The House Committee on Energy and Commerce

Improving the Coordination and Quality of Substance Use Disorder Treatment May 8, 2018 1:00 p.m., 2123 Rayburn Office Building

<u>Purpose</u>

The purpose of this hearing is to examine issues surrounding patient privacy and quality care coordination in the treatment of substance use disorders (SUD), and the benefits of draft legislation entitled "Overdose Prevention and Patient Safety Act" would carry.

Presiding Members

Chairman Michael Burgess, Ranking Member Gene Green

Rep. Blackburn, Walden, Pallone, Matsui, Mullin, Barton, Sarbanes, Guthrie, Matsui, Eshoo, Lance, Castor, Long, Bucshon, Brooks, Griffith, Carter, Engel, Bilirakis

<u>Witnesses</u> <u>Panel I</u>: **The Honorable Earl Blumenauer**, Member of Congress, Washington D.C.

<u>Panel II</u>: **Dr. H. Westley Clark**, Dean's Executive Professor, Public Health Program, Santa Clara University

Mr. Gerald DeLoss, Officer, Greensfelder, Hemker, and Gale, P.C.

Mr. Jeremiah Gardner, Manager, Public Affairs and Advocacy, Hazelden Betty Ford Foundation

Mr. Dustin McKee, Director of Policy, National Alliance on Mental Illness of Ohio

Ms. Patty McCarthy Metcalf, Executive Director, Faces and Voices of Recovery

Opening Statements

Chairman Burgess discussed the importance of providing access to quality care for those suffering from substance abuse disorders (SUD), while maintaining patient privacy and breaking stigmas surrounding SUD. Information must be integrated into comprehensive care models in order to fully understand inhibitions to adequate, quality care.

Ranking Member Green discussed the need to ensure providers have the information they need to adequately treat their patients, but rights and privacy of people seeking treatment need to also be protected. This is especially the case where research shows patients will forgo seeking treatment in order to avoid releasing private information.

Chairman Walden discussed 42 C.F.R. Part 2 (Part 2) and whether it still is useful in protecting patients from the extreme stigma associated with SUD, as was initially intended. The health provider community has become increasingly frustrated with restrictions that

Part 2 places on their ability to improve the coordination and quality of care. The Overdose Prevention and Safety Act (H.R. 3545) strikes the balance of providing patient privacy, while arming physicians with necessary patient information to provide integrated quality care. The Act additionally works to prevent SUD by inhibiting unnecessary prescribing and reduces stigmatization of addiction, encouraging suffering patients to seek necessary treatment.

Ranking Member Pallone discussed concerns he has with the proposed Act and the consequences it will have in patients' lives. The confidentiality statute ensures patients' right to privacy without the lifetime stigma attachment.

Testimony

Rep. Blumenauer stated the current statute (i.e. Part 2), which is decades old and predates HIPAA, creates an impediment for treatment of SUD. The provisions of Part 2 are more restrictive than HIPAA and disallows integrated treatment. Doctors cannot treat a whole patient with half a medical record. The proposed legislation would treat medical records generated by a substance use treatment facility exactly the same as any other medical record. There are similarly severe stigmas associated with mental illnesses and HIV/AIDS, however, medical records for these diseases are treated with the standards of HIPAA. The proposed legislation would actually strengthen protective penalties, making patients' information more secure.

Mr. McKee discussed the experience of his brother, who died from addiction disorder at the age of 36, after receiving opioid treatment for non-addiction pain, because doctors did not know he suffered from a SUD.

Ms. Metcalf discussed her own experience with SUD recovery and her 28 years of sobriety, as well as the importance of the current Part 2 statute. Research indicates that worries about privacy keep people from seeking treatment. Stigma prevents patients from rejoining society, families, and the workforce. Part 2 safeguards patients' privacy and is essential to long-term recovery.

Mr. Gardner discussed his experience in long-term recovery from a SUD. The question in considering H.R. 3545 is whether HIPAA does enough to protect patients without the restrictiveness of Part 2. Mr. Gardner also discussed the deadly prescribing practices on his mother during her battle with an SUD. His experience has taught him that coordination is essential in knocking down barriers to adequate care. The proposed bill addresses the issues faced by the medical community in combatting the opioid epidemic and SUDs.

Dr. Clark advocated for the maintenance of Part 2 in order to protect patient privacy. Privacy, confidentiality, and consent are essential to patient care and in preventing medical records becoming a medical dossier that can be used against a patient.

