September 2025

TAC
Treatment Advocacy Center

# CATALYST

A NEWSLETTER FROM TREATMENT ADVOCACY CENTER

In this September 2025 issue of Catalyst, we bring you an SMI Thought Leaders piece by Executive Director Lisa Dailey about what Medicaid cuts mean for our community, an exciting announcement about the 2025 DJ Jaffe Advocate, the opportunity to register for TAC’s winter webinar series, and a moving Personally Speaking blog by a mother and advocate in Texas. We also look back on some highlights from the last six months of advocacy and impact at TAC!

# What Medicaid Cuts Mean for People with Severe Mental Illness

*By Lisa Dailey*

*Lisa Dailey is the Executive Director at Treatment Advocacy*

With the passage of HR1 earlier this year, I hope it's worthwhile to try to provide clarity about what the cuts are and what they will mean for people with severe mental illness (SMI) and the loved ones trying to help them stay alive and stable. We at TAC intentionally avoid partisanship politics, instead supporting policies and legislation from any party that will improve life for our constituents, and opposing any that will make things worse. In recent years, addressing mental illness is one of the rare, truly bipartisan issues in which both parties have taken an active interest. SMI does not discriminate; it can affect any person or any family. We all know someone impacted by it even if we don't know that we do.

Medicaid is the largest payer of mental health services in the United States. It covers nearly one in three adults with a serious mental illness, including many who are unable to work because of the symptoms of their illness. It funds psychiatric medications, case management, inpatient and outpatient care, supported housing, and wraparound services that help people become and stay stable and out of crisis. In many states, Medicaid is the only mechanism for getting someone into a hospital bed or securing community-based care after discharge. It is truly a lifeline for many of those who are the most vulnerable due to their illness.

Because of this reality, the cuts proposed in HR1 are a source of much anxiety for SMI-affected families. As all in our community know, these illnesses are conditions that, when untreated, can quickly lead to psychosis and a loss of years of hard-won stability in a matter of weeks. The stakes could not be higher.

HR1 made a number of changes and cuts to Medicaid. They will affect people with SMI and their families in different ways, some of which are obvious and some less so. At a minimum, people need to understand what the changes are, when they will go into effect, and what they might mean for people with SMI. There are many reasons why a person might fall off the path of treatment and stability. Sometimes a person is unable to perceive the continuing need for treatment and stops medication because that seems completely rational. Other times, a person's level of functional impairment, especially due to cognitive deficits that are common with these diagnoses, makes following a complex medication and appointment schedule difficult.

Without robust support (which often comes from family members left with no other choice) the effects of missed doses or missed appointments can compound quickly. Rapid deterioration can lead to what we call "preventable tragedies," such as suicide, homelessness, being victimized by others, deterioration of physical health, getting arrested instead of hospitalized, and even violence – often against the very loved ones trying to prevent these negative outcomes.

TAC's core mission is to eliminate barriers to getting access to and maintaining treatment for SMI. Plenty of these barriers are baked into the nature of the illnesses themselves. They are chronic illnesses that require strategizing around known treatment pitfalls. One thing that is not baked into the nature of the illness is whether Medicaid is available to cover the doctors' visits, medication(s), lab tests, and services that actually prevent these preventable tragedies. That is a decision that we make as a matter of policy. And policies, even bad ones, can always be changed.

We've created a chart of Medicaid provisions in HR1 and the impacts we anticipate as a possibility for those with SMI. I encourage readers to become familiar with them in order to be prepared to fight for continuing eligibility – it will be critical to anticipate these hurdles. Regaining lost benefits is difficult and uncertain, and we know all too well how quickly stability can turn to crisis and how unaffordable medication is without insurance.

Many of these cost-cutting measures have been tried before so we do know what to expect when they go into effect:

- Many people with severe mental illnesses will not be able to fulfill work requirements if imposed or to replace Medicaid with insurance through employment due to the limits arising from their disabilities.
- Limitations to or elimination of services will hit those with the most severe illnesses hardest.
- New holes in the treatment path will open and those with SMI will fall through them.
- Rising financial pressures on states and providers will lead to cherry picking of patients and the refusal to treat those with the most high-maintenance and high-cost needs.
- Access to providers who understand and treat SMI, already scarce in many parts of the US and especially rural areas, will be further reduced by hospital closures.
- Whether intentional or not, those with the most functional impairment from SMI who are eligible for Medicaid will start to be eliminated because they cannot keep up with the paperwork and red tape.
- Without the access to treatment and supportive services that Medicaid provides, we will see a rise in homelessness and incarceration for those with SMI.

