



# SMI ADVOCATE

A NEWSLETTER FROM TREATMENT ADVOCACY CENTER



## TAC Collaborates with S&PAA for Spring Summit

TAC and Schizophrenia & Psychosis Action Alliance (S&PAA) collaborated for their annual Spring Summit, held May 15-16, 2024, in Washington, D.C. Grassroots SMI advocates from across the United States heard from TAC Executive Director Lisa Dailey, who participated in a panel discussion about mental health policy. Leslie Carpenter, legislative advocacy manager at TAC, gave a

presentation about decriminalizing SMI and shared TAC's proposal to help states shift people away from the criminal system by instead providing civil court-ordered services through assisted outpatient treatment (AOT). Carpenter shared TAC's handbook, written by the AOT Implementation Team: [Dismiss Upon Civil Commitment with AOT](#).

*Leslie Carpenter presents about decriminalization of SMI at the S&PAA Spring Summit.*



*Panelists at the S&PAA Spring Summit include (left to right): Jon McHenry, vice president of North Star Opinion Research; Dr. Tim Murphy, a psychologist and former U.S. Congressman; Lisa Dailey, TAC's executive director; and Joel White, president of Horizon Government Affairs.*





## SMART Network

In the summer of 2024, TAC joined in a collaborative effort with other organizations focused on severe mental illness (SMI) to create the SMART Network. SMART stands for **SMI Advocacy Resource Team**. As a network of allies, we can amplify our collective voices and share resources and ideas to grow a movement toward much needed system change.

### **SMART includes:**

Association for the Chronically Mentally Ill (ACMI)  
Bipolar SMI Family Education and Advocacy Group  
Arizona Mad Moms  
CURESZ Foundation  
Families Advocating for the Seriously Mentally Ill (FASMI)  
Johnny's Ambassadors  
Iowa Mental Health Advocacy  
LA Healing Minds NOLA  
Mad Moms CO  
Mad Moms Midwest  
Mothers of the Mentally Ill (MOMI)  
National Shattering Silence Coalition (NSSC)  
Schizophrenia and Psychosis Action Alliance (S&PAA)  
Schizophrenia and Schizoaffective Society  
Team Daniel  
The Angry Moms  
Transforming Treatable Tragedies  
Treatment Advocacy Center (TAC)

SMART had a kickoff meeting in August to share information and resources and establish a distribution list for ongoing collaborations. To be added to the list, please email [advocacy@tac.org](mailto:advocacy@tac.org).



## Advocacy Bootcamp Pilot a Success

TAC's advocacy department offered a new educational opportunity in the fall of 2024 and plans a second offering in spring 2025. "Advocacy Bootcamp" provides interactive, virtual sessions on a range of severe mental illness (SMI) topics to prepare and inspire grassroots advocates committed to working on much-needed SMI system improvements at the local, state, and national levels.

TAC trained 27 advocates in the 14-session pilot program. Participant surveys rated the quality of the class at a 4.95 out of 5. Commenters expressed appreciation for robust group discussions and role-play that made the sessions inspiring and engaging as well as educational.



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One participant commented, *“The supportive demeanor and tone of you all as facilitators of our learning, and reinforcement that practice would give us confidence over time, was invaluable.”*

Another shared, *“I have learned so much from all of you and I feel immense gratitude for TAC, as you are the people who truly understand what we face. In time, and with your inspiration, I know that I will grow into a fierce advocate, and I look to each of you as role models.”*

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### Advocacy Bootcamp topics:

- Advocacy 101
- SMI basics: psychosis, anosognosia, stigma versus discrimination, language considerations
- Full continuum of care
- Involuntary treatment and medication over objection
- IMD exclusion
- State hospital beds and competency restoration
- AOT and mental health courts
- Homelessness and housing solutions
- Research and evidence-based practices
- Cannabis / THC
- Care partner engagement
- Clozapine / REMS
- Opposition arguments
- Putting it all together: Crafting a compelling advocacy narrative

To be added to the interest list for future offerings, please email [advocacy@tac.org](mailto:advocacy@tac.org).

