



case statement

“It is hard to adequately convey what it is like to lose a smart, funny, sensitive child to mental illness, and to constantly worry about his safety and his future. But it is even more heartbreaking to know that effective medication is available to treat this terrible illness, but that my son refuses to take it.”

—A mother whose son has schizoaffective disorder

the case

“What do I have to do

have him kill someone

to get him treatment?”

—Libby Head, shortly before
her son killed her

Imagine.

Someone you love is diagnosed with schizophrenia. This devastating disease affects his brain so severely he doesn't recognize he is ill. He lives in another reality altered by his illness. Aliens have taken over the neighborhood, his medication is poisoned, and you and his doctor are part of a conspiracy against him. His thinking befuddled, the simplest tasks are impossible.

When you look for help, you find the law does not protect the person you love. Instead, it protects his right to be psychotic.

For many families facing this helplessness each day, the only sureties are despair and fear for the person they love.

Some afflicted by these insidious diseases retreat inside themselves or their bedrooms—a heart-breaking waste of potential. The suffering of others culminates in a flash of private pain—suicide, a life lost behind bars—or public tragedy—a murder, a life lost on the streets.

If you don't know you are sick, how can you make rational decisions about treatment?

While scientists look for causes and cures for schizophrenia and bipolar disorder, the Treatment Advocacy Center fights for more humane mental illness treatment laws, policies, and practices.

A humane system is based on someone's need for treatment.

A humane system protects those too sick to seek or accept care voluntarily.

A humane system doesn't require someone to brandish a knife to get help, or require them to hit rock bottom before they can be lifted up again.

The Treatment Advocacy Center (TAC) is a national nonprofit organization dedicated to eliminating barriers to timely and effective treatment for people with severe psychiatric illnesses who are not receiving appropriate medical care.

TAC was founded in 1998 by internationally respected psychiatrist, researcher, author, and advocate Dr. E. Fuller Torrey. Today, TAC fights for those with the most severe mental illnesses who are left untreated because of deficient laws, policies, and research.

Expert. Other organizations constantly shift their strategy to chase the latest trend or grant opportunity. TAC is a trend setter. In a world of generalists, TAC has deep expertise on untreated severe mental illnesses—the consequences of nontreatment, the risk of violence, the need for and most effective means of delivering mandated treatment. Our staff are experts in the science and the laws that affect this population, and understand the real-world application of both.

Efficient. Charity Navigator awarded TAC 4 stars for organizational efficiency—its highest rating. A full 83 percent of TAC's funding went directly to program services in 2005. A small, dedicated staff and a disciplined prioritization of resources create a focused and efficient pursuit of our mission.

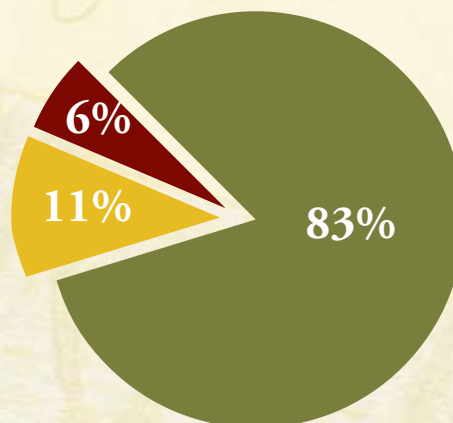
Effective. Since TAC was formed, treatment laws have been reformed in 17 states. TAC's successful advocacy has changed the tenor of the debate in newspapers and in legislatures.

Established. TAC staff often testify as national experts in legislative hearings, respond to media requests, and consult with decision-makers. TAC's messages are often cited in scientific literature, the mass media, and by grassroots advocates.

“The Treatment Advocacy Center has been the catalyst for many positive changes in our laws and a shift in our perception of the importance of intervention. Their unique advocacy is restoring the important balance between individual freedom and caring coercion.”

— Dr. Steven Sharfstein, President,
American Psychiatric Association (APA)

APA awarded TAC its 2006 Special Presidential Commendation for “extraordinary advocacy on behalf of the most vulnerable mentally ill patients who lack the insight to seek and continue effective care and benefit from assisted outpatient treatment.”



Source: Charity Navigator
(www.charitynavigator.org).

the credentials

What is assisted outpatient treatment? Assisted outpatient treatment (AOT) allows a court to order outpatient treatment for someone with a severe mental illness who is unable to help himself or likely to present a risk to others. AOT gives family members and the community a tool to help those most at risk who refuse needed treatment.

