

Catalyst

New Edition of *Surviving Schizophrenia: A Family Manual*

People contact the Treatment Advocacy Center for many reasons, but an untold number tell us that they learned of our organization from the written work of our founder, E. Fuller Torrey, MD.

With these supporters in mind, we are pleased to announce that a revised and completely updated 7th edition of *Surviving Schizophrenia: A Family Manual*, is now available.

Perhaps the most renowned of Dr. Torrey's writings, *Surviving Schizophrenia* has helped countless families to cope with a loved one's severe mental illness and to navigate the tangled web of a badly broken mental health treatment system. With almost half a million copies in print, it remains the standard reference book on schizophrenia for those afflicted, families, and mental health professionals alike.

In the newest edition Dr. Torrey includes a number of reader comments

WITH ALMOST HALF A MILLION COPIES IN PRINT, IT REMAINS THE STANDARD REFERENCE BOOK ON SCHIZOPHRENIA FOR THOSE AFFECTED, FAMILIES, AND MENTAL HEALTH PROFESSIONALS ALIKE.

inside the front cover as well as important new content.

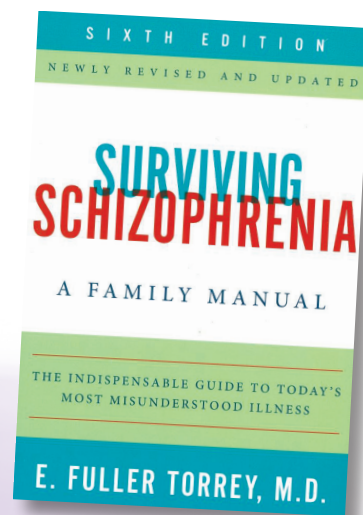
In particular, the 7th edition offers a new chapter on "What Good Services Should Look Like," with new treatment plans for first-break psychosis and guidance in selecting among the 20 available antipsychotics, and new sections on exercise; the recovery model; Hearing Voices Network; and "successful schizophrenia." The book also includes an updated section titled "Useful Online Resources on Schizophrenia" by author and advocate D.J. Jaffe.

As it has done for 35 years, *Surviving Schizophrenia* tells it like it is. Here are some highlights:

In chapter four, Dr. Torrey explains that the recovery model "has both positive and negative aspects, with the latter having been too often ignored."

Chapter five takes aim at "Mental health professionals who deny that schizophrenia is a brain disease," saying they "probably also believe that the earth is flat."

Meanwhile, in chapter eight Torrey argues that the Hearing Voices Network "is a return to blaming-the-family theories of the last century."



"Imagine how different the service system would be if rehabilitation outcome measures were used to determine the compensation of the mental illness professionals," muses Dr. Torrey in chapter nine, adding that "We need to acknowledge the need for some long-term psychiatric beds for the severely disabled."

In addition, the book includes criticism of outdated laws and so-called patient advocates, again pulling no punches.

For example, Dr. Torrey writes in chapter ten, "The greatest utility of the HIPAA law to date is in protecting the backsides of public officials." And, in chapter fourteen, he says, "Sadly misguided civil rights lawyers and 'patient advocates' regularly defend the individuals' right to be psychotic; the thinking of the lawyers and advocates is more thought-disordered than the people they are defending."

The seventh edition of *Surviving Schizophrenia* was published in March. We encourage you to pick up a copy today. All royalties come to the Treatment Advocacy Center.

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Message from the Executive Director

Supreme Court Justice Louis Brandeis famously wrote, “states are the laboratories for democracy.” This is especially true for the laws and policies that shape our mental health system. It is why the Treatment Advocacy Center has dedicated so much of its work to state ad-

vocacy. Quite simply, that is where mental health reform happens.

This edition of *Catalyst* dives into the work of mental health reform taking place across the country, from commitment law changes in Pennsylvania to reforms of treatment in jails in Minnesota to assisted outpatient treatment (AOT) implementation across the ocean in Guam. As you will see, we are on the ground throughout the United States, working to make treatment a reality for those most in need.

