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Addressing Stigma and False Beliefs About Mental Health: A New Direction for Mental Health Parity Advocacy

Claire Sontheimer* & Michael R. Ulrich**

Despite laws designed to protect mental health and substance use parity in the United States, real parity remains an aspiration.1 Under the current system, insurance companies use multiple tactics to deny coverage for or delay the provision of mental health and substance use disorder (MH/SUD) treatment.2 The difficulty of enforcing parity creates a barrier to achieving the goal of accessible behavioral health services.3 Rather than a continued effort to legislate our way out of this conundrum, it may be useful to look further upstream. Critical impediments to achieving such parity include the basic attitudes and beliefs about mental and behavioral health that underlie the current stagnation in enforcement efforts.4 A small body of research suggests that a lack of belief in the effectiveness of MH/SUD treatment and negative feelings about people with MH/SUD are correlated with lower support for mental health parity.5 While more research is needed to fully understand this connection, researchers, advocates, and policymakers should

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1 Jenny Gold, When it Comes to Insurance, Mental Health Parity in Name Only?, NPR (Apr. 4, 2015, 6:11 PM), https://www.npr.org/sections/health-shots/2015/04/04/397043323/when-it-comes-to-insurance-mental-health-parity-in-name-only (indicating that parity laws are hard to implement as mental health and physical health are two different things, “and it's hard to make them exactly equal when treatment often doesn't line up and success can be harder to measure on the mental health side.”).


3 Id.


consider using anti-stigma campaigning as a new advocacy tool in the fight for mental health parity.

In Part I, this article examines the parity problem in the United States. Despite recent legislative efforts, the apparent failure to achieve equity suggests that additional statutes are unlikely to propel this country toward parity.\(^6\) Part II examines stigma and false beliefs as an underexplored barrier to parity, further demonstrating the limitations of a regulatory approach. Instead, emerging research illustrates that misunderstandings of mental health and substance use disorders will continue to impede progress toward parity if unaddressed.\(^7\) Finally, Part III looks upstream and suggests anti-stigma work as a necessary intervention to succeed in accomplishing the goals of previous legislative parity efforts.

I. THE PARITY PROBLEM

The history of federal mental health parity laws in the United States begins with the Mental Health Parity Act (MHPA, or the “Act”), which Congress passed in 1996 and became effective in 1998.\(^8\) The Act banned the practice of insurers placing dollar limits on mental health care that was different than those limits prescribed for medical care.\(^9\) However, the Act did not apply to substance use disorder care and contained far too many loopholes, leading many to believe “the passage of the MHPA was more symbolic in nature than it was a signal of substantive policy change.”\(^10\) The next major national legislation addressing parity was the Mental Health Parity and Addiction Equity Act (MHPAEA) which Congress passed in 2008.\(^11\) Congress enacted the MHPAEA in response to insurance company attempts to circumvent parity, such as placing different quantitative limits on MH/SUD care than on medical or surgical care and using separate, and often higher, deductibles for MH/SUD treatment.\(^12\)

Broadly, the MHPAEA prohibits quantitative treatment limits (QTLs), such as a limit on the number of inpatient days insurance will cover, and non-quantitative treatment limits (NQTLs), such as medical necessity reviews for

\(^6\) See Shana, supra note\(^2\)

\(^7\) Id.


\(^9\) Id.

\(^10\) Id.

\(^11\) Id.

\(^12\) See id. at 423 (detailing the many requirements of MHPAEA that insurance companies must follow).
both mental health and substance use benefits. But, importantly, these treatment-limit prohibitions apply only to the extent that those treatment limits are stricter than limits on comparable physical health benefits. Thus, MHPAEA did not actually prohibit the use of QTLs or NQTLs for mental health care; rather, the treatment limits on mental health benefits must not be stricter than the limits on physical health benefits. In addition, under the MHPAEA, insurers are not required to provide mental health coverage—the stipulation is that, if they do cover mental health, that coverage must be equivalent to the coverage provided for medical care. Also, the MHPAEA, by its terms, originally only applied to group health plans and group insurance coverage, potentially leaving many individuals outside of its scope.

