Testimony of Jeremiah Gardner, MA, LADC, Hazelden Betty Ford Foundation Before the House Energy and Commerce Committee Subcommittee on Health On H.R. 3545 – May 8, 2018

Summary: Mr. Chairman, thank you very much for inviting me to participate in this important hearing. I am grateful to you and the Members of the Subcommittee for your leadership in addressing the opioid addiction crisis, and for the opportunity to testify in support of H.R. 3545.

My name is Jeremiah Gardner, and I am a person in long-term recovery. For me, that means I haven't used alcohol or other drugs in almost 12 years and have been able to build a life, family and career defined by service, community, purpose and gratitude. I'm also the son of a wonderful woman whose life ended three years ago due to her opioid use disorder – one of the hundreds of thousands of Americans lost to overdose in recent years. I am a recovery advocate in my community and nationally. I also have a master's degree in addiction studies and am licensed as a counselor in Minnesota. In addition, I work as a communications professional for the Hazelden Betty Ford Foundation, a nonprofit that has been fighting for patients and their rights for decades.

H.R. 3545 would be a key step in giving those with opioid use disorder greater access to the lifesaving health care they need. The bill would reform the outdated and onerous 42 CFR Part 2 ("Part 2") privacy regulations, which have become a barrier to access and patient safety and deprive patients of the full benefits of modern health care services. Part 2 regulations, enacted in the 1970s, are applied neither fairly nor uniformly, applying only to a small subset of addiction treatment providers. They have never been enforced and actually perpetuate the very stigma that causes discrimination, rather than providing any real extra protection against it. By aligning Part 2 with the Health Insurance Portability and Accountability Act ("HIPAA") for "treatment," "payment," and "operations" purposes – thus allowing the use and disclosure of patient information when needed to facilitate optimal care and protect patient safety – H.R. 3545 will continue Congress's effort to bring much-needed parity between care for addiction and care for physical health conditions. The bill will enable addiction care to become more fully integrated within the broader health care system so patients have multiple access points and can get support for this chronic condition beyond the acute care stage. At the same time, it will strengthen Part 2's protections against discrimination and other potential abuses of information in criminal and civil courts. For all of those reasons, H.R. 3545 is an essential piece of the federal opioid response.

While this testimony is professionally informed, I will focus primarily on my personal experiences as a patient, a person and advocate in recovery, and a son who lost his mom to addiction.

Testimony (Cont.): For whatever reason, Sept. 25, 2006, was my turning point. When I woke up in a hotel at 10 a.m. that Monday – late for work, sick, tired, and crying – I made the fateful decision to stop fighting the reality of my substance use disorder and ask for help. I called a friend and within several hours was admitted to a treatment center. We didn't once talk about privacy that day; it wasn't the slightest factor in my help-seeking decision. I did, however, make some calls before I was driven to the treatment center. I called my boss first. I figured it would be hard to skip work – or in my case, multiple weeks of work – without explaining. It didn't even cross my mind to keep it a secret. I don't even know how that would have been possible. I also called some fellow volunteers to let them know I wouldn't be at an upcoming community event. And I called my girlfriend to let her know, too. And then I got the help I needed at a small, nonprofit facility subject to Part 2.

What sort of message do you think I internalized when I was asked to sign multiple consents at multiple times during my care? It wasn't that my provider or the system cared deeply about me or was trying to protect me. Instead, I was getting the subtle, stigmatizing message that my illness may demand extraordinary secrecy. Before, I hadn't been under the impression that I needed to or could keep my treatment a secret. In fact, getting help had seemed like a good thing. To be sure, nobody wants to go to the hospital, clinic or an addiction treatment center. And there's some confusion and frustration around not being able to get healthy on one's own, born of ignorance about the disease. But I hadn't planned to feel shame for getting help. I can tell you I had also intuitively expected that anyone working with the facility would know about me, and that anyone with my insurance company who needed to know would, too. Why would I expect anything differently? And yet, the unusual culture of secrecy seemed disconnected to the other idea I was learning – which is that I had a health condition, rather than a problem of will or morals.

