Creating greater accountability within the mental healthcare ecosystem



PHARMACEUTICAL COMPANIES OF Johnson Johnson

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Introduction

The covid-19 pandemic has made it clearer than ever that mental health is essential for wellness, yet many individuals struggle to access consistent, affordable care. In the US, an estimated 44 million adults require mental health services; however, access to these services can be enormously challenging.¹ Health insurance providers generally offer mental health services that are far more restrictive than those offered to maintain physical health. Ranging from fewer covered behavioral health visits to higher deductibles and copays, these restrictions further burden those seeking treatment for mental illness.²

The health consequences for this are manifold, resulting in suicides and overdoses but also negatively impacting physical health. Conversely, patients with chronic conditions including cardiovascular disease, cancer, diabetes and arthritis are more likely to experience mental health disorders.³ Combined, these mental and physical health challenges lessen the likelihood that a patient will effectively follow a treatment plan for their illnesses.⁴ The intertwining of physical and mental health makes parity of coverage essential. Patients need a sustainable, accessible and equitable healthcare system to be truly well.

All involved stakeholders must be accountable for addressing the ongoing mental health crisis exacerbated by the covid-19 pandemic. Expanding on the World Health Organization's health system building blocks, Economist Impact identified five domains for examining the role of accountability in the healthcare ecosystem. These domains include: state and local policies; finance and incentive design; infrastructure and data; workforce and training; and service delivery and cultural acceptance. In this paper those domains were combined into three core stakeholder groups: policymakers and insurers; technological innovators and users; and patients and providers as shown in Figure 1. Success in these domains is interdependent, and this overlapping accountability will be our focus. Through the combined effort and innovation of all stakeholders, patients struggling with their mental health can finally receive the care they need.

Policymakers and insurers Patients and providers Workforce shortages A sustainable, Cultural Resolving accessible and barriers to fragmentation equitable service through mental health care delivery innovation ecosystem Unregulated Internet as patient data infrastructure Implementation ` challenges for telemedicine telemedicine telemedicine and users

Figure 1. Stakeholder groups and domains of accountability

Source: Economist Impact

Policymakers and insurers

The Mental Health Parity and Addiction Equity Act (MHPAEA) of 2008 took a major step forward toward establishing parity between mental and physical health. This act mandated that providers offer benefits for mental health disorders and substance use issues equal to those offered for physical health. The act was more comprehensive than past parity laws. It required plan management strategies and non-quantitative treatment limitations on par with physical healthcare requirements. The Patient

"Our laws and financing haven't caught up with how society is now thinking about mental health. And that's tricky because, as you know, once the economic systems are in place, the motivation to change them is hard to find."

Angela Kimball, national director, government relations, policy and advocacy, National Alliance on Mental Illness

Protection and Affordable Care Act (ACA) of 2010 went further, expanding the MHPAEA by classifying behavioral health benefits as "essential health benefits," thereby requiring individual and small-employer insurance plans to provide coverage. The previous presidential administration threatened

this progress in 2017-18 by easing restrictions on healthcare plans that did not comply with the ACA's mental health requirements. Had that attempt (and others in the past) to overturn the ACA been successful, millions of people with preexisting physical and mental health conditions would have been at risk of losing their coverage.⁷

Federal policy, state implementation

While these laws offer more financial protection for patients seeking behavioral healthcare, they are not consistently implemented across states.8 In particular, states vary greatly in their enforcement of the laws. To rectify this, several changes can be made on a state level to guarantee fair enactment of parity laws.9 First, all disorders in the Diagnostic and Statistical Manual of Mental Disorders (DSM) and International Classification of Diseases (ICD) should be recognized by insurers. Second, to reduce the disparate financial burden between physical and mental illness, all copays and outof-pocket costs should be the same, no matter the diagnosis of the patient. Third, quantitative treatment limitations (QTL) and non-quantitative treatment limitations (NQTL) in insurance plans should be equal in coverage. And fourth, regulatory bodies should be empowered to enforce MHPAEA (also referred to as the Federal Parity Law) and require moderating agencies to regularly report on this compliance.

