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November 3, 2015

The Honorable Joseph Pitts
Chairman
Subcommittee on Health
Energy and Commerce Committee
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Gene Green
Ranking Member
Subcommittee on Health
Energy and Commerce
2322A Rayburn House Office Building
Washington, DC 20515

Dear Chairman Pitts and Ranking Member Green:

Thank you for allowing me to enter my statement into the record for today's markup on H.R. 2646, the Helping Families in Mental Health Crisis Act. Let me begin by saying that we all agree that our current mental health system is in crisis. As a trained psychiatric nurse, I believe that I can and have contributed to the conversation surrounding mental health legislation. After working for a year on the Energy and Commerce Subcommittee on Oversight and Government Reform to take a deep dive into the flawed mental health system, Congressman Tim Murphy (R-PA) invited me to work with him to reform, repair, and revamp it. Our focus the whole time has been on patients and their families. They are the people that truly matter in this conversation.

Unfortunately, federal mental health policies have not been helping our most severely mentally ill patients. While working as the Chief Psychiatric Nurse for the Veterans Affairs hospital in Dallas, I personally saw the harm caused by federal mental health policies. For example, the Institutions for Mental Diseases (IMD) Exclusion, which prevents Medicaid from paying for care received in a mental health facility if the hospital has more than sixteen beds, is a major cause of increased homelessness and incarceration. Along with the IMD Exclusion, there are several other policies that Rep. Murphy and I agree would be beneficial in helping patients gain access to treatment.

H.R. 2646, the Helping Families in Mental Health Crisis Act, a collaboration by two mental health providers who are members of congress, reflecting feedback from stakeholders and other members of congress, addresses many of the policies that we can change now to help patients struggling with severe mental illness and substance use disorders. Small changes to the Health Information Portability and Accountability Act (HIPAA), expanding Assisted Outpatient Treatment, restructuring the Substance Abuse and Mental Health Services Administration, and repealing the IMD Exclusion were the large federal policies to tackle. I would like to take this opportunity to express my thoughts on these four policies.

First, passed in 1996, the Health Insurance Portability and Accountability Act (HIPAA) was enacted in order to improve the continuity of insurance coverage and to combat waste, fraud, and abuse within healthcare. HIPAA also directed the Department of Health and Human Services (HHS) to issue a rule governing the use and disclosure of individually identifiable health information. This HIPAA Privacy Rule, since its inception, has resulted in confusion among providers and triggered over 70,000 complaints in less than a decade. The Privacy Rule is extremely frustrating for well-meaning family members and caregivers of a loved one with severe

mental illness or substance abuse disorders. Treatment providers often do not understand what information they are allowed to share with a caregiver or what information they can accept from family members. Notably, the authors of HIPAA never intended to create such obstacles in the mental health and substance abuse community. We all agree that the goal of any mental health reform legislation must address these discrepancies.

H.R. 2646 provides an extremely narrow change to the HIPAA, allowing a caregiver or loved one to receive information on diagnosis, medication, and follow-up appointments. Certain criteria must be met by a loved one or caregiver in order to receive this type of protected information. Extensive research, including a National Institute of Mental Health's "Recovery After Initial Schizophrenia Episode" (RAISE) first episode psychosis study recently published in October showed that patients who were prescribed medications complemented with therapy and family support were more successful in the program than those who did not have family support. Parents and caregivers become powerless to ensure that prescriptions are filled, taken, and transportation to appointments is arranged if they are unable to access information about diagnosis, treatment, and appointments. For families and caregivers that already provide housing, care, management, and support, receiving this information is positively life-altering. While only 4% of the population has a serious mental illness, this fix would only apply to an even smaller subset of those individuals.