In Pennsylvania, we celebrate reforms of the Commonwealth’s outdated AOT laws. Advocates have worked for years to move the outpatient commitment standard there from one requiring clear and present danger to one that seeks to avert danger.

We also detail our newest report on the use of AOT in California: *A Promising Start, Results from a California Survey Assessing the Use of Laura’s Law*. The results indicate that the state still has much work to do, but we are heartened that counties adopting Laura’s Law are seeing significant benefits.

Our director of advocacy Frankie Berger highlights an important discussion taking place as states struggle to care for incompetent pre-trial defendants. She argues that the drive to devote more beds to competency restoration misses the point and the focus should instead be on providing alternatives to redirect people who need it into real treatment.

On the implementation front, we highlight a trip our policy director Brian Stettin took to the U.S. territory of Guam. There, he conducted a three-day intensive training on AOT and demonstrated, through his actions, how far we will go to ensure that AOT is available.

We also note our first-of-its-kind national AOT symposium that we will be holding in Ohio this fall—one designed to attract

teams of leaders from across the country and assist them in developing, implementing and sustaining AOT programs. We hope to see you there!

We also celebrate a major milestone in our *#aBedInstead* campaign. U.S. Health and Human Services Secretary Alex Azar announced significant reforms to the IMD exclusion – the discriminatory provision that prevents Medicaid from reimbursing for treatment beds. The onus now moves to the states to take advantage of this important opportunity to mitigate suffering of people with severe mental illness.

WE ALSO NOTE OUR FIRST-OF-ITS-KIND AOT SYMPOSIUM THAT WE WILL BE HOLDING IN OHIO THIS FALL—ONE DESIGNED TO ATTRACT TEAMS OF LEADERS FROM ACROSS THE COUNTRY AND ASSIST THEM IN DEVELOPING, IMPLEMENTING AND SUSTAINING AOT PROGRAMS. WE HOPE TO SEE YOU THERE!

In addition, our cover story marks the release of a completely updated 7th edition of Dr. Torrey’s seminal work, *Surviving Schizophrenia: A Family Manual*. Regarded as the treatment “bible” for countless families seeking help for a loved one with schizophrenia, Dr. Torrey’s book helped make him a legend in the psychiatric field.

Thank you for everything you do. Your support is essential to our success, and a big reason why I know the Treatment Advocacy Center’s best days lay ahead.

John Snook

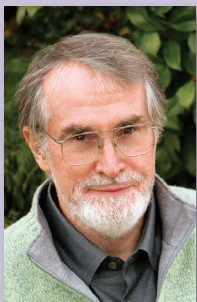
Saying NO to Big PHARMA

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 accept no funding from the corporations most closely allied with mental illness treatment: pharmaceutical manufacturers.

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, especially to children and individuals with dementia.



STANLEY MEDICAL RESEARCH INSTITUTE STUDY: *The “Kissing Disease” and Schizophrenia*

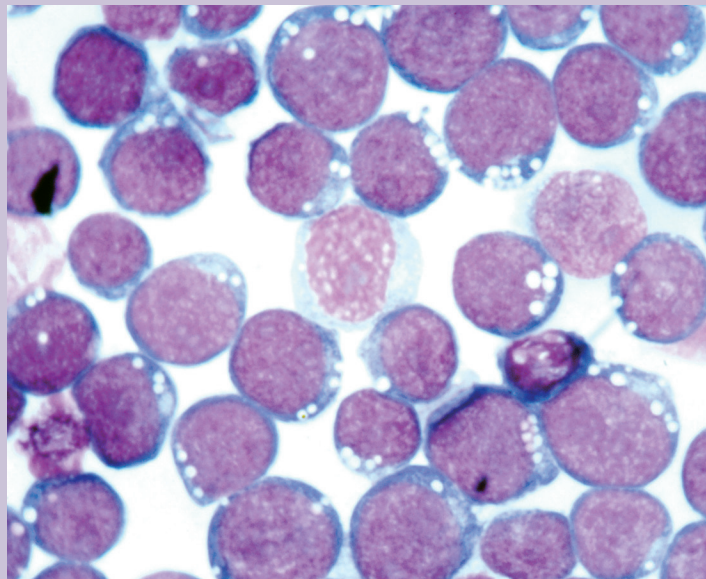
By E. Fuller Torrey, M.D.