The New York Parity Report Act is one example of new state laws to effect these types of changes. The law aims to improve transparency in the treatment and coverage of mental health and substance use disorders, to "compel insurers, health plans, and behavioral health management companies to submit key data and information to the Department of Financial Services for analysis and evaluation of compliance with the federal and State's MH/SUD [mental health/substance use disorder] parity laws culminating in the publication of a report on the Department's website."10,11 Even if these reforms are successfully implemented (and enforced), some patients will of course continue to face barriers to care, often financial as shown in Figure 2. While establishing parity to guarantee that copays and out-of-pocket costs for mental health do not exceed those for physical health is a key step, payment reform is also necessary to create financial sustainability within health systems and ensure access for patients regardless of income.

Figure 2. Top reasons for not receiving mental health services among those who have never received support



Source: NAMI12

Further, integrating behavioral health services into primary care will require sustained financial backing for it to succeed.¹³ Policy-making must embrace a model of collaborative care to treat patients more effectively. Angela Kimball, national director, government relations, policy and advocacy, National Alliance on Mental Illness (NAMI) summarized the problem this way: "We have a society that's talking about mental health, recognizing that mental illness is happening within our families, within our neighborhoods, our workplaces and our communities. But our laws and financing haven't caught up with how society is now thinking about mental health. And that's tricky because, as you know, once the economic systems are in place, the motivation to change them is hard

Resolving fragmentation through innovation

Any conversation about mental illness would be incomplete without discussion of substance use disorders, given how frequently these are "co-occurring" disorders. Approximately half of individuals with serious mental illnesses also struggle with substance use.^{14,15} But fragmented healthcare systems often mean treating only one of these conditions, not both.

New York State is trying to establish a partnership between the New York State Health Foundation, the Office of Mental Health and the Office of Alcoholism and Substance Abuse Services. The hope is that increasing collaboration between these agencies will result in the care patients with cooccurring disorders need. To this end, the agencies have already eliminated financial and regulatory barriers to integrated care. 16

Innovation in federal policy-making, however, is generally lacking. For example, changing Medicaid payment structures may impact continuity of care for low-income individuals. One study found that those with co-occurring disorders,

older adults, and linguistic minorities are at higher risk for inadequate care. ¹⁷ In the future, if policy changes expand Medicaid coverage and increase collaboration and accountability between stakeholders and institutions, individuals with cooccurring disorders are more likely to access the care they need.

One example of Medicaid reform is the new Medicaid Reentry Act. If passed, this act would offer Medicaid coverage to currently incarcerated individuals who qualify, beginning 30 days before their release. This extension would help bridge a gap in coverage by providing needed services and medications at release, including necessary testing and care for covid-19 before these individuals return to their communities.¹⁸

While wider structural change at the federal level is necessary, steps have been taken to improve access to mental health services. One example is the new National Suicide Prevention Lifeline Number. In 2020, the FCC established a new three-digit number (988) to replace the previous lifeline number (1-800-273-TALK). ¹⁹ The hope is that individuals in crisis will be more likely to remember the shorter number. In the case of a mental health crisis, 911 responders may not have the specialized expertise to properly assist. In these cases, having trained mental health responders via the 988 helpline can address the specific needs of someone in crisis. ²⁰

Technological innovators and users

The emergence of covid-19 forced telemedicine to the forefront since patients needed to access care from home. Even among providers already utilizing telemedicine, 17% of virtual health providers used telemedicine daily before the pandemic, whereas during the pandemic that number rose to 40%. Providers also reported feeling more comfortable using the technology and highly satisfied with the care they were able to offer. Many said they anticipate continuing to use telemedicine more after the pandemic ends.²¹ By adapting to new technologies and embracing the accompanying changes, providers may be able to reach patients who previously did not have access to care, while simultaneously maintaining high-quality care for those patients they previously saw in person.

Internet as infrastructure

Telehealth has been particularly beneficial for rural populations and used to great effect in some states. For example, Arkansas provides some specialized medical care through telemedicine, including mental healthcare, to improve accessibility in rural regions. The initiative's success has resulted in deploying similar strategies to reach diverse and atrisk populations such as incarcerated women and people living with HIV.²² Alabama has established a similar program. A rural mental health clinic with limited resources but access to patients has been partnered with an academic health center capable

of providing care.²³ Innovative partnerships like Alabama's can improve access to care and work toward parity.

