

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

January 27, 2016

Dear Chairman Upton and Ranking Member Pallone,

We, the undersigned privacy and advocacy organizations, write to strongly oppose H.R. 2646, the Helping Families in Mental Health Crisis Act of 2015. The Act seeks to protect public safety by dedicating resources to mental health services and facilitating sharing of patient records but we believe the sections that address the issues outlined below would instead significantly weaken privacy protections for some of the most vulnerable populations in the United States, while adding little to existing legal protections and potentially having unintended consequences for families and individuals impacted by mental health crises.

Mental health and mental illness are issues that touch most Americans and their families. According to the National Alliance on Mental Illness, 1 in 5 adults in the United States – 43.8 million or 18.5% - experiences mental illness in a given year.¹ We believe that Americans deserve effective and privacy-protective mental health and mental illness law and policy, and our organizations are at the forefront of efforts to develop solutions.

Though we appreciate the bill's attempt to address public safety concerns, we are deeply troubled by H.R. 2646's proposed changes to the Health Information Portability and Accountability Act (HIPAA) and the Family Educational Rights and Privacy Act (FERPA). Maintaining strong privacy protections for unwarranted and unwanted sharing of medical and educational records is a critical component in ensuring that individuals obtain the medical care they need in a trusted environment. Mental health related data should be afforded heightened protections due to the particularly sensitive nature of the information, including the potential for bias or discrimination. Rather than augmenting existing protections, the following sections of the proposed legislation would weaken and undermine established protections for this category of personal data.

H.R. 2646 would significantly weaken existing protections under the HIPAA Privacy Rule, a statute that already allows robust information sharing.

H.R. 2646 creates unnecessary sharing exemptions under HIPAA.

H.R. 2646 unnecessarily creates an exemption under HIPAA that allows providers to

¹ National Alliance on Mental Illness, Mental Health by the Numbers. <https://www.nami.org/Learn-More/Mental-Health-By-the-Numbers#sthash.11XEHNjT.dpuf>

disclose protected information to caregivers including the ability to overrule an individual's wishes. HIPAA does not prevent information sharing - in fact, there a number of exceptions in the statute that facilitate access and sharing of health information for patient care. For example, providers can communicate with caregivers about a patient's care and have discretion to share more detailed information if the patient is incapacitated or if it is in her best interest. Providers can communicate with caregivers to facilitate care without oral or formal written consent or authorization from the patient. HIPAA-covered entities are also expressly permitted to use or disclose information to avert a serious threat to health or safety. In 2014, the Department of Health and Human Services' Office of Civil Rights issued guidance² to providers on information sharing under HIPAA to dispel the myth that the law doesn't permit this type of disclosure.

H.R. 2646's definition of "caregiver" is too broad allowing a larger category of individuals to receive highly sensitive medical information.

Under HIPAA, health care providers and family members (a term that is not defined and therefore includes partners and friends) are empowered to make decisions about sharing a covered individual's medical records when there is a health or safety threat. H.R. 2646 broadens this definition to include any person with established long-term responsibility for a patient's basic needs. Individuals that meet the proposed law's new definition would vary by state law, thus designated caregivers under H.R. 2646 could vary from a healthcare provider, to a landlord, to a state employee who is designated as a "personal representative" for social security matters. Some of the individuals allowed to receive information under this definition would have a conflict of interest that should prohibit them from receiving this information without further safeguards. Additionally, it's conceivable that more than one person could meet the definition of caregiver under the bill, forcing providers to navigate the caregiver(s) that with whom must contact and share information.

H.R. 2646 does not appropriately define when medical information may be shared.