A more recent piece of federal legislation impacting parity was the Affordable Care Act of 2010. The ACA deemed mental health and substance use disorder coverage ‘essential health benefits,’ which was considered a major victory in the fight for parity. The ACA also addressed a gap in the MHPAEA’s requirements: under the ACA, parity requirements apply to individual plans as well as to employer-based ones. These two aspects of the ACA were extremely important in addressing shortcomings of the previous statutes and ensuring that parity protection would cover substantially more people.

13 Amber G. Thalmayer et al., The Mental Health Parity and Addiction Equity Act (MHPAEA) Evaluation Study: Impact on Qualitative Treatment Limits (QTLs), 68 PSYCHIATRIC SERVS. 435, 436 (May 1, 2017).
15 See Meiram Bendat, In Name Only? Mental Health Parity or Illusory Reform, 42 PSYCHODYNAMIC PSYCHIATRY 353, 358 (2014) (defining that when QTLs/NQTLs are applied to mental health services in particular, the limits cannot be stricter or more stringent than those prescribed to medical and surgical interventions).
19 Id.
20 The Mental Health Parity and Addiction Equity Act (MHPAEA), supra note 17.
Despite these major pieces of legislation, evidence shows a persistent and striking lack of parity between MH/SUD and medical coverage. This disparity can be seen in a variety of data sources, whether it be healthcare spending data, self-reported data from consumers and stakeholders, or a thorough analysis of insurance plans themselves. Claims data provided by Aetna, Humana, Kaiser Permanente, and UnitedHealthcare and independently analyzed by the Health Care Cost Institute show that even while out-of-pocket costs for inpatient medical and surgical care decreased between 2013 and 2016, the same out-of-pocket costs for inpatient mental health and substance use treatment substantially increased. Another study examining health insurance plans from two states found that only about 75% of plans sold on their ACA exchanges followed the requirements set forth by parity law. In a 2014 poll, respondents were more than twice as likely to report that they or a family member had their mental healthcare coverage denied by a private insurance company for lack of medical necessity than reporting that they were denied medical care coverage for the same reason.

Existing legislation has largely been successful in minimizing quantitative treatment limits (QTLs). However, use of non-quantitative treatment limits (NQTLs) is still more widespread for MH/SUD coverage than for medical and surgical coverage, despite law mandating the equal use of NQTLs for medical and MH/SUD care. For example, a wide variety of stakeholders in California agreed that achieving NQTL parity remains the
dominant

23 See infra notes 24–27.
25 See Kelsey N. Berry et al., A Tale of Two States: Do Consumers See Mental Health Insurance Parity When Shopping on State Exchanges?, 66 PSYCHIATRIC SERVS., 565, 566 (2015) (detailing two state’s ACA exchanges, noting that 75% of products offered on the exchange platforms met the requirement of offering equivalent, or more generous, benefits for MH/SUD services when compared to offerings for medical and surgical benefits).
27 Thalmayer et al., supra note 13.
issue. The difficulty in defining what it means to achieve parity creates a challenge for advocates who are working to reduce the use of NQTLs in MH/SUD treatment. While there are validated tools that mental health clinicians can and do use to measure progress in MH/SUD treatment, it may be more difficult for a third party to conceptualize and observe improvements in mental health than it is for that same third party to conceptualize and observe improvements in physical health. Seeing a wound or broken bone heal, for example, is much more apparent to even the lay individual than improvements in depression, which are perhaps less likely to be linear in one individual or uniform across individuals. Therefore, it may be more difficult for an individual making coverage assessments to accept that mental health care is evidence-based and effective, even if the type of care provided is appropriate to treat the presented condition.

Insurance companies impose these NQTLs using a variety of tactics, but perhaps the most common are through determinations of medical necessity and by performing utilization reviews. Insurance companies are known to use databases that provide standardized guidelines on appropriate care (such as Milliman Care Guidelines or InterQual) as a tool to make a decision as to whether the form of care the patient’s clinician is providing or recommending is medically necessary and appropriate. While the care guidelines and the patient’s provider may disagree, such conflicts do not always stem merely from reasonable uncertainties within medicine. For example, the American Society of Addiction Medicine has tried to highlight the use of substandard medical necessity criteria that do not adhere to validated, reliable, and acceptable guidelines. More troubling, the necessity criteria often places

