



Mental Health Parity in Rhode Island: *Experiences of patients and professionals*

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A letter from the Executive Director of the Mental Health Association of Rhode Island

The Mental Health Association of Rhode Island is pleased to share its 2019 Parity Initiative Report, *Mental Health Parity in Rhode Island: Experiences of patients and professionals*. Founded in 1916, the Association is a nonprofit organization whose mission is to promote mental health, prevent mental illness, and improve the system of care for the mental health needs of all Rhode Island residents through advocacy, education, and the dissemination of research.

In 2008, Congress passed the *Mental Health Parity and Addiction Equity Act*. Despite this law's central requirement that insurers cover mental health, including addiction treatment, at the same level as medical and surgical treatment, inequity persists. Insurers continue to erect barriers that restrict our access to mental healthcare. These include arbitrarily limiting the number of days one can see a provider or denying residential treatment. This discrimination is pervasive and systemic, sometimes setting off a chain reaction that can have fatal results. It persists because most of us are not aware of our legal rights and the problem is compounded by stigma and shame.

People who desperately need help and are legally entitled to it are languishing without adequate care. The Association's Parity Initiative was borne out of the hope that raising awareness about the parity requirement would empower consumers to demand equal coverage from their insurers. Indeed, as you will learn from the report, this educational project has touched many lives already. Additionally, to our great pleasure, the initiative has supported an ongoing conversation among consumers, providers, and policy-makers. We are learning as much as we are teaching, and this will help our light shine brighter on the places where the system is broken.

A lot of work remains to be done: the current healthcare paradigm is penny-wise and pound-foolish. We let problems fester and grow instead of addressing them early on. What would happen if we placed a premium on the early detection of abuse, neglect, and mental illness? Early interventions, particularly those that "treat to outcome," not only produce better results for the patients, but also save money in the long term because higher and more costly levels of care can often be avoided. Therefore, let us put our money where our values are by investing in early diagnosis, comprehensive outpatient services and programs, and long-term residential treatment.

Let's do this hard work together. Mental health is a collective endeavor, and each of us has a role to play.

Laurie-Marie Pisciotta, Executive Director



About the RI Parity Initiative

The Mental Health Association of Rhode Island's *RI Parity Initiative* aims to increase public awareness about a patient's right to equal insurance coverage for services and treatment of mental illness, including addiction disorders, and to develop recommendations to expand and improve parity for all patients.

Background

Mental illness is prevalent in Rhode Island across all demographics. According to Mental Health America and the Kaiser Family Foundation, over 1 in 5 adult Rhode Islanders has a mental illness. The Truven Report estimated the combined met and unmet need for all Rhode Island adults under 65 to be 27.2 percent, close to 10% higher than the national average.¹ The Substance Abuse and Mental Health Service Administration's (SAMHSA's) Behavioral Health Barometer for Rhode Island, Volume 4, reported that in Rhode Island, an annual average of about 37,000 adults aged 18 or older (4.5% of all adults) experienced a serious mental illness (SMI) in the past year.²

Yet, despite this prevalence, there is a documented history of insurers erecting barriers to accessing behavioral health services for a range of conditions. A recent study conducted by Milliman found that nationally, behavioral health patients are about five times more likely to have to go out of network - and thus pay out of pocket - for behavioral health outpatient care.³ A 2018 market conduct examination by the Rhode Island Office of the Health Insurance Commissioner (OHIC) found that Blue Cross Blue Shield of RI (BCBSRI) "engaged in behavioral health utilization management practices that were unreasonable, inequitable, and that did not properly consider patients' welfare and safety."⁴ Market conduct examinations of other carriers active in Rhode Island are forthcoming.

State and Federal mental health parity laws are designed to address this problem and yet, based on these studies, appear to remain aspirational.

Goals

The overarching goal of the Initiative's use of focus groups is to help shape a broader understanding of the issue of mental health parity in Rhode Island and to incorporate the voices and ideas of patients and professionals in moving aspiration to equality.