It’s true, of course, that many of us feel guilt and shame over the behaviors that were the symptoms of our health condition. But the idea that getting help and getting well might be a secret we want to keep is an idea that was planted in me. Ultimately, I chose to be as open as I would about any other illness – to be authentic and not establish dual identities – because it felt intuitively like the healthy choice.

Now, had I lost a job after I got back to work because of my treatment, that would have been terrible. It also would have been clearly discriminatory, actionable and wrongheaded. Yes, discrimination happens, and we must prosecute it to the full extent of the law. But if we want to take that next step as a culture, and create an environment that produces less discrimination and addresses addiction more openly, we have to change the laws and institutions that unintentionally validate stigma. We cannot fight discrimination with stigma. And we cannot treat addiction as a health condition unless we do just that – actually treat it like a health condition. It’s time for our law to reflect the cultural change we want and need to see. Lives depend on it.

Even if I had tried to keep my illness a secret, Part 2 would not have protected any more than HIPAA against my employer finding out about my treatment. If that information got to my employer without my consent, it would have constituted a HIPAA violation. Indeed, if you examine the privacy breach scenarios most often cited by those concerned about this bill, they are violations already addressed by HIPAA.

It may be true that the more health care and insurance company employees who touch my record, the greater chance there is someone may violate HIPAA. I will stipulate that, conceptually. But is that a widespread problem in the real world? For-profit addiction treatment centers are not subject to Part 2. Is HIPPA failing their patients? I don’t think so. Are we seeing more privacy violations at the Department of Veterans Affairs, where patient record regulations are already aligned with HIPAA? Not that I’m aware of.

Congress decided that Part 2 provides no extra protection for our veterans, service men and women, and their families when you exempted the VA from the burdens of Part 2 last year. That legislation was passed without controversy, and the harms warned of by those concerned about H.R. 3545 have not manifested. If HIPAA is sufficient to protect the privacy of our veterans and service members seeking treatment for substance use disorders, why would it not be for civilians?

HIPAA provides sufficient protection, and its violations are rigorously enforced, unlike Part 2 violations, which have never been enforced by a single court – mostly because Part 2 violations are almost always a HIPAA violation, too. It's no surprise the health care system, as an ecosystem, is attuned and geared toward HIPAA compliance. And yet, think of the coordinated care and patient safety we sacrifice for Part 2's illusion of extra protection.

Just three short years ago, my stepfather found my mother dead on her bed at home, leading to the worst phone call of my life. I am the oldest of five kids; she also had seven grandkids and, like a lot of moms, was a towering presence for our entire family. But, in an instant, she was gone. Just 59 years old. Prescription opioids – which she once described as the "monkey on her back" – had finally become something much worse.

My mom had started taking prescribed opioids about 20 years earlier for pain, at the onset of what would come to be known as our national opioid crisis. Like so many, my mom never got off the pills. Eventually, she was taking 400 mg of morphine a day, as prescribed. We kids were mostly unaware. But I did learn in the early-90s, prior to HIPAA, that my mom went to addiction treatment for what I understood to be alcohol problems. I didn't really know or comprehend what having a problem meant at the time, and honestly, it was something that sort of came and went for our family.

But, all the while, my mother’s opioid journey continued unabated. I won’t pretend to know all the details, but I can’t imagine a scenario where her doctors knew about her prior addiction treatment, even though it was a significant fact in her health history. My mom’s pain never got better, by the way – only worse. And longtime opioid use eventually contributed to other ailments, deteriorating mental health and additional medications. It was a vicious cycle of problems, more medication, and more problems to justify more medication. Not to mention, more doctors. And, until she opened up to me about this painful history during those final months of her life, my mother’s battle was fought mostly internally, quietly and secretly.