Shouldn't people voluntarily choose treatment? A small number of people with severe mental illnesses are unable to make informed treatment decisions because the illness affects the very organ used to make decisions—the brain. If someone lacks insight into her illness, a neurological deficit known as anosognosia, it doesn't matter how ideal the treatment is. If she doesn't understand she needs treatment, she may never voluntarily seek or accept it. Studies show lack of insight is the most common reason patients refuse treatment.

What does the research say about AOT? AOT makes a dramatic difference in quality of life and vastly improves treatment compliance. In Arizona, “71 percent [of AOT patients] ... voluntarily maintained treatment contacts six months after their orders expired” compared with “almost no patients” who were not court-ordered to outpatient treatment. In Iowa, AOT “promotes treatment compliance in about 80 percent of patients while they are on outpatient commitment. After commitment is terminated, about three-quarters of that group remained in treatment on a voluntary basis.”

What do severely mentally ill people who participated in the program say about AOT?

In New York, 75 percent of participants interviewed said AOT helped them gain control over their lives, 81 percent said AOT helped them get and stay well, and 90 percent said AOT made them more likely to keep appointments and take medication. Researchers in another study assessed AOT's impact on quality of life, including social relationships, daily activities, finances, and living situation. Their findings? People who underwent sustained periods of AOT had measurably greater subjective quality of life at the end of the study year.

Of participants in New York's AOT program:

87% fewer experienced incarceration

83% fewer experienced arrests

77% fewer experienced psychiatric hospitalization

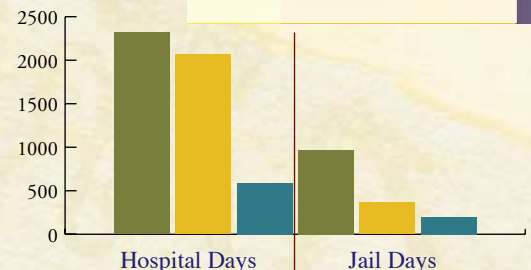
74% fewer experienced homelessness

SOURCE: N.Y. State Office of Mental Health (March 2005).

Kendra's Law: Final report on the status of assisted outpatient treatment. New York: Office of Mental Health.

Ulster County

- Before
- Enhanced services
- Enhanced services and AOT order



SOURCE: Ulster County (New York) Mental Health Department, Assisted Outpatient Treatment (AOT) Presentation March 24, 2005

"I wish when I had been homeless and severely mentally ill ... someone had mandated to me I either take medication in the community or I would have to go to a hospital. I believe I would have taken the medication and not endured the great dangers of being vulnerable and exposed on the streets."

—Valerie Fox, advocate, writer, and TAC board member

"Instead of taking responsibility for sick people—some of whose very illnesses prevent them from making informed choices—our system 'frees' them to homelessness or delusions until they do something for which it can exact revenge."

—Washington Post editorial, April 22, 2006

TAC educates about improving—and using—effective treatment laws, policies, and practices.

Influencing court rulings. TAC educates judges and attorneys, and has submitted briefs and presented oral argument on cases in state courts and the U.S. Supreme Court.

Influencing the debate. TAC testifies before legislative committees and task forces across the country, and mobilizes grassroots advocates and local experts to do the same. Legislators often rely on TAC staff to draft legislation, counter opponents' arguments, analyze amendments, and weigh in on strategy.

Influencing opinions. Researchers and reporters turn to TAC's website as the primary source for materials about lack of treatment of severe mental illnesses. With more than 300,000 hits each month, overall web traffic has increased by more than 20 percent in the last two years. TAC's message informs everything from scientific research to newspaper editorials.

Influencing advocates. With daily blog entries, weekly email newsletters, and a periodic print publication, TAC regularly disseminates practical information to families, professionals, and policymakers who are advocating for change.

Influencing the future. Staff often inform student dissertations and support documentary filmmakers. TAC also created and teaches a George Mason Law School course on "Mental Illness and the Law."

Influencing public opinion. TAC educates through newspaper articles and opinion pieces in America's biggest papers, like the *Wall Street Journal*, *New York Times*, and *Los Angeles Times*, as well as some of the smallest. We reach about 50 million readers each year and the number keeps growing. That kind of reach means better laws, a better understanding of AOT, and better coverage of tragedies—coverage that takes nontreatment into account.