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More specifically, in the first round of groups, the priority was to hear directly from both consumers and mental health professionals about (1) their understanding of mental health parity, (2) their experiences in getting adequate coverage for behavioral health services and treatment, (3) their broader experience of social stigma associated with mental illness, and (4) their thoughts and ideas for meaningful messages for the Initiative's public awareness campaign.

Design

- Eight focus groups were facilitated between June and October 2018 following a defined agenda.
 - Five groups were facilitated with a total of 35 consumer participants. Consumers were defined as patients, parents or family members;
 - Three groups were facilitated with a total of 25 provider participants. Provider participants were defined as any professional who bills and receives payment for mental health services.

¹ Truven Report, page 38

² SAMHSA. Behavioral Health Barometer Rhode Island, Volume 4: Indicators as measured through the 2015 National Survey on Drug Use and Health, the National Survey of Substance Abuse Treatment Services, and the Uniform Reporting System. 2015. Pg. 8

³ Melek, Perlman, Davenport. Milliman Research Report: Addiction and mental health vs. physical health: Analyzing disparities in network use and provider reimbursement rates. December 2017. Pg. 3

⁴ OHIC-24-3. Examination Of Health Insurance Carrier Compliance With Mental Health & Substance Use Disorder Laws And Regulations. August 2018

- Local Rhode Island non-profit organizations advertised the focus groups among their constituencies to recruit participants.
- Each group was facilitated by at least 1 lead facilitator with at least one note-taker and were audio recorded verbatim for transcription.

Limitations: Among the 35 consumer participants, all were adults who had experienced a mental illness themselves or whose child had experienced mental illness. While there was a balance of gender and age, a limitation proved to be a lack of racial and ethnic diversity, and participation of those whose experience was primarily the result of a substance use disorder. These limitations will be addressed in a second round of groups to be scheduled in 2019.

Findings

The results from the eight focus groups yielded several recurrent themes, including:

1. A general understanding of parity as a concept, but confusion regarding parity laws and regulations;
2. Disempowerment of both patients and providers in the insurance system that results in barriers to necessary care;
3. Network inadequacy, coupled with the unequal allocation of financial resources between inpatient and outpatient levels of care;
4. Fragmentation and complexity of the insurance system;
5. Lack of coordination, communication, and understanding between primary and mental health care providers as experienced by patients;
6. Presence of stigma within the hospital network and physical health institutions, and how it impacts patients when it is combined with network inadequacy, and;
7. Persistence of a broader social stigma, with negative implications on how they feel they are perceived by others.

The presence of these themes across focus groups is critical, as focus groups were either consumers or providers, never a combination. There are clear disparities in the mental health system that are experienced and understood by both groups. A more comprehensive summary of each theme is presented in the subsequent subsections.

General understanding of the term “mental health parity” as a concept, but confusion regarding parity laws and regulations

This research utilized the following working definition for the term *mental health parity*: “the set of federal and state laws that dictate equal health insurance coverage for mental health and substance use disorder services and treatment.”

Most participants, when prompted, contributed at least part of the definition, indicating that they had a basic understanding of what parity is. In general, consumer participants understood parity as the availability to healthcare, the equal coverage for both mental and physical illnesses, and the ease of access to healthcare services. In addition, a focus group made up of patients with chronic mental illness added that parity provides for adequate and timely reimbursement from insurers for supported health services. Provider participants, on the other hand, had a more empathetic understanding of parity, referencing “equity” and “accessibility” of services as well as reimbursement for service providers. The term “parity” was comprehensively defined by a focus group made up of sexual assault and trauma clinicians as the rules, laws, and values of equality in the treatment of mental and physical ailments.