29 See JoAnn Volk et al., Equal Treatment: A Review of Mental Health Parity Enforcement in California 17 (2020) (emphasizing the need for oversight of utilization management).
30 See id. (stating that “Provider and patient representatives said greater standardization and specificity is needed to ensure patients with the same profile aren’t treated differently based on how strictly their insurer or health plan applies medical necessity criteria,” which amounts to parity).
31 See Volk et al., supra note 29 (stating, “New York, for example, requires insurers to use evidence-based criteria approved for use by the state Office of Mental Health. Other states have enacted requirements that medical necessity determinations for substance use disorder be consistent with criteria established by ASAM (Illinois, Delaware, and Maryland)
34 Id.
the burden on patients to provide concrete, objective proof that their condition will deteriorate in the absence of the proposed care.35

While medical utilization reviews are the most common tactic used by insurers to deny coverage, insurance companies employ other NQTL methods as well.36 For example, insurers can maintain small groups of in-network providers.37 Many places in the U.S. already experience mental health provider shortages, and a small network can increase lengthy wait times for in-network care and may ultimately prevent some people from receiving care at all.38 Insurance companies may also continue to include providers who have left the area or are not accepting any new patients on their lists of providers, which results in artificially inflated “ghost networks.”39 Under another strategy, insurers apply formal or informal ‘fail-first’ or ‘step therapy’ policies to mental health care.40 These policies require patients to try a less expensive form of care before more expensive care will be considered for approval.41 In a 2013 survey of practicing psychiatrists, 50% of respondents reported that these fail-first or step therapy policies were a barrier in providing effective care.42 In the mental health and substance use context, “failing” with a cheaper form of care can result in attempted or completed suicide, overdose, or other severe distress that can have broad, long-lasting effects.43

It is difficult to prove precisely what motivates insurance companies to use NQTL tactics, since these companies do not openly admit to using them. Some advocates cite cost containment,44 and the idea of cost containment as a motivating factor for insurers’ actions has been raised in court.45 In Wit v. United Behavioral Health, for example, the plaintiffs alleged that United Behavioral Health breached their fiduciary duty to members by prioritizing

35 Id.
36 See e.g., Volk et al., supra note 29 at 16 (providing an example of other NQTL methods).
37 Id.
40 Shana, supra note 2
41 Id.
43 Shana, supra note 2
cost savings over members’ interests in developing guidelines more restrictive than those that are generally accepted.\footnote{Id.}

These cost containment efforts may have a detrimental impact on the mental and behavioral health of individuals across the country, trading their health for potentially reduced spending in the healthcare system. Others have also highlighted that denying mental health care is “kicking the can down the road” when it comes to members’ mental health, leaving the costs of deleterious mental health to others in the future.\footnote{Clayson, supra note\textsuperscript{44} at 19:45.} High churn in the employer-based insurance market means that, in many cases, an individual may be out of an insurance company’s network in short time, leaving any increase in future costs due to deteriorating health for another company to consider.\footnote{Id. at 20:40; see also Sommers et al., Insurance Churning Rates for Low-Income Adults Under Health Reform: Lower Than Expected but Still Harmful for Many, 35 HEALTH AFFS. 1816, 1817 (2016) (“People going through any of these transitions may become uninsured for a time. Such a gap is likely expose people to significant financial risk and impaired access to care. But even a transition with no coverage gap may have negative effects because insurance benefits and provider networks often differ across coverage and plan types, and simply changing providers has been linked to adverse outcomes.”).}

Therefore, even if providing mental health treatment earlier would ultimately be cost-effective for the healthcare system on the whole, individual insurance companies still may not want to be the ones to bear that cost.\footnote{Clayson, supra note\textsuperscript{44} at 07:35.}

However, it is not clear that controlling costs can entirely account for the insurance industry’s focus on denying coverage for mental health and substance use treatment. Indeed, if denying coverage were simply a way to lower costs and increase profits, then increasing denials of coverage for all types of care (without differentially targeting mental health care) could accomplish the same result. Why target mental and behavioral health? The answer may relate to stigma.

