Congress of the United States
Washington, DC 20515

October 23, 2015

The Honorable Fred Upton
Chairman
Energy and Commerce Committee
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Frank Pallone, Jr.
Ranking Member
Energy and Commerce Committee
2322A Rayburn House Office Building
Washington, DC 20515

Dear Chairman Upton and Ranking Member Pallone:

We write to you as Members of the Committee who are deeply concerned with our nation's broken mental health system. For far too long, mental health and mental illness have been left in the shadows, and we believe the only way we can fight stigma, improve access to services and treatments, and bring mental health up to parity with physical health is to start treating the brain as a part of the body. Our policies and systems need to reflect the fact that mental illness is a disease and that if the right services, supports, and treatments are available, people can and do recover.

We are encouraged by the bipartisan discussions that are taking place in the Energy and Commerce Committee on this topic, and we thank you for your leadership. We also thank Representative Tim Murphy, a Member of the Energy and Commerce Committee, for his passion in bringing mental illness, particularly serious mental illness, to the forefront and for participating in this Committee effort. However, while there are many concepts and ideas in Representative Murphy's bill, H.R. 2646, that we can support and would like to see move forward, we would like to take this opportunity to express our concerns with specific provisions we believe would do more harm than good if enacted.

We strongly oppose provisions that would restrict patients' civil rights. Individuals with mental illness should not have different rights under the law than all other types of patients. We can't say in the same sentence that mental illness should be treated *equally* to physical illness, but that patients with mental illness should be treated *differently* than patients with physical illness. To truly address the problems with our mental health system, we need to fight to ensure access to treatments and services that work, the same way we would for other diseases that afflict our nation, like cancer or heart disease. Regressive reforms to the mental health system that diminish patient rights and create a less welcoming treatment environment will result in worse quality of care.

First, we oppose provisions that would restrict patients' privacy rights. Federal privacy laws such as the Health Information Portability and Accountability Act (HIPAA) provide patients with important rights and protections with respect to their health information. In general, such privacy protections allow patients to seek treatment with confidence that their health information will not be shared except as they direct.

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While maintaining patient privacy is paramount, the ability of family and caregivers to be involved in a patients' care can also be a critical part of the recovery process, and loved ones should be included when possible and in the patients' best interest. Fortunately, HIPAA does *not* currently prevent information sharing in many cases, despite a widespread misunderstanding that it does. For example, providers may always listen to caregivers and family members. Providers also have the discretion to share information with family and caregivers when a patient is incapacitated and it would be in the patients' best interest to do so.

Section 401 of H.R. 2646 would create an exception to HIPAA that would allow health care providers to disclose protected information to the caregivers of individuals with serious mental illness, including in circumstances overruling the specific direction of the individual against such disclosure. By reducing existing privacy protections, this provision would deter individuals from seeking the treatment they need. As the Department of Health and Human Services (HHS) Office of Civil Rights has stated, "[e]nsuring strong privacy protections is critical to maintaining individuals' trust in their health care providers and willingness to obtain needed health care services, and these protections are especially important where very sensitive information is concerned, such as mental health information."

Section 401 also discriminates against individuals with serious mental illness. Section 401 would create the first and only diagnosis-specific exception to HIPAA's Privacy Rule that would leave individuals with serious mental illness with fewer rights and protections than other patients. We should not support such discrimination against any population, including individuals with serious mental illness.

Secondly, we oppose provisions that would rescind funding from States that have not passed and implemented Assisted Outpatient Treatment (AOT) laws as prescribed by H.R. 2646 or provisions that would provide financial incentives to encourage States to pass or implement such laws. While we understand the intent of Section 206 of H.R. 2646 is to take a less extreme approach than the previous Congress' version of the bill, as currently drafted, Section 206 would eliminate all block grant funding for states without AOT laws. Moreover, even if the bill is read assuming the intention of not punishing states that do not have AOT laws, ignoring the plain text of the legislative language, the bill would still financially punish States that do not have AOT laws on the books. Giving block grant funding preference to states that have enacted AOT laws would reduce funding for other states due to the limited pool of resources.

AOT, also called involuntary outpatient commitment, is court-ordered involuntary outpatient mental health treatment, which can include medication, for certain individuals as a condition of their remaining in the community. Unlike inpatient commitment laws, which generally rely on a finding that an individual poses a threat to self or others, AOT laws generally have lower standards for committing someone into outpatient treatment, such as a finding by the court that an individual needs mental health treatment. Currently, AOT programs are created by State laws and implemented by local communities, such as counties. AOT orders do not provide any treatment services but are court orders compelling individuals to seek specific treatment services from community-based providers.

