

## Recovery community talking points on SUD privacy rights

Substance Use Disorder (SUD) federal Patient Privacy rights in 42 CFR Part 2 are under attack. What is at risk is your right to consent (or not consent) to release your highly sensitive SUD related information and to decide who gets it.

There are business interest groups making inaccurate claims about how SUD information is shared. Including:

- The assertion that 42 CFR Part 2 requires multiple consents. This was changed in 2017.
- That there are barriers to clinicians sharing information that is essential to proper care. Clinicians are permitted to talk with other clinicians with patient consent without barriers under the current regulations
- Claims that the regulations impede coordination of care. The current regulation is compatible with full coordination of care with patient consent.
- Claims that there is a need to “modernize” the regulations to align with HIPAA to strengthen protections. These efforts will weaken protections, not strengthen them, in ways that will remove your right to say who gets your highly sensitive information.

What is true is that most persons with SUD present at hospitals and within medical care settings that do not meet the definition of “federally -assisted” and as a result do not fall under 42 CFR Part 2. One of the biggest barriers is a lack of understanding of how these rules apply.

- This is not well understood in medical care circles.
- The primary barrier to effective care for SUDs is when medical professionals do not pick up on symptomatology of SUDs that present in medical care institutions.
- 90% of persons with SUDs do not ever get treatment in what are called federally assisted SUD treatment programs.

Stigma and discrimination are still a reality in our society. Without these protections, persons with SUDs could face loss of health and life insurance benefits, housing, employment, and other sanctions. It is wholly inappropriate to align these regulations with HIPAA.

- The proposed changes are couched as being for our wellbeing but lack any means of legal remedies and damages for the patient if information is used improperly, lost or stolen and used in ways that harm the patient.
- If legislators and lawmakers truly believe that discrimination and stigma is not a risk and does not currently happen in the system, patients should be given the right to personal right-of-action to sue, which neither Part 2 nor HIPAA allow for.

The media reports that there are profound problems with electronic record interoperability, creating serious risks to patient care and privacy. In 2016, approximately 175 million health records were hacked. Placing information in those systems that can be used to discriminate against people in housing, employment, insurance and other ways should not be considered as they put our community at grave risk for harm.

On the federal level, there is talk about eliminating the Affordable Care Act, including the protections against denying coverage for pre-existing conditions. Moving our records, including historic records, into this system will be used to deny or dramatically increase the cost of healthcare for our community. Records previously protected by Part 2 face the potential for being shared, despite previous consents and protections, if Part 2 is eliminated.

Patients and people suffering with SUD are already skeptical of treatment. According to SAMHSA data, only 20% of people will receive or seek out treatment. The removal of privacy laws will likely add to barriers to treatment.