In the end, she had a complex combination of opioid use disorder, chronic pain, acute pain, depression, anxiety, arthritis and other physical conditions, an assortment of social stresses, and – because she relied so much on pills for so long – a deficit of healthy coping mechanisms. Her pain, as it is with so many chronic pain patients, was profound – manifesting itself, like addiction does, physically, mentally, emotionally, socially and spiritually.

What my mom needed was a good year or more of integrated, coordinated care and checkups – surrounded by support. She needed her multiple care providers to have the full picture of her health and to work together. Instead, they kept prescribing deadly amounts and combinations of drugs to someone with the disease of substance use disorder. At the very end, while her primary doctor was on vacation, a fill-in prescribed her fentanyl patches to help with the pain that followed two knee surgeries and was complicated by the chronic pain and poor health she had developed over her 20 years of opioid use. My mom misused the fentanyl patches along with Vicodin and anxiety medications, and it killed her just a couple of rooms away from her husband and 13-year-old grandson.

Now, I can’t tell you exactly where Part 2 and HIPAA fit into my mom’s story. But I can say unequivocally that my mom had a severe substance use disorder and did not get anything close to the coordinated care she needed. Instead she got subpar care. Could she have been more forthcoming and actively coordinated her care herself? Yes. But as a professional in this field, and someone with lived experience, I can tell you that's an impossible expectation of someone who is in active addiction – someone whose brain is not functioning properly. In reality, there's no way my mom would have volunteered information that would have prevented her from getting pills for her pain – even though she knew the pills were a problem. That irrationality, indeed, is the very nature of addiction – and is all the more understandable in a health care system that may have been prone to just take away her pills, rather than get her the critical care she needed.

Addiction is a disease that has been neglected and marginalized for generations. It's time to bring the full weight of our healthcare system to bear against America's longstanding addiction crisis, which the opioid epidemic has tragically revealed to the masses. Mainstream health care is finally at the table, no longer avoiding this illness and the people who have it, but seeking to treat it on par with other conditions and physical ailments. It's time for primary health care and specialized care providers like Hazelden Betty Ford to work together to address this public health crisis. Part 2 gets in the way with cumbersome regulations and leaves baked into our law the idea that addiction warrants extraordinary secrecy, which perpetuates the very stigma we continue to work so hard to smash.

I have the utmost respect for the folks who have expressed concern for this bill. But please don't think they represent the entirety of the patient community or that patients are unified against this change. I talk to real people every day who are in recovery or still struggling. My organization works on the ground day-in-and-day-out, helping thousands of people a year. We're in the trenches on this, and I'm telling you, when patients are in the help-seeking mode, they generally just want to know: *Can you help? And how can I pay for this?* This bill addresses the questions patients and their families care about most.

More and more people are recovering out loud, and saying “no” to secrecy and shame. There is even now a certain kind of stigma against those who stigmatize people with addiction. In other words, we’ve made good progress, and aligning Part 2 with HIPAA will continue that progress in an important way.

This bipartisan bill is about priorities and the future of addiction treatment in the United States. If you believe patient safety is the most important priority, I urge you to vote for H.R. 3545. And if the future you envision is one with less stigma; open, routine conversations about addiction and addiction care; and more people getting the best possible help on par with other health conditions, I also urge you to pass this important legislation.

Because I work for the Hazelden Betty Ford Foundation, the largest nonprofit provider of substance use treatment, education and prevention services in the world, I also have submitted, as supplemental material, a letter from our CEO and Chief Medical Officer, further highlighting our organizational insights on this bill.

We have arrived at a pivotal point in the history of addiction treatment and recovery. Part 2, once valuable in the absence of HIPAA, is now impeding progress toward the kind of coordinated care that will better protect and ensure patient safety. Maintaining unnecessary barriers to care during the nation’s worst addiction crisis ever would be a missed opportunity and potentially grave mistake.

Thanks again for the opportunity to share my views. I look forward to answering your questions.