Disempowerment of both patients and providers in the insurance system that results in barriers to necessary care:

Focus group respondents overwhelmingly indicated that the insurance system has a high degree of control over both providers and consumers, creating a sense of disempowerment and overly severe restriction of access to care. As one mental health professional stated, “It’s frustrating...when you’re consistently coming against barriers, and you can’t help the clients to be where they need to be, that feels disempowering.” (Provider, Group 6)

One consumer participant explained a situation in which she was required to negotiate payment with her doctor to receive services. She was significantly ill and disabled – unable to go to work or even brush her hair – but recalls still needing to argue for her right to be seen by a mental health professional. (Consumer, Group 1)

The majority of consumer participants reported significant barriers to care as a result of insurance carrier restrictions. As one consumer stated, “it is demeaning to have to beg for some understanding...to get treatment for an illness.” (Consumer, Group 4)

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Another participant described her struggle to get coverage for her daughter: “[She] needed mental health treatment beginning at the age of 16. We had [private] health insurance, and it was a covered benefit for residential treatment for [her] disorder. We were denied that residential treatment. We were told by the insurance company that she would do better at a lower level of treatment although she had completed a lower level of treatment and only got worse.” (Consumer, Group 5)

In another group, a mental health professional vouched for the frustrations experienced by consumers, stating, “Our work is not what’s best for this patient. It’s, well, what will the insurance pay for?” (Provider, Group 2)

These experiences represent the systemic violation of mental health parity as exemplified by the findings of the 2018 Market Conduct Exam of Blue Cross Blue Shield of Rhode Island (BCBSRI) conducted by the RI Office of Health Insurance Commissioner (OHIC). OHIC found that, “BCBSRI had applied their utilization review criteria in a clinically inappropriate manner.”⁵ And that they “engaged in unreasonable, and inequitable review procedures.”⁶

Medicaid provides health insurance coverage for more than 300,000 Rhode Islanders with comprehensive coverage including for mental health services.⁷ Yet, several mental health professionals reported they are unable to accept patients covered by Medicaid because frequently they are improperly or not at all reimbursed for their services by Medicaid Managed Care Organizations (MCOs).⁸ In addition, reimbursement rates in both private and public plans are often not adjusted for inflation, so they do not cover the costs to “provide necessary and accessible services to [patients] with behavioral health needs.” (Provider, Group 6) This experience is substantiated by the findings of a 2017 Milliman Research Report that “found that medical/surgical

⁵ OHIC-2014-3, Examination of health insurance carrier compliance with mental health & substance use disorder laws & regulations, 13

⁶ Ibid, 18

⁷ RI Caseload Estimating Conference, 2018

⁸ Providence Journal, April 6, 2019, PEACE OF MIND: Mental health parity still lags behind other medical health

providers received higher reimbursement rates than behavioral providers for comparable services.” Milliman found that rates paid were as much as 17-22% lower for mental health professionals.⁹

The consequences of slow and low reimbursement to providers, particularly for outpatient care, contribute to other recurrent themes expressed in the focus groups, especially the issue of network inadequacy.

Network inadequacy coupled with the unequal allocation of financial resources between inpatient and outpatient levels of care:

Network inadequacy poses great risk for consumers as they struggle to find the resources to receive appropriate mental health care. Data shows that the current allocation of financial resources in the realm of mental health heavily favors inpatient care, such as emergency hospital visits and acute hospital care.¹⁰ Participants also reported that the Rhode Island state government “has been complicit in cutting [funding] out of community behavioral health services,” and as a result outpatient services are “extremely limited because the financial burden is too great.” (Provider, Group 6) Research conducted by Truven Health Analytics on behalf of the state found that, “public financing for behavioral health care for adults and adolescents dropped from \$110 million in 2007 to \$97 million in 2014; within that, state funding went from \$60 million in 2007 to \$38 million in 2014.”¹¹ Consequently, the waitlists for outpatient services can be months long. This can be especially stressful for patients because outpatient services are an integral factor in their recovery protocols. Limited accessibility to outpatient services may significantly hinder recovery, and may even result in subsequent re-hospitalization.¹²

“... when [someone is] discharged from a hospital with a mental health [disorder], where do [they] go?”

where do [they] go?” (Consumer, Group 4) She further explains that she believes there would never be a waiting list to get into physical recovery programs, but from her experience, it is seen all the time with mental illness.

