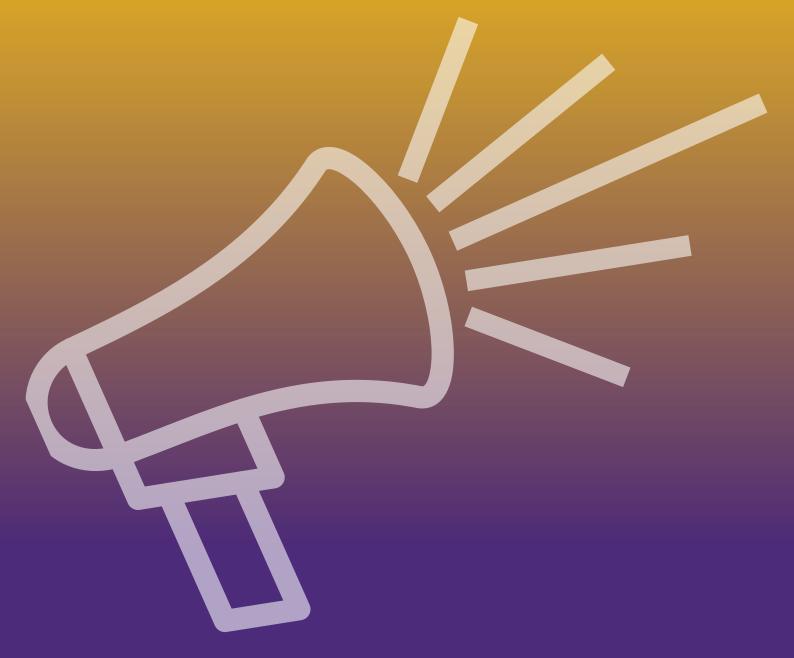


# Make Them Hear You



2 0 2 1 I M P A C T R E P O R T



The Treatment Advocacy Center is a national nonprofit organization dedicated to eliminating barriers to the timely and effective treatment of severe mental illness. The organization promotes laws, policies and practices for the delivery of psychiatric care and supports the development of innovative treatments for and research into the causes of severe and persistent psychiatric illnesses, such as schizophrenia and bipolar disorder.

#### DEAR FRIENDS.

We had hoped that by the time we published this report, the global COVID-19 pandemic would be behind us and that, after enduring the worst economic and health crisis of our lifetimes, we would be resuming normal life.

Sadly, that hasn't happened yet. As a result, Treatment Advocacy Center has had to pivot, adapt and find ways to push forward.

We have learned how to operate in the new normal and imagine new ways to reach and serve our constituency. As such, we are committed to doing things even better than before — to carrying out our mission to eliminate barriers to the timely and effective treatment of severe mental illness with the benefit of lessons learned from the ongoing pandemic.

Chief among those lessons has been the need to make our work and ourselves more accessible to our local advocates — sharing our wisdom directly with our supporters and training them to become effective advocates.

Thus, in her first year as executive director, Lisa Dailey has made public education about severe mental illness and SMI policy a top priority for Treatment Advocacy Center.

"Go out and tell our story, make it echo far and wide," sings the character of Coalhouse Walker, Jr. in the Broadway musical *Ragtime*, based on the 1975 novel of the same name. "Make them hear you."

The theme of this year's annual report is *Make them hear you*, and we have been steadfastly committed this year to helping our supporters raise their voices.

As you will read in these pages, this year we trained more than **450** participants in our AOT Learning Network spanning 40 states, lent technical assistance to over **30** AOT programs throughout the country, testified more than a dozen times in front of legislative bodies, helped pass seven priority bills, published **52** editions of *Research Weekly* and appeared in **300** news stories.

This report proves the impact that your support is having. Thank you for helping us achieve our mission of eliminating barriers to timely and effective treatment for severe mental illness.

We are so proud of what we have accomplished and are confident we will be able to increase our impact in the years to come.

Lisa Dailey

Executive Director

Dr. Michael Knable

Chair.