Mr. DeLoss stated that the only change that would occur under the proposed legislation would be in disclosures for purposes of medical treatment. Patient privacy surrounding

SUD would be maintained under existing standards of HIPAA. The bill also provides substantial enforcement regulations that actually heighten standards of privacy.

Question and Answer

Rep. Mullin discussed the inadequacies of Part 2 and its effect on inhibiting the medical profession to provide quality treatment of SUDs.

Ranking Member Green asked whether there is other language that could be added to the proposed bill to provide more protection. **Dr. Clark** responded that if a patient doesn't trust their physician, they will not disclose a SUD, and this is the underlying issue.

Chairman Walden asked whether the proposed legislation includes anti-discrimination language and whether this language strengthens protection for the use of such information in criminal proceedings. **Mr. Gardener** stated it does include such language, which does strengthen protections.

Ranking Member Pallone asked about why people do not seek treatment for SUD. **Dr. Clark** responded reasons include costliness and stigma. **Ranking Member Pallone** asked what he would suggest to ensure Part 2 protections are maintained or promoted. **Dr. Clark** responded he would encourage Congress to take steps to facilitate the acquisition of electronic health records by the substance use delivery system.

Rep. Barton asked whether patients could be asked to waive their Part 2 protections. **Mr. McKee** responded he was not aware whether his brother was ever asked, but questioned that the physician would have known to ask.

Rep. Guthrie asked about the potential for data breaches of patient information. **Mr. DeLoss** responded there are breach disclosure requirements under HIPAA which include enforcement provisions. Currently under Part 2 there are no such affirmative disclosure requirements.

Rep. Guthrie asked whether patients have a right to the highest quality of care. **Mr. Gardener** responded over time a culture of secrecy, rather than that of openness, incites environments that lead to stigma.

Rep. Matsui asked whether information could only be shared between treating providers, or whether it could be shared between entities as well. **Mr. DeLoss** responded the information could be shared between covered entities, and could not be shared with any business associates.

Rep. Blackburn asked what physician visibility would have meant to treatment. **Ms. Metcalf** responded coordination and her consent meant the world to the success of her treatment and continued recovery. **Rep. Blackburn** asked how a conversation on consent to waive Part 2 restrictions typically divulges. **Ms. Metcalf** responded she has been in many such conversations in which patients are empowered to accept coordinated care. **Rep. Eshoo** asked what is lacking in HIPAA that did not sufficiently address SUD. **Ms. Metcalf** responded the ability to consent to the patient's care and disclosure of information was significant.

Rep. Lance asked whether aligning Part 2 with HIPAA would provide improved outcomes for patients. **Mr. DeLoss** responded this alignment would allow for the free-flow of information in a way that provides coordinated care, leading to better overall quality of care.

Rep. Castor asked about the importance of Part 2's patient consent requirement and the role this plays in overall treatment. **Ms. Metcalf** responded the process of providing information greatly contributes to coordinated care and long-term recovery.

Rep. Long asked whether allowing health providers to see the complete medical records of patients would help save the lives of patients. **Mr. McKee** responded it would greatly improve their chances, and H.R. 3545 is a step in the right direction.

Rep. Bucshon asked whether it is realistic to believe that patients are going to disclose all pertinent information about an SUD. **Dr. Clark** responded that patients are not going to tell you everything about everything, but when a trusting relationship is established patients are more likely to disclose.

Rep. Brooks asked whether care coordination is not vital in treating people with chronic conditions, like SUD. **Mr. McKee** responded care coordination is essential in providing adequate and quality care. **Ms. Metcalf** added that care coordination is important but not at the expense of losing the ability to choose who views patient information. **Dr. Clark** added that care coordination in giving their own consent.

Rep. Carter asked whether integrated care can change a patient's trajectory and what would be the downside of allowing better integration through H.R. 3545. **Mr. Gardner** responded yes, integrated care significantly changes a patient's trajectory in recovery.

Rep. Engel asked about the education on changes to Part 2 in the delivery system. **Ms. Metcalf** responded the changes often add complications which require education and guidance by SAMHSA educating to get all providers up to speed.

Rep. Bilirakis asked whether the proposed legislation will discourage people from seeking treatment. **Mr. Gardner** and **Mr. McKee** responded they did not feel it would discourage patients from seeking treatment.