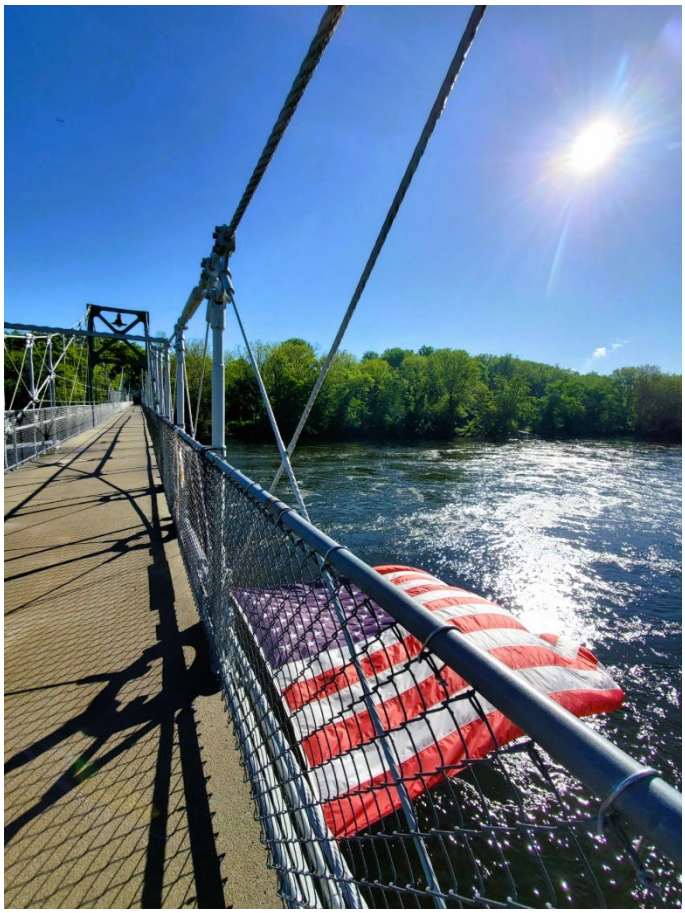
Revisiting the Algorithm of SUD Care Discrimination



In May of 2022, I wrote about the use of algorithms in substance use care and related discrimination against persons disorders, this is a revisit on that piece. The recent article in Wired Magazine, Eventbrite Promoted Illegal Opioid Sales to People Searching for Addiction Recovery Help, on how data about peoples addiction and recovery illustrates how our community members are being preyed upon using data gathering and market targeting strategies. Investigations found thousands of Eventbrite posts selling escort services and drugs like Xanax and oxycodone alongside addiction recovery events. People's recovery history being used to entice them to resume addictive drug use and engage in illegal conduct. I suspect we shall see a lot more of this as AI becomes more prevalent, particularly if we do so without laws to explicitly prohibit its use in this way that include stiff penalties.

As noted in my original piece, persons like me in long term recovery can also face horrible treatment in the hands of our healthcare system if it becomes known we have had a substance use condition. This is particularly true when we may need controlled substances as part of our legitimate medical care. There are now algorithms being used to scan our personal and medical data to see if we may be potential drug seekers. If you get identified in this way as a possible drug addict, you are likely to get treated poorly, not helped and kicked to the curb. If we want to get more Americans into sustained recovery, we need to start treating people more fairly in our medical care systems. This must include fixing how we identify and provide care to persons with suspected addiction in our hospitals and doctors' offices.

A number of years back, I had a dental emergency. I have had a few of those in my life, unfortunately. I had a procedure and the antibiotics the dentist gave me were not strong enough. The infection came roaring back with a vengeance. The side of my face looked like I had a golf ball in my cheek. It is the most pain I have ever experienced. An 11 on the 10 point pain scale. This occurred while I was visiting family in Western Pennsylvania. It got really bad in the middle of the night. I went into a rural hospital and asked for help. The staff took turns coming into the room to look at me. I was a sight, and I am sure everyone wanted to see the patient who looked like a squirrel with an acorn in his mouth.

