



House Energy and Commerce Committee, Health Subcommittee hearing -
“Improving the Coordination and Quality of Substance Use Disorder Treatment”
May 8, 2018

Statement by
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First, I would like to thank the Committee for hosting this important hearing and for inviting me to testify on “Improving the Coordination and quality of Substance Use Disorder Treatment.” My written and oral testimony are the results of my personal experience as a person in substance use disorder recovery and well as my professional experience as the Executive Director of Faces & Voices of Recovery.

ABOUT ME:

My name is Patty McCarthy Metcalf. I am a woman in long term recovery from alcohol and drug addiction. For me, that means that I haven’t used alcohol or other drugs in over 28 years. Recovery has allowed me to give back to my community, earn college degrees, own a home, raise a family, pay taxes, establish a career and become a leading advocate for the recovery community.

I have personal lived experience with substance use disorder (“SUD”) treatment. As a teen and young adult, I went to residential treatment three times. The third time, I had just turned 18 years old and was admitted to inpatient treatment for alcohol use disorder and cocaine use. If today I was trying to start college, starting my career, or even buying life insurance, it’s likely I wouldn’t be telling you this for fear of stigma and discrimination.

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In fact, if I had a drug-related felony and wanted to apply for federal financial aid to go to college or if I wanted to get a license to cut hair, I could be ineligible based on my past history even though I am in long term recovery. The point is that stigma and discrimination are still barriers for millions of people in or seeking recovery from substance use disorders.

ABOUT FACES & VOICES OF RECOVERY:

Faces & Voices of Recovery is a national recovery advocacy organization based in Washington, D.C. Since 2001, we have been dedicated to unifying around key priorities – to gain needed resources for recovery and to end stigma and discrimination against people in recovery. We are working to eliminate barriers to recovery for every American and every family, and to help today’s children and future generations, who often are the biggest winners in the process of recovery.

The Association of Recovery Community Organizations (“ARCO”) at Faces & Voices of Recovery is comprised of over 100 organizations across the nation with hundreds of thousands of individuals engaged in their programs and participating in recovery support services. By organizing and speaking out together, we support and give hope to individuals who are still struggling with addiction and to those who have found the power of long-term recovery.

As an organized voice protecting the rights of individuals with substance use disorders, we are adamantly opposed to the dismantling of our critically important 42 CFR Part 2 (“Part 2”) confidentiality protections. We do not want our highly sensitive, personal information shared for purposes of treatment, payment, health care operations or for any other purpose beyond current the rule without our express written consent or Part 2’s other safeguards.

PATIENT PRIVACY:

The advocacy efforts to eliminate 42 CFR Part 2 have largely been driven by coalitions of hospital associations, insurers, treatment agencies, software vendors and pharmaceutical

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companies, without representation of patient advocacy groups or people in recovery from alcohol and other drug addiction. *Faces & Voices of Recovery agrees with the Congress who enacted Part 2 in the 1970s that weakening privacy regulations will discourage individuals who need SUD treatment from seeking it.* In fact, we believe that the interaction between a SUD treatment provider and the client when discussing specific consents and disclosures strengthens the therapeutic relationship and builds trust. Patients feel secure enough to know where their personal health information is going and for what purpose. We also regularly encounter medical providers who do not understand the 42 CFR Part 2 protections and mistakenly believe it to be a barrier to care because they do not understand how 42 CFR Part 2 works or the recent changes made to them so they work in our 21st century healthcare environment. We believe that resources targeted towards educating the medical field on the current Part 2 protections and to increase understanding of substance use conditions would go far to improve care without eliminating our rights.

An essential element of treatment and recovery includes strength-based approaches that are patient-centered and empower the person to choose who to share their information with and when. Most often the treatment provider encourages their clients to provide a written consent to share information with their primary care physician. If the client is reluctant to do this, they have an opportunity to weigh the benefits and discuss options. In addition, through the updated 2017 Part 2 regulations, patients can now choose to disclose their SUD treatment records in a simplified consent form to their other treating providers in electronic health networks, integrated care systems, as well as treating provider entities (e.g., hospitals, and mental health and other outpatient health centers).

Shared decision-making and whole person care require the participation of the patient. A system that denies patient autonomy and dignity will discourage people from seeking help for a substance use condition. *An integrated, recovery-oriented system of care would not seek to keep persons with substance use conditions from being a partner in their own care.* The dismantling of 42 CFR Part 2 is the antithesis of the principle of patient-centered, integrated care, and is

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largely being pursued by groups who hold their own business interests ahead of the rights and interests of our community.