II. STIGMA AS PARITY BATTLEGROUND

There has been much discussion of stigma and the need to address it, but some have suggested that in the case of stigma there is an “intellectual and emotional fatigue that accompanies stringent calls to action that seem nevertheless continually ignored.”\footnote{Schlozman et al., Stigma and Mental Health: A Proposal for Next Steps, 40 ACAD. PSYCHIATRY 735, 735 (2016).} However, we argue that while stigma is surely not an easy problem to solve, it can be defined and addressed in a practical manner. Broadly, stigma has been defined as “negative stereotypes that include labeling, prejudice, and discrimination that are attributed to a
person or groups of people when their characteristics or behaviors are viewed as different from or inferior to societal norms.”51 The path toward this prejudice can involve false beliefs about a person or a group of people.52 Critically, in the case of mental health and substance use disorders, these false beliefs include the idea that mental health and substance use treatments are not effective.53 Thus, stigma plays an essential role in the consideration of mental health treatment and, as a result, coverage of that treatment.

This demonstrates that reforming ill-informed beliefs that treatments for mental health are ineffective and that people with MH/SUD will never recover are key in the fight for mental health parity. If treatments are seen as ineffective, then there is some logic to insurers’ denying coverage for such treatment. The stigma that leads to these false beliefs relating to mental health and substance use disorders are so pervasive that even those living with mental health conditions themselves carry doubt about treatment, which also acts as another barrier to seeking and accessing care.54 One study identified a perception of ineffectiveness as the reason over a quarter of those with severe untreated mental health symptoms did not seek treatment.55 For insurance companies driven by cost considerations, what qualifies as “medically necessary” treatment can be influenced by these types of beliefs, often at the expense of highly stigmatized or complex mental health and substance use disorders.56 This framework relies on the traditional medical model of curing disorders; however, when considering mental health and substance use treatment, this leaves little room to consider the benefits of managing symptoms. Even if most would agree that both are worthy goals, an insurance company would be especially hesitant to embrace symptom-

51 Holder et al., Stigma in Mental Health at the Macro and Micro Levels: Implications for Mental Health Consumers and Professionals, 55 CMTY. MENTAL HEALTH J., 369, 370 (2019).
53 See Andrade et al., Barriers to Mental Health Treatment: Results from the WHO World Mental Health (WMH) Surv., 44 PSYCH. MED 1303, 1313 (2013) (discussing how respondents from high income countries who previously had mental health treatment are skeptical about the effectiveness of professional help for serious emotional problems).
54 Id. at 1303 (explaining that “perceived ineffectiveness of treatment was the most commonly reported reason for treatment dropout…”).
55 R. Mojtabai, et al., Barriers to Mental Health Treatment: Results from the National Comorbidity Survey Replication, 41(8) PSYCH. MED.1751, 1754 (2011) (discussing how attitudinal barriers, including a perception of ineffectiveness, stands as a significant impediment to individuals seeking treatment).
management, given the expense that would accrue over an extended period of time.

Focusing on reducing this stigma would have an impact not only by increasing the effectiveness of current parity policies, but also by influencing oversight, enforcement, and the potential for future legislation. One study evaluated the opinions of 475 state legislators in the U.S., including at least one from all 50 states, on the effectiveness of mental health and substance use treatment.\(^{57}\) The study found that the legislators’ opinions on treatment effectiveness predicted whether they would support parity laws more strongly than their political affiliation or contextual factors in their state, such as a recent mass shooting, the opioid overdose death rate, and the unemployment rate.\(^{58}\) Those who strongly believed that substance use treatment could be effective were three times as likely to support parity legislation than those who did not strongly believe in the treatment’s effectiveness.\(^{59}\) Similarly, lower stigma—defined in the study as lower perceptions of dangerousness and lower unwillingness to work with people with MH/SUD—was associated with higher likelihood of supporting parity legislation.\(^{60}\)

Analogous results have been found among members of the public.\(^{61}\) A study using a nationally-representative sample of 1,517 adults examined the relationship between the support of mental health parity and negative feelings about people with mental illness, such as feelings of dangerousness or that they would not make good coworkers or neighbors.\(^{62}\) Those with fewer negative feelings were significantly more likely to support parity policies.\(^{63}\) The study also found that those with personal experience with mental illness or substance use, or those with a loved one who had experience with mental illness or substance use, were more likely to support these policies.