They wrote out scripts for a more powerful antibiotic and gave me a strong opioid to provide some relief. I recall them mentioning it was addictive and if I knew that there were risks. I told them I was a clinician who worked in addictions, and I did know that the meds I needed that night were addictive. I did not tell them I was in recovery. I was afraid that they would leave me in excruciating pain. I have experienced horrible treatment at the hands of medical staff who became aware I had a history of substance use issues. It does not even matter that I am in recovery. I have had hundreds of patients I have worked with who recounted similar tales of unprofessional care at the hands of doctors and nurses. I could not tell them I was in recovery; I did not want the same to happen to me on this night with that agonizing pain.

I got the meds and went to stay with my family. I took the meds and switched over to an NSAID as soon as the antibiotics began to work. I let my family know I was taking an opioid. That is my standard protocol for the handful of times in nearly 38 years of recovery I have needed to take medicine with an addictive potential. It was what I needed. I got through it fine with zero impact on my recovery. Society has a stigmatized view of people like me, that any use of a medication results in a relapse. It is simply not reality. It just means we need to be a little more cautious and practice good self-care. We are just as capable of doing so as a diabetic can navigate a day with dietary risks.

I have been thinking after reading this journal article from the annals of Emergency Medicine, In a World of Stigma and Bias, Can a Computer Algorithm Really Predict Overdose Risk? Bamboo Health has developed software that gathers peoples data to determine an overdose risk score called NarxCare. It uses an algorithm and there are reports emerging that far too often patients with legitimate medical problems end up being scored as potential drug addicts. They are then treated like pariahs by medical professionals, not offered help but kicked to the curb and treated like criminals.

As this article notes, NarxCare gathers information like criminal records, sexual abuse history, distance traveled to fill a prescriptions and even pet prescriptions to assign risk scores to each person. Race factors in as our criminal justice system has historically targeted Black, Indigenous, and people of color for drug crimes and arrested them at higher rates than whites which increase the risk score for our BIPOC brothers and sisters. Women who have more documented sexual trauma than men get scored higher. How does addiction treatment or self-identified recovery score on the algorithm? That is proprietary.

A comprehensive legal review, published in the California Law Review, Dosing Discrimination: Regulating PDMP Risk Scores, by Jennifer D. Oliva, Esq, Associate Dean for Faculty Research and Development, Professor of Law, and Director, Center for Health & Pharmaceutical Law, Seton Hall University School of Law notes that:

> *"NarxCare risk scoring likely exacerbates existing disparities in chronic pain treatment for Black patients, women, individuals who are socioeconomically marginalized, rural individuals, and patients with complex, co-morbid disabilities and OUD."*

Professor Oliva has found that the software flags people who are rural and travel far for medical care or pay cash and use multiple payment methods. Such payment methods are often used by people who are uninsured or underinsured. They scramble to try and find ways to pay for their medication and they end up at higher risk for care denial as a result.

If your sexual trauma history gets in your medical record, you may end up not being able to obtain the same medical care as others. Flagged as a potential drug addict at risk for overdose. As I noted, the software is proprietary. Not open for validation and not regulated. Professor Oliva notes in her detailed legal review of the software that:

> *"There are no other examples of automated predictive risk scoring models created primarily for law enforcement surveillance that are used in clinical practice. This is likely because such cross-over use of risk assessment tools is ill advised. That stated, to the extent that clinicians do use PDMP risk scores to inform or determine patient treatment, PDMP software platforms ought to be subject to the same regulatory oversight as other health care predictive analytic tools used for similar purposes. The significant questions raised about PDMP risk score accuracy and such risk scores' potential to disparately impact the health and well-being of marginalized patients demand immediate regulatory attention."*

This article at Wired.com by Maia Szalavitz describe how a woman got barred from receiving services by her primary care provider. Her dogs had been prescribed opioids and benzodiazepines. That gave her a high score for potential addiction in the algorithm. She was flagged for care denial. She became a medial care pariah. She got the drug addict treatment. She was shown the door and terminated from care. This proprietary software influences medical care for millions of Americans. I found that Rite Aid uses it in Pennsylvania and 11 other states as does Walmart and CVS.