UNINTENDED CONSEQUENCES:

Federal confidentiality regulations are intended to protect the right to privacy for individuals with all substance use disorders, not just those with opioid use disorders. An estimated 16 million people in the United States have an alcohol use disorder (“AUD”), according to the National Institute on Alcohol Abuse and Alcoholism. Research has repeatedly shown that people with AUDs experience stigmatization (by the public as well as from health professionals) more severely than people with other mental disorders. A high perceived stigma in persons diagnosed with an AUD has been shown to reduce the probability of using health care services and thereby contributes to a decreased likelihood of treatment seeking. Research also indicates that worries about privacy keep people from seeking treatment. (*Source: NIAAA, Alcohol Alert, Number 81: Exploring Treatment Options for Alcohol Use Disorders.*)

Making changes to minimize 42 CFR Part 2’s protections will have long lasting effects for a wide range of individuals and family members. For example, my daughter participated in counseling (at a Part 2 program) as a requirement of a diversion program for a possession of malt beverage charge (underage drinking). Without privacy protections, this information would be automatically prominently displayed on her medical record and could negatively impact her for the rest of her life. Had the counseling been related to *illicit* drug use, the harm could be devastating to her future. As a proud parent, I am happy to report that my daughter graduated college with a 4.0 GPA last week. As another example, a truck driver with a commercial driver’s license may participate in counseling and driving under the influence (“DUI”) classes at the advice of his or her attorney after a first DUI offense. If a medical screening is a requirement for employment, as it is for many professions, the physician could potentially disclose his or her substance use disorder treatment history. The potential for negative consequences of stigma and discrimination with regard to employment and education is real for millions of Americans even after years of sustained recovery from alcohol and drug addiction.

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Unlike most other medical illnesses, substance use disorders often have criminal and civil legal consequences. Part 2 provides safeguards for patients against potentially disastrous results of unauthorized disclosure. Unlike individuals with other illnesses or disabilities, SUD patients are vulnerable to arrest, prosecution, and incarceration. Additionally, many people with SUD (who are currently using illegal drugs) are not protected by federal or state civil rights laws that protect people with disabilities from employment, housing and other types of discrimination. Loosened confidentiality protections for SUD patient records can not only discourage patients from seeking treatment, but also subjects them to the risk of experiencing severe negative consequences and discrimination.

SUD patients may be hesitant to reveal they have been discriminated against. Someone using illegal drugs would have to reveal this fact, as well as the activities associated with the use of the illegal drugs. The vast majority of persons who will have this happen to them will lack the resources to determine who used their information in an improper way. Even if they did, in most cases individuals would not do so as by the very act of trying to assert their rights would acknowledge drug use and addiction in a way that would open them up to prosecution and discrimination.

The assertion that 42 CFR Part 2 is a barrier to health care is patently false. Part 2 simply requires that a patient decide if they want to share their personal information with another party. That's all it does. It is not a barrier, because it includes the patient in determining what risk the patient is willing to assume when their personal information is being shared with others. Part 2 as it stands today is a key element of integrated care in the most fundamental way. It upholds the autonomy and dignity of the patient by allowing the person with the substance use condition to decide who gets to get their information. We cannot integrate care by excluding the patient from the ability to make choices about what happens to their information. This is paternalistic and misguided.

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There are protections that people would lose if HIPAA becomes the standard for substance use information. Law enforcement authorities could seize patient records with subpoenas and general court orders and use them to prosecute people in addiction treatment programs. The Health Insurance Portability and Accountability Act (“HIPAA”) does not provide significant protections against information in substance use disorder (“SUD”) records being routinely seized to investigate and prosecute patients in substance use treatment. Under the federal substance use disorder confidentiality regulation, Part 2 treatment programs are prevented from releasing patients’ SUD information to law enforcement authorities, and judicial or administrative bodies, without a special court order.

CONCLUSION:

Beyond the significant harm that this proposed legislation (H.R. 3545) would do in our communities, it is entirely unnecessary. It is deeply disturbing to us that organizations who ostensibly support recovery and patient autonomy are supporting the elimination of these rights for our community. Others appear to be signing on for financial gain, convenience, other unknown purposes.

There is far too much at stake here to those of us depending on these protections in order that we may heal and realize our potential as productive citizens of this great nation. Congress was wise in its adoption of these important protections in the early 1970’s when they passed the law. They recognized at that time that these protections were necessary as they were facing a heroin epidemic and they understood that they were important in order to allow people to seek help for their substance use conditions without fear of their information going out further than necessary. As recently as last year, the regulations have been updated to reflect our changing health care system while ensuring our ability to consent to share it. We believe that many medical providers are unaware of these changes. The current Part 2 protections should be given an opportunity to work instead of pursuing these efforts to eliminate our rights.

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While it is true that there are many parallels between substance use conditions and other medical conditions, by its very nature, substance use conditions may involve use of illicit substances which is an illegal activity. The recognition of this fact led to the very protections that this bill seeks to dismantle. These protections are as critical as they were 40 years ago and must be maintained to ensure that individuals and families will seek help.

Many of us have made it clear that we would not have gone to substance use disorder treatment or accepted these services if we thought that our information would have been shared with other entities without our permission or knowledge. We would not have put our careers, reputations, or families at risk of stigma and discrimination if we were not assured that information about our substance use disorder was safe and would only be shared with our consent.

At a time when the opioid overdose crisis claims 144 lives every day, barriers to achieving a life free from the effects of harmful drug use must not be erected. Barriers to recovery hurt not only the individual, but that individual's family, community and the larger society as well.

As a person in long-term recovery, as a parent, and on behalf of the recovery community. I look forward to working with you and the Members on this Committee to advance meaningful legislation while protecting patient privacy. Thank you for the opportunity to testify today and for your commitment to addressing such an important issue that impacts millions of American families every day.

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