Advocacy Bootcamp online sessions help advocates learn to craft and share their stories alongside data and well-informed asks for action.

Examples:

Tell your story for impact → Connect to data → Make an ask

- Informal engagement (Jerri)
- Testimony (Leslie)
- Letter to the editor (Nina)

TAC Advocacy Bootcamp





## Grassroots Advocacy in Action

Clozapine is the only antipsychotic medication approved by the Federal Drug Administration (FDA) for treatment-resistant schizophrenia and is evidence-based to reduce symptoms and improve quality of life for people with illnesses that include psychosis. Unfortunately, access to clozapine is very limited because of the FDA's regulatory requirements known as REMS (Risk Evaluation and Mitigation Strategy).

On November 19, 2024, the FDA hosted a joint meeting of the Drug Safety and Risk Management Advisory Committee and the Psychopharmacologic Drugs

Advisory Committee at its headquarters in Silver Spring, Maryland, to hear presentations and public comment about the REMS and their impact on treatment access. The hearing resulted in a nearly unanimous recommendation to change the requirements, but the FDA has not yet acted.

Testimony from advocates, researchers, and other stakeholders included many of TAC's advocacy partners, including The Angry Moms, Mad Moms, and Team Daniel. Their united message called for the FDA to amend or repeal the REMS.

The joint committee voted 14-1 that safe use of clozapine did not require the current REMS. This recommendation by the committee is a huge win for advocates! The FDA has historically followed recommendations from its expert advisory panels.

TAC provides a resource with more information: [Clozapine: Medication for treatment resistant schizophrenia](#).



*Rachel Streiff, Nina Richtman, and Kate Rawlinson at the FDA Hearing on Clozapine REMS.*

# 5

## Five Easy Action Steps for TAC Advocates

### 1. Sign up for TAC newsletters

SMI Advocate, Research Briefly, Catalyst, AOT Learning Network  
[Join Our Newsletters - Treatment Advocacy Center](#)

### 2. Sign up for TAC Action Center alerts

Check out active campaigns and initiatives here and write to your representatives via TAC Action Center. <https://www.tac.org/tac-action-center/>

### 3. Register for the AOTLN (Assisted Outpatient Treatment Learning Network)

AOTLN is a virtual network to keep you engaged with your counterparts from across the United States and facilitate the sharing of resources, great ideas, and common concerns regarding AOT.

<https://www.tac.org/membership-account/aot-portal-registration/>

### 4. Join TAC's grassroots networks (for advocates in Oregon, Maryland, and California)

State specific networks for systems advocacy and state specific resources

#### Oregon

<https://www.facebook.com/groups/oregontac>

#### Maryland

<https://www.facebook.com/groups/tacmd>

#### California

<https://www.facebook.com/groups/catac>

### 5. To start or join a network in your area, please fill out our short form via Voter

**Voice.** We will reach out if we have a grassroots network getting started in your area. <https://www.tac.org/get-connected/>



## Volunteer Opportunity

*Nina Richtman, TAC's director of advocacy, is a member of Disability Rights Iowa (DRI) PAIMI council. She and Wendy Anderson, DRI board member, connect at DRI's 40-year anniversary celebration.*



Did you know that every state has a Protection and Advocacy organization (P&A), often called Disability Rights, and that each of those P&As has a PAIMI (Protection and Advocacy for Individuals with Mental Illness) council? Joining your state's council is a great opportunity to advocate for the unique needs of those with SMI since those unique needs are often less represented on these types of councils.



# Grave Disability and Psychiatric Deterioration State Legislative Work

Many states lack adequate, explicit, and clear criteria for involuntary treatment for those with severe mental illness (SMI) and so fail to encompass the various ways a person might be a danger to themselves. This leads to worsened conditions and avoidable harm. While 47 states recognize grave disability (when an individual cannot meet basic survival needs), only 34 include psychiatric deterioration (foreseeable harm from untreated psychiatric conditions) as grounds for involuntary treatment. Among these, four states restrict the psychiatric deterioration provision to involuntary outpatient treatment.