One consumer participant drew the comparison between physical and mental health services stating; “physical ailments, such as cancer, have a follow-up protocol. When a cancer patient is discharged they receive immediate care in terms of chemotherapy, surgery, or physical therapy, but when [someone is] discharged from a hospital with mental health[disorder],

Network inadequacy is especially prevalent in child services. As highlighted in the 2018 Kids Count Factbook, a serious lack of in-patient psychiatric beds for children results in unreasonably long waits in hospital emergency rooms: “In Federal Fiscal Year (FFY) 2017, 462 Rhode Island children and youth awaited psychiatric inpatient admission for an average of four days on medical floors at Hasbro Children’s Hospital.”¹³

Focus group participants reported the painful experiences of families in these crises, “What they do in the ER is—they’re put into a teeny tiny room with a bed and a TV. My daughter becomes like a caged animal... There’s security guards sitting outside. It’s difficult enough to be in that kind of environment for a few minutes, never mind more than 24 hours. It’s horrible. It’s a nightmare.” (Consumer, Group 4) Another participant affirmed, stating, “It’s not even a matter of maybe you’re there for 24 hours. There’s no psych beds available. You could be there for six or seven days in the emergency room.” (Consumer, Group 4)

⁹ Melek, Perlman, Davenport, Milliman Research Report: Addiction and mental health vs. physical health: Analyzing disparities in network use and provider reimbursement rates, December 2017, 2

¹⁰ Rhode Island Behavioral Health Project: Final Report, September 2015, Truven Health Analytics, 4

¹¹ Ibid, 4

¹² Lippincott, Williams & Wilkin, www.co-psychiatry.com, Volume 25 Number 6, November 2012, 552

¹³ 2018 RI Kids Count Factbook, 58

Fragmentation and complexity of the insurance system

In addition to the emphasis placed on inequities, participants also raised the issue of complexity within the insurance system, particularly among consumers. Many consumers reported that they find themselves fighting for insurance authorization, even though the services sought were thought to be covered as a part of their plan and from providers thought to be in network. One participant explained, "...it's July, we got the insurance in January, and they just told me that my provider is not ...under my insurance. Now I owe all those services back." (Consumer, Group 3)

"...it's July, we got the insurance in January, and they just told me that my provider is not...under my insurance."

Participants expressed that it is difficult to obtain a transparent, comprehensive insurance policy that consistently and adequately addresses their mental health care needs. As the previously quoted participant continued, "If...you have as many medical issues as some of us do, on top of our mental health, we really need the right insurance. I didn't feel that I got directed in that path [to find the right coverage]. It makes me mad. It builds up my anxiety. It builds up my PTSD." (Consumer, Group 3)

Professionals also recognize the lack of standardization exemplified by different authorization requirements and claim review processes among various carriers and plans. For example, providers explained that they spend a majority of their time completing insurance reviews instead of actually seeing patients: "It's a large part of my time and very aggravating." (Provider, Group 2)

Lack of coordination, communication, and understanding between primary and mental health providers

Lack of access to outpatient mental health care means that primary care physicians "are frequently on the front lines of initially diagnosing, treating and managing mental health conditions."¹⁴ According to the National Institute of Mental Health, "the primary care provider can treat mental disorders, particularly through medication, but that may not be enough. Historically, it has been difficult for a primary care provider alone to offer effective, high-quality behavioral health care."¹⁵

It was mutually agreed by participants in nearly every focus group that there is a "lack of coordination" and "lack of understanding among physical health providers." (Consumer, Group 5) A consumer participant explained it this way, "I had been in and out of therapy in my earlier years, in my 20s and 30s, and had success with it, with and without medication, it was mostly for depression and anxiety. Then, things changed in my life and I didn't need it. Then, in really hitting the pits after my mother died, my general doctor started asking me questions about how I was feeling with my depression, did the depression test. He prescribed medication, but he never suggested therapy. The medication changed here and there, and it was adjusted. I took myself off. Then I went back on. I was basically doing it myself, only because I didn't know where to begin. My favorite therapists were all gone...Finally; I took myself off of it for some of the side effects. I know I could definitely benefit from some therapy." (Consumer, Group 1)