Experts with more expertise than I have in how all of this will damage our healthcare system and our broader economy (for which healthcare is such a significant driver) have weighed in already. What I want people to think about is how this is going to affect families and family relationships. Parents and loved ones of people with SMI will do what they've always done: step in for a system that fails their loved ones at every turn. Very few families can pay for medication out of pocket, but many will try.

Severe mental illness will not go away without Medicaid coverage for treatment and medication. It will only become more visible, dangerous, and crisis based. That is not the future that anyone wants. Let's make sure that it doesn't come to pass.

We will continue to do what we've always done in the weeks and months ahead: support families impacted by SMI in every way that we can. For support on your or your family's situation, we provide Helpline services to assist with troubleshooting. [https://www.tac.org/helpline/ 703-951-9760] We also believe that our personal stories are powerful and need to be heard by our elected officials. Let us know how you are being impacted by the changes to Medicaid. Reach out to share your story with us.

# 2025 National AOT Symposium & Learning Collaborative

## 2025 National AOT Symposium & Learning Collaborative

In March, more than 300 people dedicated to advancing treatment options for people with SMI and driving reform within systems that serve them gathered for the **2025 National AOT Symposium & Learning Collaborative** in Annapolis, Maryland! Attendees included case managers, clinicians, court personnel, peers, advocates, family members, and other key collaborators. More than 40 judges and 15 psychologists from across the country were in attendance.

The Symposium kicked off with a heartfelt address by Debra Bennett *(pictured)*, member of the Maryland Commission on Behavioral Health Care Treatment and Access, former volunteer Maryland Ambassador for TAC, NAMI member, and nationally certified Family Peer Specialist. Bennett spoke about the tragic loss of her son, Ben, underscoring the critical importance of the work being done.

Highlights included an inspiring video featuring four AOT graduates sharing their stories of resilience and growth; keynote speaker and award-winning journalist Meg Kissinger *(pictured)*; attendee-choice-style workshops, and expert-led panels. Dr. Robert Laitman, renowned internist and producer of the documentary “Into the Light: Meaningful Recovery from Psychosis,”

**Mental health advocate Debra Bennett sits following her opening address.**

**Journalist Meg Kissinger addresses the audience during her keynote presentation.**

**Group photo outside the Westin Annapolis.**

delivered a compelling presentation highlighting the critical role of clozapine for individuals who have not responded to traditional antipsychotic medications.

A favorite session amongst attendees, “Ask Us Anything,” provided an open forum in which audience members had the opportunity to engage and ask questions directly of the National AOT Institute Advisory Committee *(pictured)*, a panel of subject matter experts from across the country.

TAC’s AOT Implementation Team who led planning for the event are pictured outside.

The National AOT Institute Advisory Committee answers audience questions.

## Announcing the 2025 DJ Jaffe Advocate: Leslie Carpenter!

We’re excited to share that **Leslie Carpenter** has been selected as the 2025 DJ Jaffe Advocate. Beginning this September, Leslie will lead the *SMI Professional and Direct Care Staff Training Project: Bridging the Knowledge Gap in Compassionate, Competent Care*.

This national initiative will deliver tailored, evidence-informed training to mental health professionals and direct care staff serving individuals with severe mental illness (SMI). The project aims to improve understanding of SMI, particularly the symptoms of psychosis and anosognosia, which impede voluntary care resulting in dire outcomes without intervention. These critical topics are often missing from formal provider training, making targeted education essential. The goal is to increase provider understanding of these conditions, to promote person-centered care, and to increase family engagement to help improve outcomes. Delivered through accessible online modules, the training will equip providers with the tools necessary to deliver more compassionate, coordinated, and effective services and supports.

Leslie brings unmatched dedication and lived experience to this work. As an advocate, caregiver, and legislative leader, she exemplifies the spirit of DJ Jaffe — unyielding in her commitment to those too often left behind by our mental health systems. We are honored to support her in advancing this urgently needed national training program.