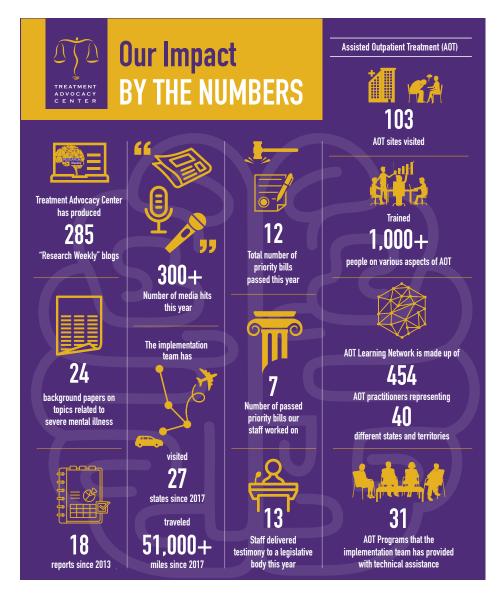
Treatment Advocacy Center Board of Directors Dr. E. Fuller Torrey

ounder

## Our Impact: At a Glance

This year, Treatment Advocacy Center committed to making our work more accessible and replicable for our supporters and local advocates. While we have always advocated for the best interests of people with severe mental illness, this year we put greater emphasis on "training the trainers," sharing our tools, tips, strategies and best practices for SMI advocacy through more in-person and online trainings, webinars, speeches, op-eds and podcasts. As a result, our supporters and local advocates are better equipped than ever to join us in the fight to eliminate the barriers to treatment for people with severe mental illness.

While we have been making our supporters smarter and stronger, we also have been diversifying our audience. This year, we made it our mission to be more inclusive by translating some of our materials into Spanish and making space for Black people with SMI and their families to tell their stories. There is more work to be done and we are committed to accomplishing it. We are all in this work together.



# **Educating the Public on Key SMI Issues**

## IMD Exclusion

The Institutions for Mental Diseases (IMD) exclusion is open and flagrant federally sanctioned discrimination in plain view of lawmakers and the public. We have worked tirelessly to educate lawmakers on the need to both repeal the law and work with states to pass waivers this year. Legislative and Policy Counsel Michael Gray published an op-ed in July arguing for the discriminatory law to be repealed, "A law hindering treatment for severe mental Illness must be repealed." His piece was

"At a time when movements for equity and social justice have captivated the nation's attention and galvanized activists, one of the most ongoing and notorious forms of discrimination in this country remains enshrined in federal law."

— Michael Gray

widely read and commented upon, having been shared nearly 800 times directly from *The Hill*'s website.

With an issue that that can be fixed using both state law and federal law, it can be difficult for advocates and

supporters to see progress. To help with this, Gray hosted a webinar in November to give advice on how to be a better advocate for this issue. The webinar, titled, "IMD Advocacy Update," was paired with a VoterVoice campaign that helped people contact their congressperson to urge them to cosponsor Rep. Grace Napolitano's (D-Calif.) legislation to repeal the IMD exclusion. One hundred sixty five people used the campaign to contact their congressperson.

On Jan. 1, the Maryland Department of Health gained authority to waive the discriminatory IMD exclusion. Treatment Advocacy Center staff, with support from Board member Evelyn Burton on the ground in Maryland, fought tirelessly to obtain this waiver. We pushed the state to start this process and then worked with Maryland policymakers to make sure they obtained the maximum amount of federal money to treat Marylanders with serious mental illness.

We are proud to be a leader in the field on this issue and will continue to push back on this legally-sanctioned discrimination until the law is repealed.



## Tweet this now to push your legislator:

The IMD exclusion legally discriminates against those with **#SMI** and **#HR2611** would repeal it. (your congressperson), will you cosponsor this critical bill?

We need your support . **#EndIMDExclusion** 

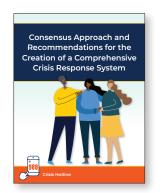
#### What is the IMD Exclusion?

The exclusion prevents federal Medicaid funds from covering inpatient services in a psychiatric facility with more than 16 beds, unless states and facilities meet specific requirements for waivers or utilize other mechanisms that allow for payment. It bars Medicaid enrollees with "mental diseases" from receiving the same level of care that enrollees without severe mental. illness receive for physical ailments such as cancer and heart disease. In doing so, the exclusion denies equal protection under the law to the very group of people it is supposed to help.

## **Educating the Public**

## 988

Treatment Advocacy Center joined our nation's other leading mental health organizations in releasing a comprehensive roadmap for reimagining crisis response for mental health, substance use disorders and suicide prevention in November. Executive Director Lisa Dailey was one of the primary drafters of the roadmap to make sure that communities and activists will have the right resources to make the hotline successful when it comes out in July 2022.



"The creation and launch of 988 presents us with both an opportunity and a responsibility," said Dailey in a press release. "We have a chance to rethink our entire approach to the treatment of mental illness through the lens of crisis, and in doing so better serve everyone in our communities. But we can't afford to fail."

## Co-Occurring Serious Mental Illness and Substance Use Disorders

The Office of Research and Public Affairs released a new report in March, "Serious Mental Illness and Co-occurring Substance Use Disorders." Of the many barriers people living with serious mental illness face, one in four of them has the added challenge of a dual diagnosis – experiencing co-occurring serious mental illness and a substance use disorder. Read the full report here.



Then, in May, ORPA released an informative fact sheet titled, "Racial Disparities in Individuals With Co-occurring Serious Mental Illness and Substance Use Disorders," highlighting, with the use of graphics and research, how racial and ethnic minorities are disproportionately impacted by the negative effects of these disorders. These same populations also tend to have the least access to care.

DJ Jaffe Advocate Sabah Muhammad, as part of her new role, oversaw translation of the fact sheet into Spanish: "I knew we could do more to get behind our own mission to eliminate barriers to treatment for the most vulnerable. Translating the documents that we use to help families advocate won't eliminate the language barrier overnight, but it's a step in the right direction." Going forward, Treatment Advocacy Center hopes to translate more of the website into Spanish and to translate to other languages that are commonly spoken in the United States, including Chinese, Arabic, Vietnamese and French.

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"It's really hard for people to find resources and information. That's why it was so helpful to have websites like your own."

Linda Snow Griffin, psychologist, author and family member

## **Research in Action**

Treatment Advocacy Center has been leading the charge to ensure that people with severe mental illness are not left behind in the fight against COVID-19. Since the start of the ongoing pandemic, we have sent letters to state health directors to ensure that people with SMI were prioritized for vaccination. We educated providers on the best way to protect those with SMI in this pandemic.

In April, ORPA provided states, practitioners, community organizations and public health leaders with **fliers** to distribute to people with SMI who were hesitant and to providers to make it easier for people with SMI to get vaccinated.



The first flier was created for people with SMI and designed to ease doubts and concerns about the vaccine. The flier listed myths and facts about the vaccine and the vaccination process and for every common myth about the vaccine, it provided an

accurate fact. For example, one myth was,
"You can get COVID-19 from the vaccine."
The corresponding fact was: "You cannot get
COVID-19 from the vaccine because it doesn't
contain the live virus." The second flier was
created for providers and included tips for
vaccine clinics to help people with SMI feel more
comfortable about receiving the vaccine.

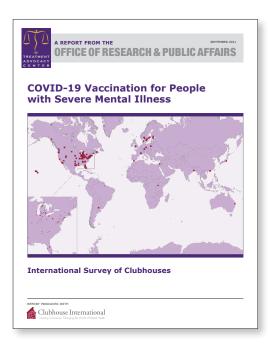
We also issued a **statement**, in April, along with nine other mental health organizations, urging the federal government to provide a strategy to prioritize vaccination for people with SMI, followed by an op-ed in *The Hill*.

A piece of what the research did was validate what we were saying as non-scientists who were trying to advocate for our clients."

"

Stacy Derrick, cofounder of Help in the Home in Rockville, Md.

## Research in Action



ORPA published a **report** in September highlighting how community investment to facilitate COVID-19 vaccination can have a tremendous impact on promoting vaccination among people with SMI.

We didn't let up: We continued advocating for people with SMI to get the support they need. Centers for Disease Control and Prevention (CDC) listened to us in October when it added schizophrenia spectrum disorders to its list of underlying medical conditions associated with higher risk for severe illness due to COVID-19 infection.

**Research Weekly** is a weekly public service of ORPA to make sure the public is up-to-date on recent research and updates from researchers. This year, we taught the public about the effectiveness of distributing COVID-19 vaccinations at psychiatric hospitals, why people with severe mental illness are at higher risk of mortality from COVID-19, how people with severe mental illness navigate college, and much more.

Find the most up to date information on the COVID-19 vaccinations and boosters on the COVID Resources page on our website.

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Given all the uncertainties surrounding the Covid-19 pandemic, it is very reassuring to know that the Treatment Advocacy Center has convinced the CDC to consider severe mental illnesses as risks for severe illness and death from the virus. Living with and managing a diagnosis is challenging enough without the additional issues a pandemic pose. I am grateful to Treatment Advocacy Center for its concern for me during these trying times.

Grace Lee, Houston, Texas

# **Promoting Assisted Outpatient Treatment**

This year, we made great progress to expand the reach of assisted outpatient treatment, the practice of providing community-based mental health treatment under civil court commitment. In 2018, Pennsylvania passed a law to provide a statutory basis for AOT, however not a single county took advantage of the new law. To remedy this, Treatment Advocacy Center's AOT Implementation Department,

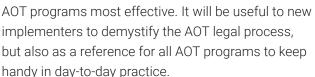


Office of Research and Public Affairs and Communications Department partnered to call attention to this missed opportunity. As part of a multi-pronged strategy, Treatment Advocacy Center launched a social media-style video urging Pennsylvania county executives to implement AOT. As a result of these combined efforts, there are now five counties in the planning stages of implementing AOT programs and our AOT Implementation Department is working alongside each of them providing technical assistance to help ensure their success. These counties include Bucks, Carbon, Monroe, Pike and Dauphin.

This past summer, California counties were required to decide whether to opt out of Laura's Law. Treatment Advocacy Center board member Randall Hagar, Executive Director Lisa Dailey and contractor Eric Smith worked in concert to push counties to opt-in and as a result, now nearly 80% of Californians have access to this lifesaving and effective tool for the treatment of severe mental illness.

We were also instrumental in improving AOT laws in both Louisiana and Nevada that will enable AOT programs in both states to expand their reach and impact in the years ahead.

Policy Director Brian Stettin wrote a guide for legal and clinical practitioners called the Texas Assisted Outpatient Treatment Practitioners' Guide. The guide explains the entire Texas AOT legal process along with some commentary on how we think the law should be interpreted, consistent with what we know makes



TREATMENT ADVOCACY CENTER
the way
forward

This summer, we released our first podcast on the extraordinary success of AOT treatment in Ohio. Titled "The Way Forward," it was produced by Emmy Awardwinning journalist Bill Retherford. Listen to it here.

Assisted Outpatient Treatment
Learning Network is a network of
AOT practitioners and stakeholders from across the nation.
Treatment Advocacy Center's
AOT Implementation Department
puts together two events each
month on Thursdays, a webinar
and a web chat. Watch some of
those events here. There are over
500 people in the AOTLN. The network connects people and drives
collaboration to help improve
everyone's AOT programs.

"Not afraid to go out front with issues that could fundamentally improve the lives of persons with SMI but were not initially seen favorably, Treatment Advocacy Center has led the way to the availability of Assisted Outpatient Treatment (AOT) in almost every state."

Dr. Jeffrey Geller,
 president of the American
 Psychiatric Association.

# **Speaking and Publishing**



"We need well-funded professionals who work with dignity to respond to crises."

- Sabah Muhammad

This year, we shared our expertise widely through coast-to-coast speaking engagements. DJ Jaffe Advocate Sabah Muhammad spoke to lawmakers and mental health care providers about how America could have a safer future by having primarily mental health professionals respond to mental health crises and described her experience at the intersection of race and severe mental illness at Mental Health America's Morris County Mental Health and Addictions Coalition's third annual Legislative Breakfast held in New Jersey in October.

Director of Research Elizabeth Sinclair Hancq and Research Associate Kelli South guest lectured at Catholic University

in April on the topic of criminalization of serious mental illness and its impact on women. The class was a seminar for senior undergraduates and was a great way to reach students and educate them on our issues.

Muhammad co-authored a law review article with Legislative and Policy Counsel Michael Gray for the *Texas Tech Law Review* last June titled, "An Untenable Space: The Dilemma of Black Families Caring for a Loved One with Severe Mental Illness and an Argument for a Legislative Solution."

Gray published a law review article in December in the *Oklahoma City University Law Review*, titled, "HIPAA, Telehealth, and the Treatment of Mental Illness in a post-COVID World." The article examines COVID-era changes to federal and state telehealth laws, their impact on the treatment of SMI, HIPAA implications, and argues that those changes should be permanent.

Together, Muhammad and Gray co-published an article, "Race, Mental Illness, and Restorative Justice: An Intersectional Approach to More Inclusive Practices," in the January issue of *The Seattle Journal of Social Justice*. The article argues for an application of restorative justice practices that benefit individuals diagnosed

Pursuing appropriate crisis response for people with SMI has become a discussion in many communities and I'm glad we've been pursuing this model more diligently. Being able to utilize Michael Gray as a resource to talk through the questions that have come up as we've been having these conversations has been incredibly valuable to ensure we can best serve the residents in our city.

"

Oklahoma City Councilwoman JoBeth Hamon

## Speaking and Publishing

with severe mental illness. Muhammad and Gray specifically focus on widespread shortcomings in the restorative justice movement like the overrepresentation of non-violent white individuals and the common requirement that the person admit culpability to enter the process.



The AOT Implementation Department hit the road in November. They traveled to El Paso, Texas, Las Cruces, N.M. and Albuquerque, N.M. to meet with AOT programs and provide technical assistance.

Their first stop, El Paso, Texas was a success, where they heard from two AOT participants, met with the full team and observed hearings in the afternoon. The hearings took place partially in Spanish to accommodate AOT participants and their loved ones. There, the Treatment Advocacy Center trio was lucky enough to witness an AOT graduation ceremony. The AOT graduate brought his wife, mother and his uncle. In an emotional address, his mother spoke to the entire team and and thanked them for giving her son back to her.



The trio conducted trainings in both Las Cruces and Albuquerque, N.M. Judges, attorneys, treatment providers and evaluators came together to hear from the AOT Implementation Department on how to best put together a program. Then our team put together a mock AOT hearing that depicted the court's consideration of whether an individual met the legal criteria to be placed under AOT, followed by a mock status check with the same individual a few weeks later.



Our AOT Implementation Department also helps many other assisted outpatient treatment programs. This year, the team provided technical assistance to 14 different programs, ensuring that AOT is running effectively all over the country.

This past summer, California counties were required to decide whether to opt out of Laura's Law, California's version of AOT. As a result, now nearly 80% of Californians have access to this lifesaving and effective tool for the treatment of severe mental illness. These counties sought

our counsel when implementing the law, so our AOT Implementation Department brought together 62 judges and court personnel from California in December and trained them on how to effectively enact Laura's Law.

## **Educational Webinars**

Treatment Advocacy Center hosted seven webinars for the public this year to support local advocates by providing them with the right tools to succeed. Starting in March, Executive Director Lisa Dailey hosted a townhall to introduce herself to the public and outline her vision for the organization this year.

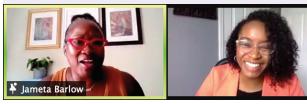
Also in March, when the Department of Health and Human Services announced that it planned to change the HIPAA Privacy Rule and asked for public comments, Legislative and Policy Counsel Michael Gray hosted a webinar titled, "The HIPAA Privacy Rule: What the proposed Changes Mean for your Family" to inform our audience and advise them on how to provide comment. Gray followed his webinar up in April with another one, titled, "Advocacy 101: How to Effect Change," in which he taught the do's and don'ts of lobbying.

In May, Communications Director Geoffrey Melada hosted a webinar titled, "Advanced Advocacy Communications Tools: How to Write Effective Press Releases and Op-Eds," in which the former journalist explained what newspaper editors look for in press releases and op-eds, and how effectively using these communications tools can shape the conversation around SMI.

Also in May, our inaugural DJ Jaffe Advocate, Sabah Muhammad, hosted a webinar titled, "Trust Black Families: Incorporating Race in the SMI Conversation" in which she shared her own experience living at the intersection of race and severe mental illness and provided space for others to do the same.

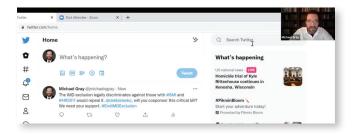
"We need to ask: How can we make sure that those who are most marginalized are taken care of? If we can address the needs of the most marginalized, we are actually helping everyone."

– Professor Jameta Barlow



To celebrate Black Indigenous People of Color Mental Health Month last July, Treatment Advocacy Center hosted an engaging, online discussion between George Washington University Writing Program Assistant Professor and community health psychologist Jameta Barlow and Muhammad. Moderated by Director of Research Elizabeth Sinclair Hancq, the discussion centered on our newly released fact sheet on racial disparities and the panelists' reflections on the intersection of race and SMI.

In November, Gray, followed up on an op-ed he published in *The Hill* with a webinar on how to best advocate to repeal the discriminatory IMD exclusion titled, "IMD Advocacy Update."



# Storytelling to Shape Policy

This year, Treatment Advocacy Center assisted staff and family members to produce stories to shape policy and make legislators see the difficult challenges people with SMI and their loved ones face daily.







Social Work Intern Eric Smith penned a helpful *Personally Speaking* blog in August on how to speak up and share your SMI journey to effect legislative change.

Senior Family Liaison Kathy Day published a thought leadership **piece** on our blog about the best practices for family caregivers of people with schizophrenia in November.

Also in November, Day published a *Personally Speaking* blog about how finding Treatment Advocacy Center made her feel less alone after discovering how many barriers to treatment her loved one would face.

Martha Stringer, a family advocate in Pennsylvania, published a *Personally Speaking* blog in December about how Treatment Advocacy Center helped her become an effective advocate for her daughter and others with SMI. After Stringer's daughter was criminalized for having bipolar disorder, she turned to Treatment Advocacy Center to help her convince her county officials in Bucks County, Pa. to implement AOT. Bucks County is now one of the five pilot programs that will enact AOT in Pennsylvania.

1

Eric, thank you for just an inspiring presentation this evening.

It was worth the price of admission.

Judge Lawrence Brown

# **Educating the Media on SMI**

The Communications Department worked hard to educate the media this year on issues pertaining to severe mental illness and helped keep those issues in the news to influence policymakers. Treatment Advocacy Center was mentioned in the news over 300 times this year. Here are some of the best media hits the team obtained for Treatment Advocacy Center:







Treatment Advocacy Center Executive Director Lisa Dailey was quoted in a *Washington Post* article about our successful push to have schizophrenia spectrum disorders added to CDC's list of underlying medical conditions with heightened risk of severe COVID-19.

Executive Director Lisa Dailey was interviewed by *CBS This Morning* to discuss whether police should handle mental health calls after a Texas sheriff's deputy violently restrained an 18-year-old woman during a mental health crisis.

Board member Evelyn Burton published an op-ed in *The Baltimore Sun* urging Maryland to reform its involuntary commitment law by defining "danger." Treatment Advocacy Center's "Grading the States" report was also cited.

Executive Director Lisa Dailey and Mental Health American's then-president and CEO Paul Gionfriddo published a joint op-ed in *The Hill*, which argued for a national strategy to maximize vaccinations for people with SMI.

Legislative and Policy Counsel Michael Gray published an op-ed in *The Hill* urging Congress to repeal the discriminatory IMD exclusion and for states to seek 1115 waivers for IMDs for those with SMI in the interim. The op-ed was shared 782 times from *The Hill*'s website and garnered 186 comments.

Treatment Advocacy Center Director of Research Elizabeth Sinclair Hancq was quoted and our research on bed shortages was cited in an *AP* story on California's struggle treating and housing people with SMI. The article was also picked up in the *Washington Post* and *ABC News*.

## **Supporters**

#### THANK YOU FOR ALL OF THE DONATIONS!

We recognize the supporters who made generous contributions to Treatment Advocacy Center during the last fiscal year. Without our supporters, our work would be impossible. The generosity of our supporters enables us to continue to remove barriers to treatment for people with severe mental illness. We are deeply grateful to recognize these gifts made between July 1, 2020 and June 30, 2021.

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Treatment Advocacy Center's just
a great resource, and one that's not really
duplicated elsewhere.

You really can't find another group that
has the same type of information —
the type of resources — needed to reform
treatment for people with SMI as the
Treatment Advocacy Center

Hon. Pat Wolke, Judge, Oregon's 14th Judicial District

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