

SUD records and the machinery of care denial in the new era of relaxed privacy rights

By William Stauffer

As noted by this recent opinion piece published by The New York Times, “Denying Your Health Care Is Big Business in America,” the process of prior authorization has been around for decades, but has only recently been weaponized by insurers to maximize profits and reduce the provision of health care services. The piece documents people going blind, becoming paralyzed or dying when necessary health care procedures are denied. Around 80% of the time, patients simply give up. Medical care offices have hired huge staffs to battle prior authorization denials. One of the focuses of the piece is on efforts to make prior authorization for medical care by for-profit companies illegal. It is stalled in Congress.

The recovery community is no stranger to broad denial of lifesaving treatment. In the mid-1990s as noted in the article, “The Impact of Managed Care on Substance Abuse Treatment,” it was rampant. Managed care organizations (MCOs) carved out substance use disorder (SUD) care, and coverage for treatment declined by 75% compared to a reduction of 11.5% for general health care. Prior authorization was a primary tool in care denial for persons with SUDs. It led to a dramatic reduction in frequency and duration of inpatient care with no corresponding increase in outpatient care. People with SUDs were easy pickings for the machinery of care denial because of the shame, stigma and lack of organized voices advocating for SUD patient protections. The rise of the new recovery advocacy movement came out of this era, in part as a response to these abuses leading to the deaths of so many people who sought help and were denied care. An HBO documentary in my home state of Pennsylvania highlights what things were like.

One of the few protections that people had at the time was the lack of ability for insurers to get whole chart access, which could be used to find reasons to justify care denial. As noted in the recent [Department of Health and Human Services] HHS Fact Sheet on the 42 CFR Part 2 Final Rule, whole records (beyond therapy notes) are now accessible to insurers with a single consent for all future uses for treatment, payment, and health care operations. This is a result of the CARES Act of 2020. The Act required both easement of access to SUD patient records and anti-discrimination protections; the easement of access to these records containing highly sensitive information has moved forward to final regulatory form. The portion enumerating anti-discrimination protections has not even been released for initial public input. It took four years for a final rule on easier access to these records for insurers and their business associates. How many years will it take to get the protections?

Persons with SUDs are some of the most discriminated against people in our entire society. Even with robust protections, it is likely that people will get discriminatory care. The protections that Congress required are not in regulatory form, even as the information is set to flow into the same insurance care system that gutted SUD care in the 1990s. Considering The New York Times’ opinion piece mentioned above, if insurers deny care in ways that incapacitate and kill patients with non-stigmatized conditions, what can we expect that they will do with increased access to SUD patient records without even the rules in place to protect people against discrimination?

Why is access to highly sensitive information in these patient records being made more easily accessible without the anti-discrimination regulation occurring in tandem? This would be analogous to building a highway and noting that there are speed limits, and then opening up the highway to motorists without having enforcement and penalties for speeding in place. It is asking for trouble. The difference is that the people impacted in this situation are highly stigmatized and the most likely in our society to experience discrimination. Whether the intended message was that our rights are a secondary concern, it is the message that is being sent.

Many of us in the recovery community expressed our concerns formally as feedback on the proposed rules and asked that they be delayed until anti-discrimination rules were in place. Our feedback went unheeded. With what other condition would patient anti-discrimination measures be treated as a secondary consideration? The message to insurers is to get those records and use them to JUST SAY NO to treatment. HHS, please delay implementation until we are protected! •

References

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