# Families Learn to Navigate Complex Systems in TAC's Winter Webinar Series

TAC Advocacy Navigator

In January and February, TAC hosted a six-part virtual webinar series designed for families navigating the complex systems surrounding severe mental illness (SMI). Each 30-minute session included a presentation with time reserved for audience questions.

The webinar series opened with a virtual tour of TAC's Joan C. Scott Community Resource Center, giving attendees an inside look at how to find tools and information related to their SMI circumstances. Subsequent sessions covered essential topics: treatment access, psychosis and anosognosia, civil and criminal courts, emergency planning, and HIPAA. Recordings of all sessions are available within a playlist on TAC's YouTube channel.

The popularity of the live webinars, combined with high numbers of views on YouTube, indicates strong demand for accessible, family-focused resources in the SMI space. Another webinar series is planned for Fall 2025, with online registration open now for the 6 - 6:30 p.m. ET sessions on Thursdays, Oct. 30 - Dec. 7 (no session Nov. 27).

The 2025 webinars will provide information about SMI medication management, treatment during incarceration, how to seek AOT, unlocking HIPAA handcuffs, and an involuntary treatment toolkit. Register here.

# Personally SPEAKING

## My Son Needed Care, The System Waited For A Crime

*By Anonymous in Texas*

My son is a gentle and kind soul. When he is stable on his medication, he is my friend, and he always looks out for his family. He enjoys music and hiking and writes poetry, short stories, and song lyrics. Like many people with severe mental illness (SMI), he is capable of thriving with proper treatment. But the system isn't built to help him thrive. Instead, he's been ignored or treated like a dangerous criminal whenever his treatment needs have increased. He is currently doing well only because of my own costly efforts combined with a small bit of luck.

He was first diagnosed about seven years ago, after a series of difficult and confusing episodes. I learned about evidence-based treatments for schizophrenia, and I had so much hope! It seemed clear that with the right team of helpers, my son could live a successful life despite his disability. I learned the hard way that barriers were going to make those evidence-based treatments almost impossible to access, and I wouldn't be able to intervene on his behalf when he most needed me.

My son has been incarcerated four times during psychotic episodes. Each time, I have actively begged his providers to help him access an inpatient bed to re-stabilize. I have contacted the local crisis response service. I've taken him to the emergency department for an evaluation. Each time, every professional has told me that he's not sick enough to warrant hospitalization. Each time he was found not dangerous enough until he met criteria to be arrested instead.

The most recent time this happened was in 2023. A few hours after the emergency department dismissed him, my son was involved in an accident. He was arrested and charged with vehicular assault that caused severe bodily injury. That met criteria for that elusive hospitalization, but he was of course incarcerated instead. While he was in jail, no one would provide any information about his legal status or his condition. His mental health team said they couldn't do anything, now that he was justice involved.

I was desperate. I did not know whether my son was injured in the accident, if he was receiving any medical or mental health treatment. Because no one directly involved in his care would communicate with me, I wrote letters to my state elected officials and every news and radio outlet I could think of. I got no response from anyone. I was clearly the only one who felt any urgency. I found myself wondering what would have been different if my son had a stroke or was only injured in an accident. Would he and I be treated this way?

After about a month of no response from anyone who was supposed to care for my son, including his defense attorney, I hired a private attorney. This cost $10,000 I couldn't afford, but I was able to negotiate a payment plan. Over six months, my son's court hearings were postponed for a range of reasons until finally a court-appointed evaluator assessed him and concluded that he was fit enough to face his charges. My privately hired attorney recommended I hire an expert psychologist, costing me $2,000 (a discounted rate because they took pity on us after hearing my story). Meanwhile, I was visiting my son virtually (for a fee), as in-person visits were not allowed. His health was deteriorating quickly. He was withdrawn and had lost 100 pounds, down to a very unhealthy weight.

After reviewing the report from the psychologist I hired, the state-appointed psychologist changed their decision and found him unable to act in his own defense. After that, the case shifted toward a not guilty by reason of insanity plea and he was court-ordered into inpatient services at the state hospital. I had to pay nearly a thousand dollars in court fees.

Ultimately, it took almost two years and $15,000 for my son to get the inpatient care he had needed all along. While the state failed him, he experienced brain damage from untreated psychosis and tremendous trauma. I, too, have been severely traumatized, all because the requirement for medical care was "dangerousness," not my son's obvious need for treatment.