Physical distance from behavioral health services is a common reason that military service members go untreated. Frequently members of rural communities themselves, approximately 300,000 service members and over 1 million of their dependents are geographically distant from mental healthcare providers, making it even more unlikely they will use such services.²⁴

While there are many advantages to the accessibility of telemedicine, that access is not equal. Over 20 million Americans still do not have broadband internet, making telemedicine unavailable.²⁵ Without high-speed internet, providers are unable to connect with patients, limiting the expansion of health programs designed for those in rural communities.²⁶

Access to telehealth services is also affected by race. During the pandemic, Black patients were less likely to receive care via telehealth and, when they did, were more often limited to audio-only calls.²⁷ Maggie Merritt, executive director of the Steinberg Institute, an advocacy organization dedicated to improving mental health policy-making, explained that the devastation of covid-19 has only exacerbated the inequities experienced by

communities of color: "Covid has really poured salt in the wounds that have been long held by populations that have been especially weighted down by poverty, discrimination, and all of these social factors that we're very well aware of." The federal government must be held accountable for providing high-speed internet to all Americans so that they can access virtual healthcare as well as other essential resources.

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Implementation challenges for telemedicine

Even for those with internet access, other barriers can keep patients from receiving virtual care. The Department of Veterans Affairs attempted to implement a telehealth program that would allow veterans to access mental health services. While the program initially got a positive response from participants, less than half of providers reported actually using the service. The most common barriers to use in this case were reported to be lack of training and a high administrative burden.²⁸

Telemedicine can also be a challenge for older adults. While they may be open to learning how to use the new technology, other factors such as dementia or social isolation (meaning there is no one to help them use the technology) may make telemedicine impossible. Older, disadvantaged patients are disproportionately less likely to be able to access telemedicine services. For these vulnerable

populations, in-person visits remain a key part of their care.²⁹ Further, it is estimated that 50% of older adults with mental illnesses do not receive treatment, whether through telemedicine or in person, because of a combination of stigma and lack of diagnosis.³⁰

Other diverse populations may struggle to access telehealth because most telehealth systems are not designed to be culturally appropriate in different contexts (including individuals who do not speak English, who have varying levels of privacy in their own homes, etc.). Richard Frank, senior fellow in economic studies and director of the Schaeffer Initiative on Health Policy at the Brookings Institution, argued that, "as we think about extending telehealth, I think we need to be creative about how we use the technology to address populations that use the mental health system differently." Without making patients aware that virtual care is available to them and without sufficient training on how to access that care, patients cannot benefit from these technological advancements.

Unregulated patient data

The benefits of virtual care are many, but they can also come at a cost. With the rapid rise of telemedicine technology and mental health apps, patients at times sacrifice privacy to receive the promised care. A data breach or even standard data sharing between app developers and third parties can compromise patients' privacy. Should an individual's private mental health information become public, it could be harmful to their reputation, health or even future healthcare coverage.³¹

Privacy is often a major concern for technological companies, and mental health app developers must be held accountable for how they manage their users' data. Due to the private nature of healthcare,

the exchange of such data for profit is of significant concern. Users may not realize that they cannot expect the same level of privacy they would get from a psychiatrist when providing data to an app that could share their diagnosis or medication usage with third parties. ³² Regulation for these apps is lacking, and risk-assessment models do not exist to help patients and providers evaluate the efficacy and reliability of mental health apps. ³³ App developers are not held to the same standards as medical professionals, and while the service they offer might resemble traditional healthcare, they think of individuals who download their apps as "users," not patients.

A study conducted in 2016-17 and updated in 2018 identified 61 major mental health apps (56 of which were still active in 2018), of which 41% did not have a privacy policy to let users know how their personal data would be shared. Additionally, these apps requested permission to access various private aspects of a user's device and often encouraged users to share their data with an online community.³⁴ "You have no idea what people are doing with your data in a lot of these systems.... we've sort of skipped past a lot of the protections that you usually have with HIPAA. [In terms of] privacy, [I'm] not clear how that works," said Richard Frank.