It all leads to lives saved.

the tactics

5

the results

Enactment and implementation.

TAC supported Florida advocates' efforts to improve the state's abysmal treatment law. A key component was media coverage. Twelve papers wrote 33 editorials in support of the bill, reaching more than 6.6 million people. Letters and opinion pieces by advocates and family members reached more than 7.4 million readers.

The Baker Act reform legislation became effective January 2005.

TAC then teamed with a Florida county to help establish a model program that would use the new law to help those in dire need. In the first twelve months, the program diverted 25 of 29 people from state hospitalization.

"AOT has given my daughter a real life and new hope for the first time in fifteen long and terrible years..."

—A mother, whose daughter was untreated, homeless, and victimized for years before she was placed under AOT.

"My mother had me committed against my will three times, and I would get so mad at her. But thanks to her willingness to help me when I was not able to help myself, I have now been in treatment for a number of years, and have gained insight into my illness... I often now think that my mother must have loved me very much to intervene when my illness made me push her away."

—An author and advocate with bipolar disorder

"[I] can have clear thoughts about living my life... and now I am moving into my own apartment..."

—Participant in the Seminole County program's first year

Most moving are the personal stories. One client with paranoid schizophrenia had his own apartment, but was found living in his car in the park. Under AOT, he now initiates social contact with others, which he never did in the past. He states he "never really gave his medications a chance." All who know him cannot believe he is the same person.

Another client, also with paranoid schizophrenia, is now stable, working, and learning computer skills. He requested to remain on AOT for an additional six months because he says "this is the best [I] have ever felt."

Since the Treatment Advocacy Center opened its doors in 1998, 17 states improved their treatment laws and policies.

Staff focus on a handful of states at one time and nurture emerging reform efforts in others. Nationwide, TAC provides information, technical assistance, and help reforming and implementing mental illness treatment laws.

Dr. E. Fuller Torrey, TAC's president and founder, is adamant that our efforts actually help real people. "This is not an academic exercise," he says. "The final goal of change must always be to secure lifesaving treatment for people with severe mental illnesses."

To that end, TAC works not just to help create treatment laws where none exist or to improve existing laws to make them more humane, but also to foster the use of existing laws.

*“If I weren’t committed and forced to
go into the hospital, I would be dead.
No doubt in my mind.”*

—Diana Kern, advocate

*“No other organization has been so effective
at improving the lives
of persons suffering from mental illness.”*

—A parent and supporter

We are proud of our many achievements thus far, and hopeful for sufficient resources to accomplish the critical work that lies ahead.

Simply put, the more resources we have, the more people we can help. Whether through a special project or core program support, we welcome the opportunity to partner with you to help accomplish our mission.

TAC is a different kind of advocacy organization.

Unaided. The general reluctance of other mental illness organizations to address issues surrounding the need for mandated treatment means the Treatment Advocacy Center is the only organization focused on the critical issue of assisted outpatient treatment.

Undaunted. We aren’t afraid to fight uphill battles, even if the frankness of our message sometimes closes the door to funding sources common in the more politically correct portions of the mental health advocacy arena.

Untainted. Since we first opened our doors, we have refused any funding from pharmaceutical companies. We firmly believe our credibility lies in our freedom from such influences.

Unabashed. Our determination to speak the truth is our secret to success, but also limits grant opportunities. TAC’s frank criticism of government agencies who fail the most severely mentally ill, such as the report “A Public Failure in Psychiatric Research,” makes government funding more difficult to get.

Our existence depends on the support of those who share our vision of humane mental illness treatment laws, policies and practices throughout America.

Our existence depends on you.
Please join us.

the challenge

7

“Uninformed calls to protect civil rights betray a profound misunderstanding of that term. There is nothing “civil” about leaving people lost to disease to live homeless on the streets, suffering rape and victimization. There is nothing “right” about leaving someone untreated and psychotic, rendering them incapable of discerning whether they are attacking a CIA operative or their own mother.”

—Mary Zdanowicz, executive director,
Treatment Advocacy Center

The Treatment Advocacy Center (TAC) is a national nonprofit organization dedicated to eliminating barriers to the timely and effective treatment of severe mental illnesses. TAC 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.



200 North Glebe Road
Suite 730, Arlington, VA 22203
p 703 294 6001 • f 703 294 6010
www.treatmentadvocacycenter.org
info@treatmentadvocacycenter.org