Before that illness episode, my son was working, taking care of his own activities of daily living, and talking about going back to college. Even when things were going well, we lived in fear that any decompensation would be devastating because each episode meant he had to lose everything all over again before getting the medical care he desperately needed. Once he was back in treatment, he came back to being his kind, loving self. Giving him back his chance at life didn't need to cost so much — for our family or the state.

TAC Treatment Advocacy Center

# SMI SPOTLIGHT

“SMI Spotlight,” TAC’s ongoing podcast in collaboration with world-renowned expert on anosognosia, Dr. Xavier Amador, has been a resounding success. Now at eight episodes, the podcast has included interviews with high-profile clinicians such as the head of the American Psychiatric Association (APA), along with moving and highly relatable conversations with family members, and several “Ask Dr. Amador” episodes which feature listener questions.

Releasing approximately once per month on YouTube, Apple Podcasts, and Spotify, “SMI Spotlight” provides clinicians, providers, family members, and people affected by SMI with valuable information, education, and support.

## Episode 1: What People Get Wrong About Anosognosia – featuring TAC’s executive director Lisa Dailey and Dr. Xavier Amador

In the first episode of SMI Spotlight, TAC’s executive director Lisa Dailey discusses anosognosia with Dr. Xavier Amador. The interview covers Dr. Amador’s journey supporting his brother with schizophrenia, studying anosognosia as a clinical psychologist, and developing the LEAP method to help connect with people and encourage them to seek treatment even if they don’t believe they have a mental illness.

## Episode 2: Anosognosia: what TV gets wrong about schizophrenia

Schizophrenia is one of the most misunderstood mental illnesses, but few people know about one of its most devastating symptoms—anosognosia. This neurological condition prevents individuals from recognizing that they have an illness, leading to treatment refusal, medication noncompliance, and a cycle of hospitalization, homelessness, and incarceration.

## Episode 3: Ask Dr Amador, navigating severe mental illness

In this SMI Spotlight episode, Dr. Xavier Amador, clinical psychologist, author of I Am Not Sick, I Don’t Need Help!, and creator of the LEAP (Listen, Empathize, Agree, Partner) method, answers listener questions about severe mental illness (SMI), including schizophrenia, anosognosia, family communication, and advocacy.

### Episode 4: Collaborative Care for Mental Illness

In this episode of SMI Spotlight, Dr. Xavier Amador sits down with Dr. Roshni Koli, Chief Medical Officer at the Meadows Mental Health Policy Institute, to explore the Collaborative Care Model — an evidence-based approach integrating mental health care into primary care settings.

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### Episode 5: A Mother's Story of Love and Loss to Schizophrenia

Maria Sutherland joins Dr. Xavier Amador to discuss the systemic failures that led to the loss of her son Michael, following complications of his schizophrenia diagnosis. Their discussion touches on the need for supportive housing, dedicated behavioral health crisis response teams, extended family guardianship, increased access to long-acting injectables, and widespread understanding of anosognosia – the lack of insight preventing many with SMI from engaging in treatment.

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### Episode 6: CEO of the APA on Decriminalizing Mental Illness

Dr. Xavier Amador is joined by Dr. Marketa Wills, CEO and Medical Director of the American Psychiatric Association (APA). Dr. Wills discusses her career journey, leading her to enter the field of psychiatry and administration. She covers her vision for the upcoming advocacy from the APA, emphasizing the need to decriminalize mental illness. To achieve this decriminalization, she discusses the need for more tools and legal mechanisms to provide treatment for individuals with severe mental illness who may be unable to see their own need for medical intervention. She also speaks to how the APA advocates to address the shortage of psychiatrists nationwide.

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### Episode 7: Ask Dr. Amador: Top Anosognosia Questions Answered

In this episode of SMI Spotlight, renowned clinical psychologist and author Dr. Xavier Amador answers your most pressing questions about anosognosia —a common and often misunderstood symptom of severe mental illness like schizophrenia and bipolar disorder.

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### Episode 8: Ask Dr. Amador: Severe Mental Illness, Substances, and HIPAA

Since launching SMI Spotlight a year ago, we've received a huge number of listener questions on severe mental illness topics, including substance use, practical application of the LEAP methods for different populations, HIPAA, and more. This month's podcast is a conversation between Executive Director Lisa Dailey and Dr. Xavier Amador, working through more of these listener questions.