Oversight of mental health apps is urgently needed. In 2016, Lumos Labs, the company behind the Lumosity "brain training" program, agreed to a \$2 million settlement with the Federal Trade Commission around charges of deceptive advertising of its games. The company had claimed that Lumosity games can reduce or delay cognitive impairment associated with age and other serious health conditions. Because mental health apps are a new frontier, such claims are not well regulated and therefore often escape oversight.³⁵

Technology has a major role in efforts to improve equitable access to mental healthcare for the one

in five adults in the US who are affected by mental illness.³⁶ Advances in telehealth present an enormous opportunity to expand access to people all over the country. However, for these efforts to be effective, providers must find the people most in need, including those who do not have internet access. And to effectively protect patients and their privacy, new mental health apps must be held accountable for the sensitive patient data they acquire.37 As JoAnn Volk, co-director of the Center on Health Insurance Reforms at Georgetown University, cautions, "Before any changes due to covid are permanent, we need more data about who is getting access for what services. I fear there will be an interest in telehealth standing in for in person care to meet access standards, but what you'd rather see is a network you can access in person or virtually. I would not want to forge ahead without understanding the inequities involved here."

Patients and providers

Workforce shortages

The most crucial step in accessing care is to connect patient and provider, and yet it is estimated that 75% of US counties are experiencing severe shortages of mental healthcare providers. Susan Gurley, executive director of the Anxiety & Depression Association of America, noted: "For a country as rich as America, there are swaths of this population where there [are] just not enough professionals who can help you. And unless that changes, it's just going to get worse for people."

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This shortage predates the pandemic, which has only worsened the situation. Covid-19 has stoked a mental health crisis, with more people needing care than ever before. Simultaneously, however,

providers have had to lay off employees, close programs, and reduce hours because of the pandemic.³⁹ Healthcare workers themselves face historically low wages combined with an everincreasing caseload. Because mental health does not receive the same attention as physical health, it is often underfunded by comparison.⁴⁰ As Nathaniel Counts, senior vice president of behavioral health innovation at Mental Health America, explained, "People talk about the behavioral health provider shortage like it's a natural resource that we're having trouble mining more of. [We don't talk about] the fact that people show up when you pay them."

An immediate barrier to care for many patients is cost. Nearly two-thirds of patients pay out of pocket for their mental health treatment.⁴¹ This can be attributed in part to underinsurance or a lack of insurance, but also to the shortage of mental health professionals. Due to this lack of providers, many patients are forced to go outside their insurance network to find care.⁴²

Cultural barriers to service delivery

Culturally, in the US there is still a stigma associated with mental illness and treatment. This can cause individuals who would otherwise benefit from care to avoid seeking it out of fear of having their mental health issues become public. As Angela Kimball

said, "We're seeing systems that are doing what they were designed to do. And that's to perpetuate marginalization and discrimination of people who live with mental health conditions."

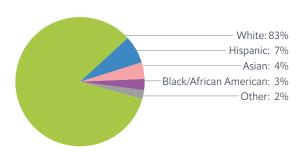
While these attitudes affect all Americans, this stigma is particularly prevalent among older populations, communities of color, and veterans. 43,44 Beyond general social stigma, for people of color, mental health concerns are often disregarded by healthcare providers or not considered in the first place due to the institutional racism of the healthcare system. 45 "The main drivers [of poor mental health] in the United States relate largely to social justice. For instance, as a population approach, levels of chronic illness correlate with income; levels of mental health problems, and substance abuse problems, correlate with income; levels of trauma experience correlate with income. And if you add the impact of racism and bias, those interact with those correlations, making them more substantial," explained Alexander Blount, professor emeritus of family medicine at UMass Chan School of Medicine and president of Integrated Primary Care, Inc.