Maia recently wrote an opinion piece in the New York Times, Say Hello to Your Addiction Risk Score — Courtesy of the Tech Industry describing a newly approved genetic test for opioid use disorder risk known as AvertD which uses machine learning to try to identify patients at risk for addiction that have similar flaws and risks of misuse. She notes that similar genetic testing strategies were approved for use by the FDA after the agencies advisory committee overwhelmingly voted against doing so. There is a black box warning on AvertD and prohibition against use without patient consent but as she notes patients can face significant pressure to consent. It is also true that such consent can be requested in ways that the patient does not read through all the 6-point font legalese to understand what they are agreeing to.

As noted above, it appears that instead of being used to help get persons who are at risk for addiction help, such software is often used to remove persons from care. I ran across countless stories where that was the outcome. This may stem from fear that doctors and pharmacist have of DEA sanctions. As persons on such medications face withdrawal as they are sent to the streets, it may actually result in increasing of legal jeopardy as people use illicit drugs and the overdose risks of patients it identifies as being at high risk.

When such scenarios leads to discriminatory treatment for the patient, they have few options for recourse. It is highly unlikely it will be corrected. Once you get flagged by this unvalidated proprietary software as a drug addict, good luck clearing it from your electronic health record. We have a system of care designed to find and fail us. You have the right to request that something be removed from your electronic health record. Your medical provider is required to respond, but they can just say no. This study, done in 2014, found that if you requested a change to your medical record in regard to drug seeking behavior, your request had less than a 10% chance of being approved. Marked with the letter A for drug addict written into at the top of your EHR for all eternity. Persons in recovery have every reason to fear how the flow of such information will influence their treatment.

As addiction is a medical disorder, we should be providing medical care to a person with a substance use condition as we would say a diabetic. Without judgement and with the same care and concern as any other patient. We do not do so in America. Being treated like a drug addict in America means being treated like an outcast. A member of an unclean caste. This says a lot about how far we must go in respect to proper care for addiction in America.

What other medical condition would the use of unvalidated, proprietary software be used to guide medical care? Hundreds of thousands of persons like me across America are forced to think about medical care bias against us every time we seek help. We must change how we treat people with substance misuse issues and those of us in recovery. We need to be cared for respectfully and with compassion, just like what we expect for any other medical condition.

Several years back, I wrote "Take the Drug Addicts Out to the Hospital Parking Lot and Shoot Them." I advocated in it for stronger privacy laws and that we must hold medical professionals accountable for discrimination in the treatment of persons having or suspected as having a substance use disorder. The opposite occurred. In February of this year, the final rule that fundamentally eases federal confidentiality protections for persons with SUDs under 42 CFR Part II within the Coronavirus Aid, Relief, and Economic Security Act (CARES) of 2020 was promulgated. As finalized, it allows our information to flow through the healthcare system, while the portions of that Act that would protect people against discrimination have not yet even been offered for public comment. Such protections should have been in place at the same time as the easement of access to the information used to discriminate against us. It is like opening a highway, posting speed limits but noting that there are no police and the consequences for violation have yet to be determined. This clearly sends the message that it is open season for discriminatory treatment.

How can we get more people into recovery in a system of care that acts so punitively towards us? If we want to increase the number of Americans in recovery, we must improve the care we provide. We need to ask hard questions about how we are protected against discrimination and being preyed upon for profit. When will we have a society in which people like me with substance use disorders do not have to be afraid of being identified as having a history of substance use disorders without fear of biased treatment. We have a long way to go to meet that standard, but we must work towards it if we are to actually help the millions of Americans who need help with a substance use disorder. A good step would be to pause the changes to our privacy laws until protections against discrimination are also finalized.

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