

HIV Health Care Access Working Group

November 2, 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:

On behalf of the HIV Health Care Access Working Group, we write you to strongly oppose Section 401 of H.R. 2646, the Helping Families in Mental Health Crisis Act. HHCAGW is a coalition of more than 100 national and community-based organizations representing people living with HIV, HIV medical providers, public health professionals, and advocates who are committed to ensuring access to vital HIV-related prevention, care, and treatment services.

While we believe strengthening our nation's mental health services is vital, we do not support the release of an individual's HIV status to caregivers without his or her consent. Section 401 would erode the protections of the Health Insurance Portability and Accountability Act (HIPAA) and allow providers to share certain protected health information of an individual with a serious mental illness with a caregiver – including diagnosis and treatment plans – even when the patient objects to their information being shared. As the bill allows the provider to share any diagnosis, this could result in an individual with severe mental illness and HIV having their HIV status disclosed against their will to any of the types of caregivers defined in the bill.

According to the Centers for Disease Control and Prevention (CDC), there are over 1.2 million people living with HIV in the United States. Studies show that people living with HIV may be more likely than the general population to develop mental health disorders, including depression or anxiety. In particular, the American Psychological Association estimates that the prevalence of HIV among individuals with a serious mental illness ranges from one to 24 percent. Compared to the general public, people who are in care for mental health illness are four times more likely to be HIV-positive. Given the critical role that mental health and substance use disorder services play in ensuring people are linked to and engaged in care and treatment, it is essential that the mental health care system support privacy and confidentiality rights of people living with HIV.

The CDC has recognized that HIV disclosure is complex and difficult and that post-test follow-up and care should include disclosure assistance services to HIV-positive

individuals. These types of services have been shown to be effective and should be made available not only upon HIV diagnosis, but also as part of ongoing care and treatment. The goal of these services is to promote a voluntary, rather than coerced, disclosure of HIV status.

While caregivers may need pertinent health information regarding an individual's mental illness, their HIV status or current, past, and/or future HIV care and treatment regimens should not be disclosed without the patient's consent. A change in policy allowing disclosure of co-occurring conditions, including HIV status, with caregivers is unwarranted and could do more harm than good.

Health care providers should make every effort to involve the patient when information is being disclosed and support disclosure as appropriate. Doing so without the involvement of the individual living with HIV could have unintended and serious consequences, including discrimination, prosecution, assault, and an undermining of the provider-patient relationship. Women, in particular, often face intimate partner violence and negative reactions from partners immediately after disclosure.

People living with HIV face stigma that affects many facets of their life. Research has shown that HIV-related stigma undermines public health efforts to combat the epidemic and negatively affects preventive behaviors such as condom use, getting a HIV test, and seeking appropriate care. Stigma can be perpetuated when an individual's HIV-positive status is disclosed to caregivers, particularly when their status does not play a relevant role in their mental health care and treatment.

As the important work on HR 2646 continues, we urge the committee to consider modifications to the bill that meet our shared goals of strengthening our nation's mental health policy without compromising long-standing privacy protections that are critical to people living with HIV. Please contact Amy Killelea with the National Alliance of State & Territorial AIDS Directors (akillelea@nastad.org), Andrea Weddle with the HIV Medicine Association (aweddle@hivma.org), or Robert Greenwald with the Treatment Access Expansion Project (rgreenwa@law.harvard.edu) if we can be of assistance.

Respectfully Submitted by the Steering Committee of the HIV Health Care Access Working Group,

AIDS Action Baltimore | AIDS Action Committee of MA | AIDS Alliance for Women, Infants, Children, Youth & Families | AIDS Foundation of Chicago | AIDS Research Consortium of Atlanta | The AIDS Institute | AIDS Project Los Angeles | AIDS Treatment Data Network | AIDS United | American Academy of HIV Medicine | Association of Nurses in AIDS Care | Community Access National Network | Communities Advocating Emergency AIDS Relief (CAEAR) Coalition | Gay Men's Health Crisis | Georgia AIDS Coalition | Harlem United | Health and Disability

Advocates | HealthHIV | HIVictorious, Inc. | HIV Medicine Association | HIV Prevention Justice Alliance | Housing Works | Los Angeles LGBT Center | Moveable Feast | National Alliance of State and Territorial AIDS Directors | National Minority AIDS Council | The National Working Positive Coalition | Project Inform | San Francisco AIDS Foundation | South Carolina Campaign to End AIDS | Treatment Access Expansion Project | Treatment Action Group | VillageCare