection and Affordable Care Act (ACA) expanded behavioral health benefit mandates even further by identifying mental health and substance use treatment as Essential Health Benefits under the law, expanding coverage to people who bought insurance individually without connection to an employer. Additionally, for states that expanded Medicaid to cover low-income adults, the ACA required that the

37. See id.
38. See id. U.S. Dep’t of Treasury, Troubled Asset Relief Program (TARP), U.S. Dep’t of Treasury, https://home.treasury.gov/data/troubled-assets-relief-program (Treasury Department’s summary of Congress’s Troubled Asset Relief Program (TARP)).
39. See, e.g., Carl Hulse, Pressure Builds on House After Senate Bucks Bailout, N.Y. TIMES (Oct. 1, 2008), https://www.nytimes.com/2008/10/02/business/02bailout.html (Minnesota Congressman Jim Ramstad identified the inclusion of the MHPAEA as important to his evaluation of whether to vote for TARP).
Medicaid program include substance use disorder treatment services, whereas before it was an option benefit under the Medicaid program.41

This journey to fair and equitable health insurance coverage and therefore access to care pre-dates the MHPAEA and the ACA. In 1996, under the Clinton administration, Congress passed the Mental Health Parity Act, which required group health plan coverage dollar limits for lifetime and annual maximum costs on mental health benefits to be at least in parity with those of medical and surgical benefits for certain group health plans.42 Although this was a tremendous step forward, the Mental Health Parity Act did not apply to substance use disorders, nor did it preclude higher cost-sharing and other utilization limits on benefits for people with mental health conditions.

Even with these mandatory and expanded benefits growing over time, parity has yet to be achieved and problems with access continue to exist, pointing to systemic compliance issues with the MHPAEA and the ACA. As a result, those impacted are beginning to seek judicial remedy, and they are finding success. In a recent federal court decision in Northern California, United Behavioral Health, which manages mental health and substance use services coverages for UnitedHealth Group, was taken to task in class action litigation for violations of the MHPAEA.43 In a scathing rejection of the insurance company’s practices, the court found that the insurer inappropriately managed people’s care by denying thousands of people access to necessary behavioral health treatment and violating the Mental Health Parity Act’s requirements for its members.44 The impact of Wit is already beginning to ripple through state legislatures. Following the Wit decision, the state of California amended its state parity law to mandate specific criteria (based on Wit) in making decisions about medical necessity for people with behavioral health conditions.45

IV. PUBLIC POLICYMAKERS ARE ADDRESSING WELL-INTENDED YET ANTIQUATED AND SEGREGATIONIST ANCILLARY STRUCTURES THAT CREATE BARRIERS TO PARITY.

Historical exclusions and gaps in insurance coverage are not the only public policy that have had the effect, over time, of structurally discriminating against and stigmatizing people with substance use disorders and co-occurring mental health conditions. In order to understand and address the barriers to parity in outcomes for people with behavioral health conditions,

42. 29 U.S.C. § 1185a.
44. See id.
public policymakers have explored beyond mere access to health insurance and care, and are now focusing on the other ways people are impacted. The treatment of a person’s disease information as part of their medical record, or lack thereof, is another example, one that is finally in the process of being addressed.

In 1975, long before the Health Insurance Portability and Accountability Act (HIPAA) was passed in 1996, the Department of Health Education and Welfare (now the Department of Health and Human Services) promulgated 42 C.F.R. Part 2, known as the Confidentiality of Alcohol and Drug Abuse Patient Records regulations (“Part 2”). The intent was to ensure that people with substance use disorders could participate in treatment without threat of one’s disease being disclosed to law enforcement, the courts, employers, and others, and used to discriminate against or stigmatize them. At the time, the addiction treatment industry was very young and largely un-professionalized, and people felt exposed if they sought help. Part 2 sought to change that, and in doing so, incentivize more people to get the help they needed without fear of consequences.

Although there is very little dispute that Part 2 was necessary at the time, along with the advancements in health information privacy at state and federal levels that followed—including HIPAA—Part 2 has created barriers to care and a growing rift in healthcare. Part 2 has been such an impediment to integration of care that the bipartisan National Governor’s Association (NGA) and thirty-nine state attorneys’ general both wrote to Congress in the last three years advocating for further alignment with HIPAA.

The practical implications of the challenges Part 2 provides ripple beyond that person’s medical record and into population health outcomes for people with behavioral health conditions. In 2015, I became Minnesota’s Commissioner of Human Services. At the time, Minnesota was innovating in population-health focused approaches to better outcomes—particularly for people with the greatest disparities in healthcare outcomes. In this effort, one key tactic for healthcare has been to use person-centered approaches to service and care delivery, essentially trying to approach an interaction with a patient around what they need to be healthy. Integrated, person-centered care is made possible in part by integrated medical records, and also Part 2.

Because it was written in the 1970s before electronic medical records and

because the intent was to separate those records, it is a barrier to that integration.

In large part due to the discrimination against people with behavioral health conditions that exists today, some advocates have argued that continued separation and segregation of medical records is necessary. Congress recently disagreed and, as part of the Coronavirus Aid, Relief, and Economic Security Act (CARES Act), sided with public policy that no longer segregated people’s records due to their disease condition for purposes of healthcare treatment, payment, and operations.49 This public policy shift aligns with those of deinstitutionalization and parity—that ultimately a person’s disease condition must not be the basis for intentional segregation or exclusion from the benefits everyone else in society experiences, in this case, the ability to access person-centered care.

Healthcare policy for mental health and substance use has been and continues to be a winding road in America. Today, the concern and momentum to create a better future is extraordinary and is focused on integration of care and services for people. Breaking down the historical silos that have fostered exclusion, stigma, and discrimination is imperative. The complexity and depth of remaining structural barriers in healthcare policy, and beyond—to education, criminal justice, and more—will continue to pose difficult challenges with complex potential solutions lawmakers must grapple with in the future, but much has already been accomplished.

Additionally, the consequences of the coronavirus pandemic on people’s mental health will again elevate the challenges and opportunities before us as a country to do better, shaping a public policy that supports better outcomes for people with behavioral health conditions. As a person whose job it is to advocate for people with mental health conditions and substance use disorders, and as a member of our community—a mom, daughter, wife, and more—it is my hope that we will continue to collectively work toward a better future, with structures that support prevention and treatment, and that bring true the promise of recovery for people with behavioral health conditions.