The sense among participants was that physical health providers, especially in emergency departments, are primarily trained for physical trauma and therefore "don't have the tools and capability to handle behavioral health very well." (Consumer, Group 4)

¹⁴ National Alliance on Mental Illness, <https://www.nami.org/Blogs/NAMI-Blog/January-2018/The-First-Step-in-Getting-Mental-Health-Care>

¹⁵ National Institute of Mental Health, <https://www.nimh.nih.gov/news/science-news/2016/adding-better-mental-health-care-to-primary-care.shtml>

One participant described the emergency room experience this way, "You are treated horribly. [Put in the] drunk tank or [only] somewhat more compassionate [treatment]. I don't remember who mentioned how inappropriate some of the people are in the emergency room, conversations that shouldn't be happening and things like that." (Consumer, Group 4)

Another described her experience during a crisis at the emergency room, "I was brought to the hospital...I was cutting and I had self-injured while in...the hospital. I was tied down and crying a lot. Another patient...in for mental health was trying to comfort me and the security guard was saying, 'Get away from her.' When the doctors finally came to me, they looked at me and said, 'What seems stressful...?'" (Consumer, Group 1)

Presence of stigma within the hospital network and physical health institutions, and how it impacts patients when it is combined with network inadequacy

The experiences above point to how highly stigmatized mental illness is by society in general, and how this stigma extends itself into the network of medical professionals that are legally required to protect their patients. This stigma is compounded by health insurance companies, as they consistently create "roadblocks for [consumers] to access a covered [mental health service] benefit." (Consumer, Group 5) Hospitals and other physical health institutions make the "assumption that mental illness involves treatment at the maximum level," especially when the treatment protocol requires medication or involves a substance use disorder. (Provider, Group 2)

While all patients are affected by the stigma present within the hospital network and physical health institutions, children are at a significantly increased risk. They cannot advocate for themselves, so they rely on a parent or guardian to provide them with access to the care they require. Many times, however, parents and guardians are met with hostility and unease, as primary care professionals often assume that they are responsible for a child's state of mental health. As one participant put it, "You're immediately put on, you have detectives coming in, [saying] "What did you do to him?'" (Consumer, Group 4)

Persistence of a broader social stigma

The social stigma regarding mental illnesses and their treatment protocols is present within personal and professional settings, such as in families, schools, and occupations. All of the focus groups discussed that the stigma surrounding mental illness is isolating and "lacks compassion, acceptance, [and] understanding." (Consumer, Group 7) From a provider perspective, most of the focus groups recognized that in general, mental illness is perceived negatively within society and is often "[equated]...with violence." (Provider, Group 2) In addition, the surveyed providers agreed that there is an even more profound stigma associated with mental illness when a substance use disorder is applied, or when a medication-assisted treatment protocol must be followed. They infer that both are seen as disabling and adversely affect an individual's ability to function normally in society.

The consumer participants shared their experiences regarding the societal impact of stigma. In several instances participants were ostracized from various communities, such as their neighborhood, workplace, or family after they were hospitalized. There is the overarching idea that the general population is very dismissive of people with mental health disorders because they do not want to get involved or expose their families 'to people with such illnesses.' One participant referred to the stigma as "judgmental and vindictive." She took a leave of absence from her professional job to receive treatment due to a "nervous breakdown" and was immediately isolated from her colleagues when they learned of the reason for her absence. (Consumer, Group 1)

Another participant was signed out of work on a one-month disability leave by her therapist, and when she returned to work, she was laid off one week later. Though it was never explicitly mentioned, she felt as though employers treat mental and physical health issues with a different

perspective, where physical health is seen as recoverable but mental health is seen as permanently debilitating.