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\(^{57}\) See Jonathan Purtle, et al., supra note 47 at 1205, 1210 (discussing how 475 legislators completed the survey and at least one legislator completed the survey in all fifty states).

\(^{58}\) Id. at 1211–1212, 1225.

\(^{59}\) See id. at 1217 (discussing how 59.6% of legislators who strongly agreed that substance-use disorder treatments could be effective strongly supported C-SBHIPL, compared with only 19.0% of those who did not strongly agree).

\(^{60}\) See id. at 1201, 1208 (discussing how stigma toward people with mental illness is inversely related with C-SBPHL support and how the items used to characterize and assess the stigma of mental illness included attitudes about the dangerousness of people with mental illness and preferences for social distance, e.g., willingness to work closely with someone with a serious mental illness).

\(^{61}\) See Barry & McGinty, supra note 34 at 1266 (discussing how most Americans favor policies to expand insurance and funding for mental health parity, but stigma was associated with lower support for both policies).

\(^{62}\) Id. at 1265–66.

\(^{63}\) Id. at 1266.
suggesting that direct and known exposure may have a significant impact on stigma and parity support.\textsuperscript{64}

On the state level, there are sometimes conflicts of interest in monitoring mental health parity. Some states use third-party review organizations, but some of these organizations are also under contract with insurance plans, which makes their motivation to avoid enforcing parity laws obvious.\textsuperscript{65} Without consistent enforcement, the burden of fighting for mental health parity falls far too often on affected individuals and families who bring lawsuits — the system “assumes insurers are doing the right thing while relying on individual patients to enforce the law.”\textsuperscript{66} But there are several limitations to relying on litigation, including resources, expertise, experience, finding a lawyer who will take the case, and, again, stigma.

In some cases, litigation has been effective in penalizing insurance companies for parity violations. In the landmark 2019 case Wit v. United Behavioral Health, a federal district court found that United Behavioral Health (UBH) was using non-standard criteria for determining the medical necessity of care.\textsuperscript{67} As a result, UBH was ordered to reprocess more than 60,000 claims using medically recognized standards of care, and a special master was appointed to oversee the process.\textsuperscript{68} However, in other cases, only monetary penalties have been issued. For example, in Illinois, a class action suit was brought against Blue Cross Blue Shield for denying residential mental health care on the grounds that it was not “medically necessary.”\textsuperscript{69} The suit was settled for $3.75 million, but no changes in the benefits evaluation process were ordered by the court.\textsuperscript{70} In 2020, another monetary penalty was applied to four insurance companies in Illinois for a total of approximately $2 million, in amounts ranging from $208,000 to $582,000.\textsuperscript{71}

\textsuperscript{64} Id. at 1265–1268.

\textsuperscript{65} Meiram Bendat, In Name Only? Mental Health Parity or Illusory Reform, 42 PSYCHODYNAMIC PSYCHIATRY 353, 362-364 (Sept. 2014).


\textsuperscript{68} Id.


\textsuperscript{70} Id.

It is unclear whether these type of financial penalties are actually harmful enough to insurance companies to act as a deterrent, or, without broader demands of structural change, whether these fines are simply the cost of doing business. Rather than relying solely on oversight, enforcement, and litigation, deeper change is needed.

III. STIGMA AS AN UPSTREAM SOLUTION

A public health approach—using the model of primary, secondary, and tertiary prevention—suggests that an effective approach to solving a problem is to intervene at a stage where it is possible to reduce the risk of the problem occurring rather than to simply address the problem after the fact.\(^{72}\) Applying this to mental health parity runs counter to the notion that the best remedy to the lack of parity in the U.S. is improving enforcement. While this could have a significant impact if done successfully, it may be even more effective to reduce the risk that insurance companies will try to circumvent mental health parity laws in the first place as a proactive safeguard, as opposed to punishing them after the fact. In an effort to reduce risk, addressing stigma could very well be the key.

The research that has emerged around the connection between stigma, false beliefs about MH/SUD, and support for mental health parity may offer a novel path forward.\(^{73}\) This research suggests that decreased stigma and decreased false beliefs about MH/SUD among the general population and key stakeholders may increase support for mental health parity and, consequently, increase parity itself.\(^{74}\) Within this frame, interventions that focus on reducing stigma and providing education about mental health and substance use treatment can be conceptualized as mental health parity advocacy.