**TAC recommends that states explicitly include both grave disability and psychiatric deterioration as grounds for involuntary intervention.** Without these updates, individuals with SMI will continue to suffer unnecessary deterioration, criminalization, and tragic outcomes. These standards enable timely intervention, authorizing treatment to prevent harm rather than requiring harm before treatment occurs.

## **Key TAC policy recommendations:**

- Criteria should not require unreasonably severe harm.
- Criteria should not force families to deny assistance to qualify.
- Criteria should allow consideration of treatment history and the likelihood of future psychiatric deterioration without treatment.

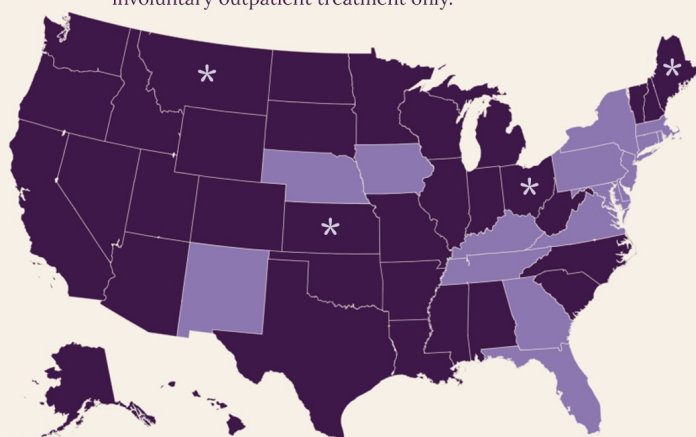
## **Notable legislative developments:**

- California and Kansas: Enacted new psychiatric deterioration laws during the 2023-2024 legislative sessions.
- Hawaii: Introduced three original bills and one companion bill in the 2024 session that failed to pass.
- New York: Two psychiatric deterioration bills failed to pass in 2023-2024.
- Massachusetts and Ohio: Each state has a psychiatric deterioration bill under consideration as of December 1, 2024. If these bills do not pass, they will require reintroduction for consideration in the 2025-2026 biennial legislative sessions.

More detailed information is available upon request to [advocacy@tac.org](mailto:advocacy@tac.org).

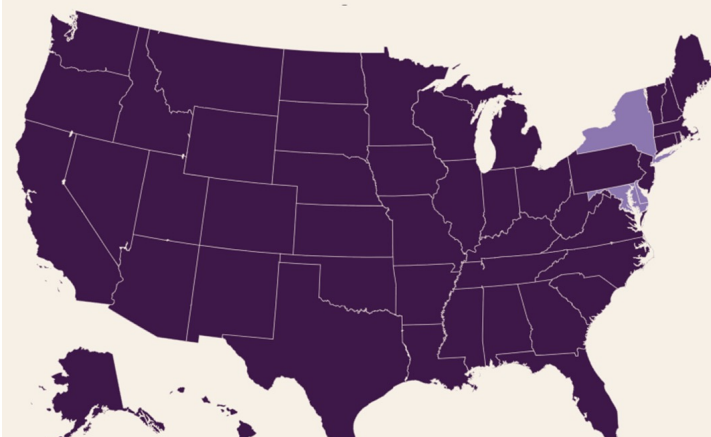
## Psychiatric Deterioration Standard in Involuntary Treatment Statute

- No psychiatric deterioration standard
- Has a psychiatric deterioration standard
- ✱ Psychiatric deterioration standards apply to involuntary outpatient treatment only.



## Grave Disability Standard in Involuntary Treatment Statute

- No grave disability standard
- Has grave disability standard







## IMD Exclusion Legislative Update

*Nina Richtman (second from left) at a panel discussion about the Michelle Go Act at the New York Junior League.*



TAC's advocacy department is actively reaching out to policymakers and staffers to gain co-sponsors and support for multiple bills related to the IMD exclusion changes and repeal. This work is critical for improving access to inpatient beds, as this discriminatory aspect of federal law prevents Medicaid reimbursement for inpatient stays in facilities with more than 16 psychiatric beds.