Overwhelmingly, both patients and providers articulated that mental illness -- including substance use disorders -- are perceived to be 'bad behavior', or a 'choice' rather than an illness or disease. As one provider participant noted, "The brain is our most important organ. I have no idea why it's been shunted to an optional,..this notion is extremely problematic, especially in terms of receiving effective care for treatable mental health ailments." (Provider, Group 2)

Surprisingly, the participants did emphasize a perceived reduction of stigma among millennials and younger people. In general, the younger generations were considered as more receptive and understanding of mental illness, including substance use. As noted in participant conversation, older generations "just don't want to talk about it" and seem to opt for institutionalized treatment, while younger people were perceived as more open and willing to engage in the difficult conversations currently surrounding mental health. (Consumer, Group 4) One participant, a teacher, expressed her optimism regarding the treatment of those with mental health concerns by her employer; "I am 100 percent positive that if I had [a] mental health issue, I could tell my principal and she would give me whatever I needed." (Consumer, Group 1) This participant, in addition to others across the focus groups, agreed that younger people, in general, are more open about their experiences with mental illness, which contributes to an acceptance of others struggling with mental health disorders.

Conclusion/Recommendations

As stated by Mental Health America, "That such blatant discrimination continues to flourish -- more than a decade after enactment of the Americans with Disabilities Act, some forty years after the adoption of the first modern civil rights' laws, and nearly a century since this organization's establishment as a movement based on principles of social justice -- attests to the deep-rootedness of the stigma surrounding behavioral health disorders. But that such ongoing arbitrary discrimination is countenanced by federal (and state) law is nothing short of shameful."¹⁶

Based on the input from mental health patients and providers, combined with current research on behavioral health systems, we recommend the following to help Rhode Island move mental health parity in our state from aspiration to reality:

- Notification of consumers' rights as well as federal and state parity laws by insurers to consumers at enrollment and to providers within 30 days of a contract start date. It is further recommended that these informative materials be drafted in collaboration with the Health Insurance Commissioner and with patient/consumer advocacy groups as named by the Commissioner. In addition, such notifications should be written in easily understood wording and available in multiple languages.
- More frequent and detailed examinations by the Health Insurance Commissioner of compliance by insurers with non-quantitative parity requirements, especially for provider reimbursement, network adequacy, and patient cost sharing.
 - Specific network adequacy recommendations include:
 - Evaluate and mandate improvements in reimbursement rates through both Medicaid and commercial insurers to guarantee that:
 - Reimbursement rates as set are sufficient for coverage of needed services, and
 - Rates are sufficient to incentivize introduction of needed services that currently are not broadly available in Rhode Island.
 - Reimbursement to providers and consumers happens in a regular and timely fashion.

¹⁶ Mental Health America. <http://www.mentalhealthamerica.net/issues/issue-brief-parity>

- More frequent review by the Health Insurance Commissioner of online provider directories for compliance with state and federal regulations, and development of an improved mechanism for consumers to report out-of-date information to the Health Insurance Commissioner.
- Removal by insurers of burdensome prior authorization and case management requirements that are not productive or are contrary to achieving parity.
- Simplify and standardize patient/provider authorization, claims, and appeals processes and improved transparency of plan benefits and restrictions.
 - A priority should also be that plan benefit changes, including drug formularies, should be restricted to the subscriber's renewal.
- Standardize treatment protocols, levels of treatment, and coverage limits for each mental illness, including substance use disorders, across insurers and plans. Treatment protocols, levels of treatment, and limits must be based on evidence and should utilize a variety of medical and mental health diagnostics, as determined by a group of mental health experts. No more than one-third of these mental health experts may be employed by, or contracted with, public or private insurers.
- Increase state funding for behavioral health systems improvements and expansion – particularly for outpatient services -- and investment in efforts to change public attitudes about mental health.
- Scale up integration of primary and behavioral health practices for better coordination and to allow for better preventative and intermediate behavioral health delivery.
 - Most particularly address improvements in treatment and integration of behavioral health care in hospital emergency rooms to improve patient experience and treatment protocols, as well as to better divert treatment to more appropriate settings
- Improve transparency by requiring insurers to prominently post benefit booklets, medical policies, definitions, and appeal processes on both their consumer and provider website portals. Their precise location should be disclosed to consumers and providers in writing on enrollment or within 30 days of the contract's start date.
- Expand prevention and wellness incentives, such as gym memberships, to include mental health focused activities such as mindfulness-based stress reduction programs.

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