Second, Assisted Outpatient Treatment is a valuable state tool that has been established in 46 jurisdictions (45 states plus the District of Columbia) and dozens of counties across the country, directing treatment in the community for patients with serious mental illness who are difficult to treat. Assisted Outpatient Treatment (AOT) is a proven and successful jail and prison diversion program for individuals with serious mental illness that can generate savings and allow states to expand community mental health services. AOT has been shown to reduce homelessness, incarceration, and emergency room visits by about 70% for participants. H.R. 2646 actively supports the states that have implemented AOT programs and encourages the five states that have not yet enacted AOT laws.

While it is largely true that AOT recipients are more likely to live in poverty, this is due to the fact that severe mental illness is often a major cause of poverty. However, AOT allows recipients to live safely in the community and avoid hospitals, homelessness, and incarceration. In 2005, as New York's Kendra's Law was reaching its initial sunset, an opposition group claimed that the application of the law had been biased against African Americans. In reauthorizing Kendra's Law for another five years, the New York legislature called for an independent study to examine this claim. In 2009, the Duke University Medical School researchers discredited the claim of racial bias. The report concluded: "Analysis implies that the AOT rate is influenced by a number of 'upstream' social and systemic variables such as poverty that may correlate with race. However, we find no evidence suggesting racial bias in the application of AOT to individuals. Defining the target population as public mental health system clients with multiple hospitalizations, the rate of application of AOT to white, black and other minority recipients approaches parity." AOT is a valuable policy option to appropriately treat individuals with serious mental illness in the least restrictive settings possible.

Third, the Substance Abuse and Mental Health Services Administration (SAMHSA) is charged with implementing 112 federal programs to address mental illness, but a recent Government Accountability Office (GAO) report documented that SAMHSA's approach to interagency coordination is lacking. The federal government spends \$130 billion towards mental health services each year, but our nation still lacks 100,000 psychiatric beds, our largest mental health "hospitals" are correctional facilities, and the federal agency that handles mental health does not employ a psychiatrist.

H.R. 2646 intends to refocus SAMHSA to be the preeminent federal agency that it can be by serving our individuals with mental illness and serious mental illness. Our focus must be bringing a clinical and evidence-based practice focus to programs, eliminating programs that do not work, and creating new, innovative programs to serve patients.

Last, the Institutions for Mental Diseases (IMD) Exclusion has been in place since 1965 when Medicaid was enacted and has, unfortunately, caused more harm than good. Seventy years ago, there were 550,000 inpatient psychiatric beds for a country half the size it is now. Today, there are fewer than 40,000 inpatient psychiatric beds. The IMD Exclusion has accelerated the shortage of psychiatric beds during the “deinstitutionalization” process severely because it gives states an economic incentive to close hospitals. The IMD exclusion has inadvertently caused our jails and prisons to become warehouses for the mentally ill and for our homeless population to grow exponentially. Patients with mental illness and especially severe mental illness need access to acute care psychiatric beds to have a chance for recovery. While repealing the IMD Exclusion is not a magic trick for getting patients psychiatric care, we must provide more options for patients, especially when they reach the point of crisis.

H.R. 2646 helps by repealing the IMD Exclusion, allowing those with mental illness to regain access to the treatment they deserve. It could also save taxpayers the burden of costly emergency room visits for patients with severe mental illness and the expense of incarcerating prisoners with severe mental illness. It can help us decrease our homeless population and instead help people gain access to treatment and stable housing by making it more economically viable for hospitals and other residential psychiatric facilities to treat them when they are in crisis or recovering from crisis.

While I understand that concerns have been raised by various groups over some of the aforementioned issues, I strongly believe that we must take action for our population with serious mental illness. We cannot sit idly by any longer. We must enact policies that bring individuals to treatment rather than leaving them on the streets and in prisons. I recognize that a comprehensive and ambitious piece of legislation such as this can always improve. However, H.R. 2646 takes a strong step forward in mental health reform. We must take action. As we debate this bill, people are denied beds, denied care, and are floating through the pervasive cycle of mental illness without attention. Everyone deserves care. Work with me to pass this bill for the sake of those who truly matter.

Sincerely,


Eddie Bernice Johnson
Member of Congress