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The involvement of the court system and law enforcement in treatment of individuals who pose no imminent threat of harm to themselves or others is also concerning. Those who refuse to comply – or do not have proper access to treatment within the community – with court-ordered treatment may be picked up by law enforcement or other designated officials and taken to a medical facility or back to court. The use of the court system and law enforcement to force individuals into care is a dramatic departure from how individuals, particularly those who pose no imminent threat to themselves or others, obtain health care services in this country.

We are also concerned about the disparate impact AOT laws have on minorities and people who live in poverty. Kendra's Law in New York has been one of the most widely implemented, funded, and studied AOT laws. Under that law, individuals who use the public mental health system and minorities have received a disproportionate number of AOT orders. For example, between 1998 and 2008, 67 percent of all AOT orders were issued to minorities, including 35 percent that were issued to African Americans. Such disparities in the use of forced treatment across different populations is concerning.

While we recognize some communities have had success carefully implementing AOT laws in conjunction with the investment in and provision of high quality community-based treatments and services, a blanket nationwide requirement for this type of program or incentivizing States to adopt new or implementing existing laws in no way guarantees success and would have an extremely high risk of both infringing on civil rights and pushing people away from the treatment system rather than toward it. We support States' rights and efforts to adopt and implement such laws that are carefully crafted to meet the needs of their state, but we believe that Congress should not restrict funding or provide funding to incentivize such action since the necessity, effectiveness, and impact of each such laws vary dramatically nationwide.

We also have concerns about provisions that would financially incentivize States to weaken the definition and standards for inpatient commitment or that would restrict funding to states that have stronger standards for inpatient commitment. As mentioned above, States generally use a 'dangerousness' standard to determine whether an individual should be committed to an inpatient facility. The Treatment Standard Under State Law provision in Section 205 of the bill would reduce that standard and could result in more individuals with mental illness, including those that pose no imminent threat of harm to anyone, being committed. This would be a drastic step backwards and brings back memories of the days where individuals could be committed to institutions for life based on very lax criteria.

Thirdly, we oppose provisions that would weaken the Protection and Advocacy system (P&A) for individuals with mental illness. Sections 811-816 would limit the ability of P&As to fulfill their mission of protecting and advocating for individuals with mental illness. In particular, we are deeply concerned about limiting P&As' ability to fight for individuals with mental illness who are the victims of discrimination, to inform individuals of their rights under the law if that information conflicts with the wishes of their caregivers, and to use their non-Federal resources to lobby government officials on policies affecting individuals with mental illness, which is their First Amendment right.

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Finally, we oppose the wholesale elimination of the Substance Abuse and Mental Health Services Administration (SAMHSA). SAMHSA plays an important role in helping individuals with mental illness or substance use disorders get the services they need to improve their lives. While we support making improvements to SAMHSA, including through providing more funding to SAMHSA, we believe that we can best meet the behavioral health needs of this country through a strong SAMHSA. Of particular concern, H.R. 2646 would redirect funding from many current, effective SAMHSA programs, including approximately $100 million in annual cuts to critical substance abuse treatment and prevention programs at a time when we are facing a nationwide opioid overdose epidemic.

SAMHSA is charged with leading public health efforts to advance the behavioral health of our nation. Those efforts include SAMHSA's work in supporting the development and expansion of peer support services, which has improved our ability to meet the needs of individuals with mental illness and substance use disorders, as well as work supporting integrated approaches to treating mental and substance use disorders. For example, SAMHSA is currently administering the Excellence in Mental Health demonstration project, which will infuse $1 billion in new funding for community behavioral health clinics that provide a wide range of services, including 24 hour crisis care and care coordination with physical health and inpatient mental health services. Additionally, H.R. 2646 would cut nearly $5 million from the Minority Fellowship Program, which provides funding to train behavioral health providers from racially and ethnically diverse populations.

Thank you very much for considering our substantive concerns with H.R. 2646 as written. We look forward to working with you in a bipartisan manner to craft an Energy and Commerce Committee mental health reform policy that really serves the needs of patients and families experiencing both mental illness and mental health crises.

Sincerely,

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Cc: The Honorable Joseph R. Pitts, Chairman, Subcommittee on Health
The Honorable Gene Green, Ranking Member, Subcommittee on Health

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