There is evidence that anti-stigma campaigns that teach people factual information about MH/SUD or refute false information can be effective in increasing knowledge about MH/SUD and reducing negative feelings about those with MH/SUD.\(^{75}\) And, importantly, the evidence demonstrates that this effect can have a lasting impact. For example, in a study of a major anti-stigma campaign in Scotland called *See Me*, participants retained a 17% drop


\(^{73}\) *See supra* notes 57-69 and accompanying text (suggesting that research exists which shows that there is a connection between stigma, false beliefs, and the increase in mental health parity which could provide a new approach for the future).

\(^{74}\) *Id.*

\(^{75}\) *See infra* notes 77-78 and accompanying text (providing concrete examples of evidence that anti-stigma campaigns are helpful in disseminating factual information about MH/SUD and refuting false information that may exist to increase public knowledge).
in the belief that people with mental illness are dangerous two years after the campaign concluded.\textsuperscript{76} A meta-analysis of 26 studies also found lasting effectiveness in reducing negative feelings about people with MH/SUD, and that educational campaigns also reduce the personal stigma which acts as a barrier to care.\textsuperscript{77} These campaigns can be made even more effective with the addition of an element of contact, where people with lived-experience of mental illness help to synthesize the educational elements of the campaign with reflections on their own lives.\textsuperscript{78}

Anti-stigma campaigns designed to increase mental health parity could take multiple formats. A campaign may target the general population, which could have an impact not only on parity, but also on stigma and education about mental health in general. A broad campaign like this would be most effective if it was supported and publicized nationally by bipartisan leaders at every level of government. This could help to expand the reach of such a program and increase public interest in and engagement with it.

On the other hand, these campaigns could closely target key populations such as insurance company policymakers, executive leaders, and any employees who work with mental and behavioral health claims. As one author notes, “Targets [in anti-stigma campaigns] are important when they play a power role vis-à-vis people with a psychiatric disability.”\textsuperscript{79} Targeting an anti-stigma campaign at people in the insurance industry who hold decision-making power regarding access to treatment for people living with MH/SUD may be the most effective use of resources, although a campaign like this has less public reach, thereby reducing the chance for a broader impact.

Even with growing support for the fight against stigma, the pressure on insurance companies to control costs and safeguard their profits will remain the same. For example, if public support for parity grows, insurance


\textsuperscript{77} See generally Kathleen M. Griffiths et al., \textit{Effectiveness of Programs for Reducing the Stigma Associated with Mental Disorders. A Meta-Analysis of Randomized Controlled Trials}, 13 WORLD PSYCHIATRY 161, 161–175 (June 2014), https://onlinelibrary.wiley.com/doi/epdf/10.1002/wps.20129 (finding that educational campaigns and interventions can assist in reducing personal stigma surrounding MH/SUD, but studies and evidence has been limited when it comes to the reduction of perceived stigma despite the fact that need exists in reducing this type of stigma).

\textsuperscript{78} Patrick Corrigan et al., \textit{Do the Effects of Antistigma Programs Persist Over Time? Findings from a Meta-Analysis}, 66 PSYCHIATRIC SERVS. 543, 543-546 (2015).

companies will remain motivated to pay as little as possible for all types of treatment, including MH/SUD treatment. Nevertheless, increasing support for parity from the public or from within the company itself puts pressure on and motivates insurance companies to look for other ways to control costs that do not include the specific and differential targeting of MH/SUD treatment.

IV. CONCLUSION

Certainly, more research is needed to better understand the connection between stigma, false beliefs, and achieving mental health parity. Studies are necessary to understand how stigma and false beliefs influence the actions and decisions of critical populations, for instance, leaders of insurance companies. However, the research that has emerged thus far presents a fascinating possibility: the use of anti-stigma works as a direct intervention and advocacy strategy in mental health and substance use treatment parity. In the future, researchers should continue to investigate this connection, and advocates should design strategies to leverage it as an upstream solution to an ongoing problem. Addressing stigma and false beliefs has the potential to transform mental health and substance use disorder treatment parity, thereby enabling this country to achieve the goal of numerous pieces of major federal legislation.