

June 14, 2016

The Honorable Fred Upton
Chairman
House Energy & Commerce Committee
2125 Rayburn House Office Bldg.
Washington, DC 20515

The Honorable Frank Pallone
Ranking Member
House Energy & Commerce Committee
2322A Rayburn House Office Bldg.
Washington, DC 20515

Dear Chairman Upton & Ranking Member Pallone:

We, the undersigned, are writing in support of Title IV of the *Helping Families in Mental Health Crisis Act of 2015* (H.R. 2646), and specifically the Sense of Congress found under Section 401(b).

According to the Department of Health and Human Services, federal privacy rules give individual Americans “rights over [their] health information and sets rules and limits on who can look at and receive your health information.” Unfortunately, in practice some areas of federal privacy regulation limit these rights. Where mental illnesses are concerned, such limitations impact not only those living with these highly disabling conditions, but also their loved ones.

Much like those dealing with the late stages of an acute illness, care for those living with a mental illness is often supported by family caregivers and community supporters. Given the nature of many mental illnesses, such support can be instrumental in ensuring health outcomes for those in need given their knowledge of a particular patient as well as the treatments they are using.

The simple fact is that when it comes to caregivers and community supporters, those with a mental illness can have fewer opportunities to these rights than patients without when it comes to their health information. Unfortunately, such inequity is not limited to those with a mental illness.

With these thoughts in mind, we support the inclusion of Title IV in the underlying legislation and urge your support for its passage.

We also believe that more work needs to be done to address barriers to data and information use that inadvertently diminish the rights of patients in need. As evidenced by the Obama administration’s recent move to ensure HIPAA was not a barrier for the families and loved ones of victims of the Orlando shooting this past weekend, much work needs to be done to ensure that our laws are compassionate to the needs of patients and can take into account individual circumstances when necessary and appropriate. We, the undersigned, are committed to supporting work in the coming Congress that strikes this delicate balance between patient privacy and their right to improve health and wellness.

Sincerely,

Genetic Alliance
Health IT Now
LifeWIRE Corp.
Mutual Autism Research and Care Community
National Alliance on Mental Illness
New Directions Technology Consulting, LLC
PXE International