H.R. 2646 amends one of the criteria in HIPAA that determines when information sharing should be compelled without patient consent. The bill moves away from HIPAA's "mental health conditions" to a much broader definition of "worsening medical conditions." This would give designated caregivers who, as discussed above, are not limited solely to healthcare providers or family members by the bill, access to highly personal information such as drug history and diagnoses, while also giving them broad latitude to interpret when such information should be shared. The bill also broadens the definition of when patients meet the criteria for non-consensual information sharing. An individual who has or has had a "diminished capacity" as determined by a psychiatrist or a doctor would be covered. We do not oppose the sharing of patient information among treating providers for treatment purposes. It is critical that providers be able to share information regarding their patients' health status, including diagnosis and medications,

² Department of Health and Human Services, Office of Civil Rights, Guidance on HIPAA Privacy Rule and Sharing Information Related to Mental Health. <http://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/special/mhguidancepdf.pdf>

for treatment purposes and to avoid harm such as interactions between medications. But we believe this provision of H.R. 2646 creates an unnecessary requirement for sharing that could have unintended consequences. For example, under this definition an individual who has a sexually transmitting disease might be included. Even without such an individual posing an imminent threat to the community, the bill would allow their private medical history to be shared with a broadly defined category of caregivers who may share or use the information without restriction.

H.R. 2646 would significantly weaken protections for students and their families under FERPA.

H.R. 2646's definition of "caregiver" and "educational record" is overbroad and vague. The Department of Education's (DOE) regulations generally restrict access to K-12 students' educational records to school officials and parents. Additionally, law enforcement, trained medical personnel, health officials, and other necessary parties (as determined by the school) may access such information during health and safety emergencies. H.R. 2646's definition of "caregiver" needlessly expands the parties that can access a student's educational record. The bill adds a new section to FERPA that gives schools the right to disclose a student's entire educational record to "caregivers", defined as "a family member or immediate past legal guardian who assumes primary responsibility for providing a basic need of such student (such as a family member or past legal guardian of the student who has assumed the responsibility of co-signing a loan with the student)". Such a broad grant of authority without further guidance as to what constitutes "a basic need" threatens both students' and their families' privacy. Furthermore, it's hard to find a justifiable reason why non-parent or non-guardian cosigners on a loan should have access to a students' health information.

H.R. 2646 also expands the definition of "educational record" to include postsecondary school students' health data. FERPA explicitly excludes postsecondary students' medical records from the definition of educational record under FERPA. DOE encourages postsecondary schools to create environments where students trust that information they share with campus medical services will not be inappropriately disclosed. H.R. 2646's expansion of the definition of educational record undermines both the spirit of FERPA and DOE's efforts to protect adult students' privacy rights.

HR 2646 unnecessarily broadens when mental health data can be disclosed.

The definition of "caregiver" in H.R. 2646 is not only overbroad, but it is unnecessary as it relates to release of health information in K-12 students' educational records. FERPA already allows an individual to access health information on a K-12 student for whom they are the primary caregiver, as well as allows release of these students' information to appropriate third parties when the student's or other individuals' health or safety is at risk. Parents and legal guardians always have a right to review their K-12 student's educational record, which includes health information. DOE regulations define "parent" to include a natural parent, guardian, and a caregiver acting as a "parent" in absence of a parent or guardian. A caregiver may include a relative or even a family friend. Further, DOE gives schools significant discretion to determine what constitutes a health or safety

emergency that would warrant release of a student's personally identifiable information without the student's or parent's consent. DOE also gives schools broad authority to determine what parties should have access to the student's information during emergencies. There is no need for an additional "caregiver" section of the statute; such allowances are largely provided for under existing regulations.

H.R. 2646 allows overly broad disclosure of a student's educational record.

In addition to the above concerns, H.R. 2646 would allow schools to share a student's *entire* educational record with a caregiver if *any* physician, psychologist, or mental health professional or paraprofessional reasonably believes disclosure is necessary, *even if* the student opposes disclosure. An educational record could include a range of information including grades, attendance records, social security numbers, financial information, contact information, and family or demographic background. FERPA regulations limit sharing of student information during emergencies to only information necessary to protect the individuals' health and safety. H.R. 2646 should similarly narrow disclosure – doing otherwise could lead to limitless, unwarranted sharing and do more harm than good to students' and school communities' health, safety and welfare.

Thank you for your consideration of these concerns. You can reach me at 202-407-8831 with any questions or to schedule a follow up discussion.

Sincerely,

Michelle De Mooy
Deputy Director, Privacy and Data Project
Center for Democracy & Technology

Undersigned Organizations: