



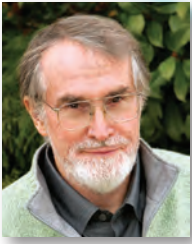
# Catalyst



# 20

TWENTY YEARS OF ELIMINATING BARRIERS TO TREATMENT

# 20



A MESSAGE FROM THE FOUNDER

# Celebrating 20 Years at the Center of Advocacy for Mental Health Treatment

*E. Fuller Torrey, M.D.*

The Treatment Advocacy Center first came to be in 1998, after Vada Stanley read my book *Out of the Shadows*. She and her husband Ted had been supporting my research on severe mental illness for years. Vada called me and asked, "Isn't there something we can do NOW to help people who need treatment for serious mental illness?"

We discussed the problem at length, agreed that advocacy to improve access to treatment for individuals with serious mental illness – especially those who were not aware of their illness – had the greatest potential. Vada and Ted Stanley then generously committed funds to start and sustain the Treatment Advocacy Center.

The rest, as they say, is history – some of which I might have predicted, and much that came as a surprise.

For example, I knew that our mission would be – and is – a challenging one. I knew the vested interests of the mental health community would not embrace our call to recognize the realities of severe mental illness or even agree that the care of those with serious mental illness should be a priority. There was simply too much money wrapped up in treating the easy cases and too much risk in taking on those people. But I also knew that we had a powerful and largely untapped resource: families. Families who knew the fear of being told there was no bed available to treat their loved one and the pain of being afraid of one's own child and the symptoms of their illness. Achieving our goals would be difficult, but the idea of accepting the status quo was unbearable.

Indeed, over the years, every one of our successes have been tempered by an even greater number of tragedies.

One day would be filled with anger at the shortsightedness of elected officials, who allowed a broken mental health system to neglect its obligations to those they were meant to serve. The next would bring more pain as we battled entrenched interests, digging in their heels to oppose even the most common-sense solutions.

Headline after headline would highlight immense suffering that could have been prevented if only leaders would take notice. There were some days when it all seemed too much.

But we never gave up. Our ranks were bolstered every day

**PUTTING AN END TO THESE TRAGEDIES HAS BEEN AN IMPORTANT PART OF MY LIFE'S WORK. AND WE HAVE ACCOMPLISHED SO MUCH IN OUR TWENTY YEARS. IT IS RIGHT THAT WE CELEBRATE. BUT WE MUST ALWAYS REMEMBER, OUR MISSION CONTINUES.**

with brave, unimaginably resilient families that had endured so much but remained dedicated to affecting change.

And finally, our hopes would be made real. Something would occur that would call attention to the disastrous treatment system and one could practically feel tectonic plates shifting underfoot. Momentum would build, policy makers would take notice, and we would make historic gains in the way our system views and responds to people most in need.

From New York's passage of Kendra's Law to the monumental federal reforms of the 21st Century Cures Act, we have made progress beyond what I ever imagined possible – progress that is literally saving lives.

However, there is no time for us to rest on our laurels. Senseless tragedies still too often dominate the news and remind us of the work that remains.

As I noted five years ago, we will know we have succeeded when there are markedly fewer people with serious mental illness who are homeless, victimized, and incarcerated.

Suicides and homicides by individuals with untreated mental illness will be the exception, not the rule. Consistent, effective treatment will be something we take for granted, rather than a rare occurrence.

Putting an end to these tragedies has been an important part of my life's work. And we have accomplished so much in our twenty years. It is right that we celebrate. But we must always remember, our mission continues.



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# Message from Executive Director and the President of the Board

*John Snook and Stephen Segal*

For twenty years, the Treatment Advocacy Center has operated with a simple mission – eliminate barriers to the timely and effective treatment of severe mental illness. The simplicity of that mission statement belies the complexity of the forces that have been arrayed against us: political correctness, bureaucratic inertia, and outright indifference to the plight of those with the most severe mental illness.

All too often, the mental health system appeared unwilling to even acknowledge the devastating impact of failing to treat severe mental illness; to actually implement reforms seemed an impossibility.

Much has changed.

This special 20th anniversary edition provides all of us in the Treatment Advocacy Center family with the opportunity to reflect on just how much the world has shifted over these two decades. Thanks to the hard work, donations and support of people like you, what seemed impossible just a few years ago is now our reality.

Together, we have seen 34 states update their mental health treatment laws. Calls for restoring vital treatment beds now come not just from the Treatment Advocacy Center, but from the pages of the *Journal of the American Medical Association*, from newspaper editorial boards, and even from unlikely allies across the political spectrum. Today, disparate voices across the nation are united in support of substantive legislative reforms.

Dr. Torrey's demands of federal agencies have moved from the pages of his books to the halls of Congress. Recently, the Substance Abuse and Mental Health Services Administration was dramatically reshaped and the National Institute of Mental Health even acknowledged some of its failings.

The metamorphosis is, at once, breathtaking and also a stark reminder of how much there is still to do.

Too many of our families struggle to find consistent care for their loved ones before crisis strikes. Unfathomable tragedies make daily headlines. Treatment beds are scarce and jail cells are crowded with people with serious mental illness. Our entire society suffers as a result.

Like many of the Treatment Advocacy Center board and staff, we first came to this organization seeking assistance. Consequently, we understand the stakes and take our charge very seriously.

As you read through this edition of the *Catalyst*, we hope you will first take a moment to marvel at how far we have come. And then, we ask that you redouble your efforts to support this important organization at this critical juncture.



*John Snook*



*Stephen Segal*

You can help in any number of ways: Engage your family and friends in discussions about the vulnerable and overlooked who, through no fault of their own, have been afflicted with diseases of the brain. Share our campaign information on your social media platforms. Make a donation in honor of our 20th anniversary. Sign up on the Treatment Advocacy Center website to become an advocate and write to your decision makers about our priority issues.

There has never been a more important time for this work. Join us as we continue to make real reform a reality.

## ***Theatrical Preview: Bedlam***

For quite a while, the Treatment Advocacy Center has been working with award winning filmmakers Kenneth Paul Rosenberg, MD and Peter Miller as they profile the debacle of our broken mental health system, and call attention to what amounts to the greatest social crisis of the 20th and now 21st centuries.

Their film is still in production, but it draws heavily from the work of Dr. E. Fuller Torrey and includes unseen interviews with him. Currently entitled "Bedlam," it immerses one in the national crisis surrounding care of people with serious mental illness from inside one of America's busiest psychiatric emergency rooms, correctional facilities where tens of thousands of psychiatric patients are warehoused, and the homes – and homeless encampments – of our communities.

We look forward to promoting this documentary and we are hopeful that the intimate stories of patients, families, and medical providers in it will help spur further mental health reforms in states across the country.



# Vada's Gift

## Jonathan Stanley

First, foremost and always, the Treatment Advocacy Center is a product of the inspiration, dedication and perseverance of Dr. E. Fuller Torrey.

Of course, many others have also been part of the unique and impactful endeavor that has helped so many get treatment who otherwise would have gone without. My parents, Ted and Vada Stanley, are among them. They helped Dr. Torrey and others jump-start the Treatment Advocacy Center when it was only a fledgling idea.

My dad was most interested in the medical research side, but mom galvanized on the pragmatic "lets help people now" mission presented by Dr. Torrey. As usual, once focused on a passion, Vada Stanley got her way. History has since validated.

I am proud of my parents' foresight and generosity and also of my contributions to the Treatment Advocacy Center, both before and after its creation.

The before was unintentional. I had a psychotic bipolar break in college. It was a tough time for me, and included mania, delusions, paranoia, a most unhappy college provost, some kind cops and seven weeks in an inpatient psychiatric facility.

My parents were forced to face that, even though I was so sick, they had no legal recourse to get me treatment if delusional me would not agree. And that was why my parents so strongly bought into the idea of getting help for people, as the Treatment Advocacy Center has since done for countless thousands.

My involvement after, with medications that brought me back to who I was before, was working for Treatment Advocacy Center. I still brag of those times — about working with senators and governors, about the many laws the organization has helped pass, and the many thousands of people helped. But that is just my ego talking.

What makes the Treatment Advocacy Center so needed is all of the people who I have talked to with loved ones in the grips of severe mental illness. People desperately trying to make sense of the senseless.

For instance, caring parents should not be faced with whether to let their kid back into their home after the fourth 72-hour hold because they worry about what will



Vada and Ted Stanley

happen. In such situations, I have sadly suggested putting inside security locks on their bedroom door. That's "a trick" that was shared by others who faced similar fears. Could there be a starker commentary on the lack of more meaningful solutions?

Ted and Vada Stanley have passed on in the last few years, but their impact on the world remains. Especially with regards to the Treatment Advocacy Center. Even my father, who was skeptical at first, said it was about the most "efficient and impactful money" he had ever spent.

## Our Mission

*The Treatment Advocacy Center is a national nonprofit organization dedicated to eliminating barriers to the timely and effective treatment of severe mental illness.*

*We promote laws, policies and practices for the delivery of psychiatric care and support the development of innovative treatments for and research into the causes of severe and persistent psychiatric illnesses, such as schizophrenia and bipolar disorder.*

## Saying NO to Big PHARMA

No nonprofit can survive, much less thrive, without reliable and generous donors. However, individuals and private foundations are unusually vital to the Treatment Advocacy Center because from the beginning — and alone among major mental health organizations — we have not accepted funding from the corporations most closely allied with mental illness treatment: pharmaceutical companies.

This is our position because we advocate for reforms that can result in individuals with severe mental illness being ordered to adhere to treatment plans that may include medication orders. And we believe that taking money from the companies that make those drugs and therefore stand to profit from the policies for which we advocate would create an unacceptable conflict of interest.

Further, we continue to be critical of pharmaceutical practices that result in the over prescription of certain psychiatric medications.

EST 1998

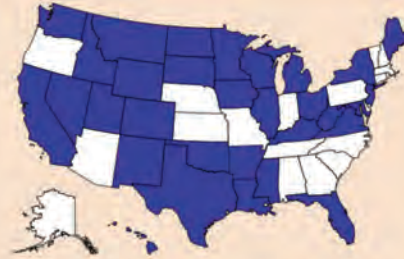
# TREATMENT ADVOCACY CENTER

20 YEARS OF ELIMINATING BARRIERS TO TREATMENT FOR PEOPLE WITH SEVERE MENTAL ILLNESS



23 independent evidence-based research reports published

170+ citations in academic literature



34 states with new or improved treatment laws or commitment standards

69 treatment laws or commitment standards passed, improved or updated

**Total # of States: 50**

**# of States with AOT Laws: 46**

**# of States without AOT Laws: 4**

Only Connecticut, Maryland, Massachusetts & Tennessee lack an AOT law



Over 20,000 friends, family members and community leaders advocating with us



400,000+ miles traveled advocating for our mission



5,000+ news articles generated about our work



550,000+ video views



280,308,190 people now live in areas with AOT laws



11,723  
Email  
Supporters



11,095  
Facebook  
likes



11,068  
Tweets



**4,023**  
Donors



# 20 YEARS OF TREATMENT ADVOCACY



- In collaboration with Mental Health Service Advocacy Center on implementing AOT laws.
- New York's Kendra's Law.
- Kentucky legislature to pass Tim's Law.



- California passes Laura's Law.
- Wisconsin Supreme Court finds its need-for-treatment standard to be constitutional.



- Louisiana passes Nicola's Law.
- Idaho and Virginia pass laws modernizing their commitment standards.



- 21st Century Cures signed by President Obama.
- New Mexico and Oklahoma pass AOT laws.
- Treatment Advocacy Center launches aBedInstitute.



- New Jersey passes Gregory's Law.



- New York passes Kendra's Law.

- West Virginia, Minnesota, Montana, Washington, Wisconsin pass improvements to their treatment laws.



- Treatment Advocacy Center founded.

- Treatment Advocacy Center develops Model Assisted Treatment Law.

- Illinois modernizes its dangerousness standard.

- Treatment Advocacy Center presented with American Psychiatric Association's Special Presidential Commendation for "extraordinary advocacy."

1998

1999

2000

2001

2002

2003

2004

2005

2006

2007

- Kendra's Law ruled constitutional by New York's highest court.

in the Substance Abuse and  
 Services Administration, the Treatment  
 conducts first nationwide trainings  
 AOT programs.

s Law extended to 2022.

e overrides Governor's veto



2018

- Iowa passes law improving inpatient and AOT treatment standards.
- *aBedInstead* campaign expands, calling for end to the Institutions for Mental Diseases exclusion.

2017

2016

2015

2014

2013

2012

2011

2010

2009

2008

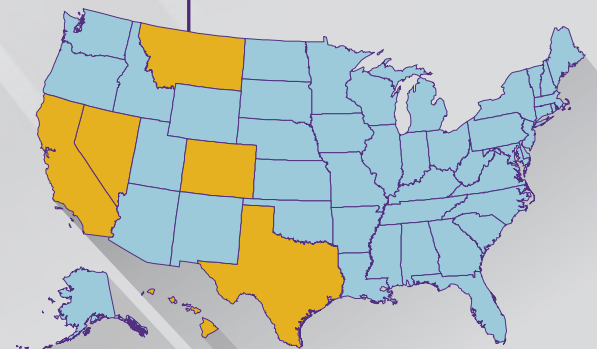
2007

- Ohio passes substantial reforms to its AOT laws.
- Maryland passes Treatment Advocacy Center-supported medication-over-objection law.
- Los Angeles, San Francisco, Orange, and Placer County vote to implement countywide AOT programs.

- Maine passes new AOT law.

- Federal government approves \$15M for the first-ever federal AOT grant programs.
- Eight new counties act to adopt Laura's Law, making AOT available to 8,260,835 more Californians.

- Department of Justice finds AOT to be an effective and evidence-based practice for reducing crime and violence.
- Virginia, Maine, West Virginia pass laws updating their treatment standards.



- Hawaii and Nevada pass AOT laws.
- Montana, Texas and Colorado pass laws updating their treatment standards and AOT provisions.
- California passes law clarifying that state Prop 63 funding can be used to support Laura's Law programs.



- Michigan passes Kevin's Law.
- Florida adopts Baker Act reform.

## Stanley Medical Research Institute and the Treatment Advocacy Center, an Update on Our Historic Partnership

The Stanley Medical Research Institute has been a supporting organization of the Treatment Advocacy Center for the life of the organization, assisting both administratively and also through contributions to mission-related research projects. Over the past decade, we have done this in two main ways.

One way has been to provide modest research funds to academic organizations in order to answer specific questions which are directly relevant to the Treatment Advocacy Center's priorities. An early example was a small grant to researchers at Duke University to establish the cost-effectiveness of assisted outpatient treatment. This was one of the first such studies and received significant publicity. Similarly, a grant in Florida reported that treating individuals with serious mental illness reduces the chances of the person being arrested as well as reducing the overall treatment costs. Such data is very useful in persuading policy makers to invest in treatment programs.

A Stanley Medical Research Institute grant in Summit County, Ohio, reported that individuals with serious mental illness who were placed on assisted outpatient treatment were less likely to be rehospitalized. The savings resulting from the reduced rehospitalizations were fifty percent greater than the cost of administering the assisted outpatient treatment program.

Another impactful grant was made to researchers at Rutgers University to collect Medicaid data on the use of clozapine in each state. Clozapine is regarded as the gold standard of antipsychotic medications, the treatment of choice for treatment resistant cases and for violent behavior. The resulting Treatment Advo-

cacy Center report described a seven-fold difference in clozapine use among the states and received wide publicity. It revived interest in increasing the use of clozapine and was responsible, at least in part, for a special clozapine report by the National Association of State Mental Health Program Directors; the formation of a special clozapine work group by the American Association of Community

Psychiatrists; and a new program under SAMSHA to make clozapine experts available for consultation to clinicians who wish to use it.

The second way in which the Stanley Medical Research Institute has substantially contributed to the Treatment Advocacy Center's mission is by carrying out relevant research and then jointly

CONTINUED ON PAGE 10

# 20 Years of Research

In 2015, the Treatment Advocacy Center established an official research arm, our Office of Research and Public Affairs (ORPA), to address overlooked or underreported public policy issues involving serious mental illness. Our research has helped impact a number of stakeholders, including law enforcement officers, hospital and prison administrators and the media, among others. Only a few years since its inception, ORPA has been generating groundbreaking reports that incorporate evidence-based research to call attention to much needed policy reforms and give public administrators the tools they need to improve access to appropriate psychiatric care. Our major publications are showcased below.

|   |  |   |   |
|---|--|---|---|
|    | <b>Beyond Beds:</b> The Vital Role of a Full Continuum of Psychiatric Care - October 2017  |    | <b>Treat or Repeat:</b> A State Survey of Serious Mental Illness, Major Crimes and Community Treatment - September 2017 |
|    | <b>A Crisis in Search of Data:</b> The Revolving Door of Serious Mental Illness in Super Utilization - April 2017                              |    | <b>Emptying the 'New Asylums':</b> A Beds Capacity Model to Reduce Mental Illness Behind Bars - January 2017            |
|   | <b>Released, Relapsed, Rehospitalized:</b> Length of Stay and Readmission Rates in State Hospitals, A Comparative State Survey - November 2016 |   | <b>Individuals With Serious Mental Illnesses in County Jails:</b> A Survey of Jail Staff's Perspectives - July 2016     |
|  | <b>Raising Cain:</b> The Role of Serious Mental Illness in Family Homicides - June 2016  |  | <b>Going, Going, Gone:</b> Trends and Consequences of Eliminating State Psychiatric Beds - June 2016                    |
|  | <b>Overlooked in the Undercounted:</b> The Role of Mental Illness in Fatal Law Enforcement Encounters - December 2015                          |  | <b>Clozapine for Treating Schizophrenia:</b> A Comparison of the States - November 2015                                 |
|  | <b>Considerations for Demonstrating the Cost Effectiveness of AOT Services:</b> February 2015  |  | <b>The Treatment of Persons with Mental Illness in Prisons and Jails:</b> A State Survey - April 2014                   |
|  | <b>Mental Health Commitment Laws:</b> A Survey of the States - February 2014   |  | <b>Prevalence of Mental Health Diversion Practices:</b> A Survey of the States - August 2013                            |

# Holding the National Institute of Mental Health to Account



In a brief entitled "Hocus Pocus: How the National Institute of Mental Health Made Two Million People with Schizophrenia Disappear," Dr. E. Fuller Torrey and Elizabeth Sinclair exposed National Institute of Mental Health (NIMH)'s misrepresentation of prevalence data on the agency website. This change had the potential effect of making two million people with schizophrenia disappear in the eyes

of the federal government. With the engagement of hundreds of advocates, the Treatment Advocacy Center called them out

on this error, contacting the media, writing letters, tweeting and calling lawmakers about the problem.

It worked. In a *Psychiatric Times* cover story, NIMH director Dr. Joshua A. Gordon conceded that his agency "did not provide sufficient context to understand or justify the selected prevalence estimate," and that the number used did not "reflect the full spectrum of knowledge available in the relevant literature." The agency is now, reportedly, "in the process of expeditiously reviewing and updating the information presented on [their] webpage."

NIMH's acknowledgement has important, real-world consequences. Federal funding is apportioned to financially strapped community mental health centers on the basis of these estimates. We look forward to collaborating with federal agencies in the hopes of improving the data set available and better determine the prevalence of serious mental illness in the United States.

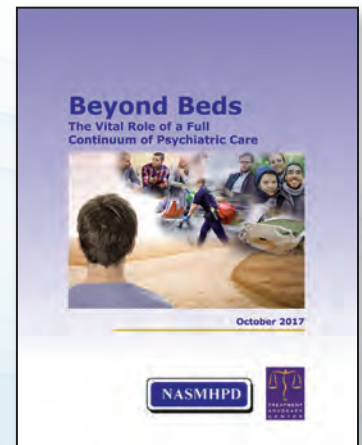
A ROBUST SYSTEM OF CARE FOR INDIVIDUALS WITH SERIOUS MENTAL ILLNESS MUST LOOK BEYOND BEDS AND OFFER COMPREHENSIVE AND QUALITY TREATMENT AND SERVICES BEFORE, DURING, AND AFTER ACUTE ILLNESS EPISODES. WITHOUT A BROADER VIEW OF WHAT IS NEEDED, INDIVIDUALS WITH MENTAL ILLNESS WILL REMAIN AT RISK OF NEGATIVE OUTCOMES, INCLUDING HOSPITALIZATION AND REHOSPITALIZATION, ARREST AND RE-ARREST, HOMELESSNESS, AND EVEN EARLY DEATH.

— *Beyond Beds*

## Moving the Conversation "Beyond Beds"

Treatment Advocacy Center highlighted the release of *Beyond Beds, The Vital Role of a Full Continuum of Psychiatric Care*, a joint report with the National Association of State Mental Health Program Directors.

The report represents the introductory paper in a 10-part series on inpatient psychiatric treatment capacity in the United States, and it posits that a robust system of care for individuals with serious mental illness must look beyond beds and offer comprehensive and quality treatment and services before, during, and after acute illness episodes. Without a broader view of what is needed, individuals with mental illness will remain at risk of negative outcomes, including hospitalization and re-hospitalization, arrest and re-arrest, homelessness, and even early death.



## Bedless Psychiatry: Rebuilding Behavioral Health Service Capacity

In assessing the capacity of the mental health treatment system, the answer to the question "How many psychiatric hospital beds do developed nations need?" remains controversial and unclear. One thing is obvious, however. Psychiatric care will continue to become increasingly bedless unless policymakers and researchers intervene, according to an article published in *JAMA Psychiatry*, co-authored by the Office of Research and Public Affairs's Elizabeth Sinclair, Dominic A. Sisti and Steve S. Sharfstein.

# New Grading of the States Coming Soon!



State laws are the building blocks of our public mental health system. Since its humble beginnings in 1998, Treatment Advocacy Center has been a pioneer in evaluating civil commitment statutes to identify legal barriers to treatment for people with serious mental illness. In honor of our twentieth anniversary, we will unveil our new methodology for evaluation – and updated grades for all fifty states plus the District of Columbia.

Apart from a detailed analysis of each state's laws, the new grading scale will provide concrete guidance for identifying and removing statutory hurdles to treatment.

The new scale was developed with three goals in mind. The first goal is to articulate the essential statutory components of good laws for emergency evaluation, inpatient commitment, and assisted outpatient treatment. The second is to provide an updated assessment of each

state's laws based on the new and more accurate criteria. Finally, in the construction of the new grade scale, our goal is to make it easier for state-level advocates and lawmakers to identify statutory barriers to treatment so they can take steps to remove them.

Evaluating a state's civil commitment laws should not resemble reading the tea leaves. Every effort has been made to establish measures that are transparent and yield reliable and replicable results regardless of who conducts the grading. We are hopeful that the new state grades will lead to improved civil commitment statutes around the country.

## Repealing the IMD Exclusion

The Treatment Advocacy Center is prioritizing efforts to engage supporters in our legislative advocacy. This year, through a partnership with the National Association of Behavioral Healthcare (formerly the National Association of Psychiatric Health Systems), we broadened our *aBedInstead* campaign and urged the repeal of the outdated and discriminatory Medicaid law known as the Institutions for Mental Diseases exclusion (IMD exclusion). This statute makes it illegal for facilities to receive federal reimbursement for providing care to non-elderly adults in need of

inpatient psychiatric care and substance use services.

To date, the president and other lawmakers have focused on how the IMD exclusion impacts people suffering from substance use disorders, but we recognize the comorbidity of substance use and mental illness and make the case that the two issues are inseparable. Our timing worked out well, as federal lawmakers are now actively engaged in discussions to eliminate this barrier to inpatient treatment.

Our digital campaign consisted of a one-minute video and shareable graphics,



like the one shown here, which were promoted across the country on Facebook and Twitter throughout the month of March in targeted legislative districts. The results were impressive. At the time of publication, we had reached more than 350,000 people on Facebook alone!

## SMRI Update

CONTINUED FROM PAGE 8

publishing reports with staff and board members. One of the first such reports was a 2009 report, "Problems Associated with Mentally Ill Individuals in Public Libraries," which is the only such analysis of this problem published to date. Another early report was the 2008 survey on "The Shortage of Public Hospital Bed for Mentally Ill Persons," which established 50 beds per 100,000 populations as the minimum acceptable number, now widely cited. The results were updated in a 2012

report: "No Room at the Inn: Trends and Consequences of Closing Public Psychiatric Hospitals."

A 2013 report, "Justifiable Homicides by Law Enforcement Officers: What is the Role of Mental Illness?" focused attention on an issue that has since become a major national policy issue. In 2014, "The Treatment of Persons with Mental Illness in Prisons and Jails: A State Survey," reported that there are now ten times more people with serious mental illness in America's jails and prisons than there are in its public psychiatric hospitals. This figure is now widely quoted.

A 2016 report, "Raising Cain: The Role of Serious Mental Illness in Family Homicides," was the first such report to analyze all of the data on family homicides in relationship to serious mental illness. Most recently, "Treat or Repeat: A State Survey of Serious Mental Illness, Major Crimes and Community Treatment," graded each state on how it provides follow-up care to people with mental illness who have committed major crimes upon their release from hospitals or prisons. These reports further the Treatment Advocacy Center's mission of eliminating barriers to treatment for people with serious mental illness.

# Celebrating Donors

The Treatment Advocacy Center expresses our deepest appreciation to all who have supported our mission.

## \$250,000+

Anonymous  
The Bowman Family Foundation  
Val A. Browning Charitable Foundation  
H. Richard Lamb  
The J. Williard and Alice S. Marriott Foundation  
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## \$100,000 – \$249,999

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National Association for Behavioral Healthcare  
Jonathan Newhouse  
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Nancy Tennyson  
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The Nathan Cummings Foundation  
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Doug Seckinger  
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Morgan Stanley  
Sue Stanley  
Gerald Tarutis  
Scott Warner

## \$1,000 – \$9,999

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Alicia Aebersold  
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Mary Alexander  
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Amgen Foundation  
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Applied Materials  
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