It is not only stigma that makes it challenging for these populations to access care. Members of racial or ethnic minorities also experience more limited access to care because of a variety of barriers, including underinsurance or lack of insurance, language barriers, distrust of the healthcare system, and a lack of diversity among the professionals providing care, as shown in Figure 3.⁴⁶ In particular, Native Americans experience a lack of mental health and substance use treatment resources.⁴⁷

Some solutions have been proposed for this discrepancy in access: cultural competency training, using cultural formulation interview techniques in psychiatric sessions, and increasing the representation of minorities as providers in behavioral health services. 49 Research has shown that a collaborative care strategy has improved

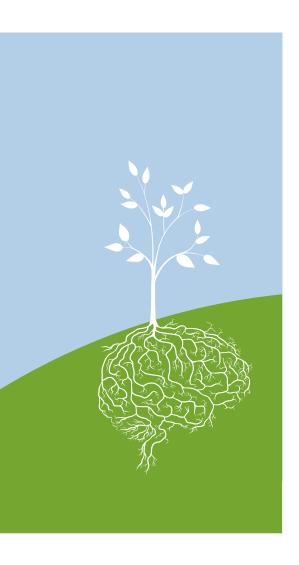
both access to and quality of mental healthcare to Hispanic and Asian populations.⁵⁰ Integrating physical and mental healthcare could improve access for many populations. Of primary care patients included in one study, 60% represented patient groups who were less likely to seek mental health assistance.⁵¹ By merging physical care with mental care, providers could reach these vulnerable populations who are less likely to access mental health resources. While efforts are being made to improve access to care and make it affordable for all patients, inconsistent quality of care remains an issue. We must ultimately answer the question: Who is accountable for holding providers to an equitable, high standard of care for all patients?

Figure 3. Race/ethnicity of the US psychology workforce, 2019⁴⁸



Source: APA. CWS Data Tool: Demographics of the U.S. Psychology Workforce. American Psychological Association; 2019. Available from: https://www.apa.org/workforce/datatools/demographics

Conclusion



Mental healthcare in the US has a long way to go before it achieves parity with physical healthcare. But as the pandemic continues with no clear end in sight, never has the importance of mental health been so apparent. The stress of covid-19 both on individuals and on the healthcare system as a whole has only exacerbated the longstanding challenges in mental healthcare. To achieve the goal of a sustainable, accessible and equitable mental healthcare system, all stakeholders (policymakers, insurers, technology developers, and healthcare providers) must be accountable for making changes to improve the future for mental healthcare. Only by approaching this issue holistically will we be able to create a mental healthcare system that serves all patients fairly and responsibly.

Appendix: About this report

Project methods overview

Creating greater accountability within the mental healthcare ecosystem is a report by Economist Impact (EI) exploring the current status of challenges and opportunities within mental health in the US. Mental health is a widely discussed topic with clear barriers to sustainable, equitable and accessible care, including challenges within infrastructure and policy, technological developers and the mental health workforce. However, accountability and the assurance of quality care is absent from the conversation. This paper aims to identify areas for greater accountability across different stakeholder domains in order to better support mental health and ultimately achieve and move beyond parity in the US.

The project began with a pragmatic literature review to identify key themes regarding the status of mental health in the United States. The structured literature search identified key recent literature by interrogating selected databases for papers related to the burden of mental health in America and why parity has been so difficult to achieve. The search covered the effects of mental health at the individual,

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- **Alexander Blount**, professor emeritus of family medicine, UMass Chan School of Medicine; president, Integrated Primary Care, Inc.
- Nathaniel Counts, senior vice president of Behavioral Health Innovation, Mental Health America
- **Richard Frank**, senior fellow in economic studies and director of the Schaeffer Initiative on Health Policy at the Brookings Institution
- **Susan Gurley**, executive director, Anxiety & Depression Association of America
- Angela Kimball, national director, government relations, policy and advocacy, National Alliance on Mental Illness (NAMI)
- Maggie Merritt, executive director, Steinberg Institute
- **JoAnn Volk**, co-director of the Center on Health Insurance Reforms (CHIR) at Georgetown University's McCourt School of Public Policy
- Anonymous, US public sector representative

community, and state/national level in order to better understand and measure challenges and successes. Literature relating to the policy environment, best care practices, and barriers to addressing challenges was also retrieved.

Grey literature was searched in order to retrieve guidelines, policies, and frameworks which were not listed in scientific databases. There was no date restriction on the search, but it focused on gathering the most recent and relevant literature.

Second, we conducted eight expert interviews to complement the literature review, and glean a practical perspective of the mental health ecosystem in the US and disparities and innovative ideas to counter them. Experts were selected based on geographic and topical expertise. We identified key categories of interviewees: clinicians, academics, community experts, advocacy organizations and policymakers or those familiar with policy.

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