### **The Michelle Alyssa Go Act (HR 8575)**

Filed by Congressman Dan Goldman (NY-10) in May 2024, this bill now has many co-sponsors:

[Dan Goldman \(D\)\\*](#), [Don Bacon \(R\)](#), [Gus Bilirakis \(R\)](#), [Julia Brownley \(D\)](#), [Tony Cárdenas \(D\)](#), [Yvette Clarke \(D\)](#), [Dan Crenshaw \(R\)](#), [Brian Fitzpatrick \(R\)](#), [Jimmy Gomez \(D\)](#), [Mike Lawler \(R\)](#), [Nicole Malliotakis \(R\)](#), [Marc Molinaro \(R\)](#), [Grace Napolitano \(D\)](#), [Andrea Salinas \(D\)](#), [Adam Schiff \(D\)](#), [Marilyn Strickland \(D\)](#), [Jeff Van Drew \(R\)](#).

If enacted, it would change the limit from 16 to 36 beds, allowing federal matching Medicaid funds to be used for facilities with up to 36 beds for psychiatric patients. While this is not the full repeal

that TAC supports, it is seen by some advocates as a positive step forward and an opportunity to educate policymakers and the public on the fundamentally discriminatory nature of the IMD exclusion that was part of the Medicaid Act of 1965.

TAC's Director of Advocacy, Nina Richtman, spoke as part of a panel in October at the New York Junior League, where Michelle Go was an active member prior to her death. Although new to SMI advocacy, the Junior League has committed to turning tragedy into action moving forward.

### **Repealing the IMD Exclusion Act (HR 10266)**

Introduced by Congressman Ritchie Torres (NY-15) in November 2024, this legislation would amend Title XIX of the Social Security Act to remove the exclusion from medical assistance under the Medicaid program of items and services for patients in an institution for mental diseases, and for other purposes.

Rep. Torres made this statement: "For me, there is no set of people who we are

failing more miserably than the severely mentally ill, who are left to languish in our subways, streets, jails, and prisons. The fact that Rikers Island is one of the largest providers of mental healthcare in America is a profound indictment of our society. As a country, we have to recognize that there are Americans whose mental illness is so severe that it requires inpatient care. Public policy at the federal level has swung the pendulum too far in the direction of deinstitutionalization, which has been a failure.”

#### [Increasing Behavioral Health Treatment Act \(HR 1201\)](#)

Introduced by former Congresswoman Grace Napolitano (CA-31) in February 2023, this act would fully repeal the IMD exclusion. Due to Napolitano’s retirement

in 2024, the bill is expected to be filed again by another legislator in 2025.

#### [Securing Advances and a Variety of Evidence-Based IMD Options Act \(S 3098\)](#)

Originally filed by Senator John Thune (SD) in 2023, the bill is hoped to be filed again in 2025.

This act would amend title XIX of the Social Security Act to make permanent the Medicaid option to remove the IMD exclusion to provide medical assistance for certain individuals who are patients in an institution for mental diseases.



## 2024 Legislative Recap

With 2024 in the rearview mirror, TAC sends gratitude to grassroots advocates working to improve the treatment of people living with SMI.

### By the numbers:

**53**

**ADVOCACY  
ALERTS**

inspired advocates to act.

**6,357**

**EMAILS**

were sent to legislators via  
our TAC portal.

**1,317**

**ADVOCATES**

sent emails.

**51**

**BILLS**

tracked by TAC were  
enacted as new state laws.

**22**

**STATES**

passed new laws to impact  
SMI treatment.

[Click here](#) to read a summary of bills passed, listed in alphabetical order by state. Please read and share with lawmakers and other stakeholders. Another state’s action might provide sample legislation for your state in the future.