Infectious mononucleosis has long been of interest to schizophrenia researchers. It is one of the only major infectious dis-

eases that occurs in adolescence and early adulthood at exactly the same time as the peak onset of schizophrenia. Its symptoms include fever; headache; enlarged lymph nodes, especially in the neck; and weakness that may last for several months. It is caused by the Epstein-Barr virus (EBV), a member of the herpes family of viruses. It is transmitted from person to person by saliva and thus infectious mononucleosis became known as the “kissing disease”.

Our Stanley Medical Research Institute-funded laboratory at Johns Hopkins University Medical Center, under the direction of Dr. Robert Yolken, has long been interested in EBV as a possible contributor to schizophrenia. There are a few cases reported in which the EBV infects the brain and causes symptoms of psychosis. A recent study reported that adolescents who have been infected with EBV are more likely to have psychotic-like experiences. There are also families who claim that the schizophrenia of their son or daughter began immediately following a bout of mononucleosis. Twenty-five years ago, we even collected blood, using the National Alliance on Mental Illness network, from 16 such cases and controls. However, since both schizophrenia and mononucleosis began in the same age group, it is difficult to distinguish a causal connection from a random correlation.

Nevertheless, despite testing over many years we were unable until recently to link EBV and schizophrenia. The change came when Dr. Lori Brando in Dr. Yolken’s lab adopted a new way to measure antibodies against EBV. Using this new method, they tested the blood of 432 individuals with schizophrenia and 315 controls collected by Dr. Faith Dickerson at Sheppard Pratt Hospital. Using the new assay, the individuals with schizophrenia had antibodies to some EBV proteins more than three times as frequently as the controls. The difference between the groups



This is an image of the Epstein-Barr Virus (EBV) stained with Hematoxylin and eosin (HE). SOURCE: NATIONAL CANCER INSTITUTE

THERE ARE A FEW CASES REPORTED IN WHICH THE EBV INFECTS THE BRAIN AND CAUSES SYMPTOMS OF PSYCHOSIS. A RECENT STUDY REPORTED THAT ADOLESCENTS WHO HAVE BEEN INFECTED WITH EBV ARE MORE LIKELY TO HAVE PSYCHOTIC-LIKE EXPERIENCES.

was most marked among the individuals who responded most strongly to the new assay. The blood of the cases and controls was also tested for other herpes viruses and there were no significant differences, thus proving that the difference was largely specific for EBV and not for herpes viruses in general.

This research was recently published in the *Schizophrenia Bulletin*. They are now testing other samples, including spinal fluid to see if the assay also works on that as well. The precise role played by EBV in the causation of schizophrenia is still to be determined. One possibility is that it might act as a trigger for another agent that the person acquired earlier in life.

The Stanley Medical Research Institute is a supporting organization of the Treatment Advocacy Center. Dr. Torrey is the Stanley Medical Research Institute’s Associate Director for Research and the founder of the Treatment Advocacy Center.

Our Mission

The Treatment Advocacy Center is the only national nonprofit organization exclusively 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.

A Major Milestone for our aBedInstead Campaign

Last November, the Treatment Advocacy Center marked a major milestone for our #aBedInstead campaign efforts. U.S. Secretary of Health & Human Services Alex Azar announced important regulatory changes that will allow states to apply for waivers to receive Medicaid reimbursements for mental health treatment in inpatient settings known as IMDs, or institutions of mental disease. These changes were part of our lobbying agenda enacted under the 21st Century Cures Act, the federal law that brought wide-ranging mental health reform with a focus on serious mental illness.

Both this presidential administration and the one before it granted state waivers to permit reimbursement for substance use disorder treatment in IMDs, but reimbursable psychiatric inpatient treatment was limited to 15 days per month. People with severe mental illness were discriminated against by Medicaid, simply because they were adults in need of inpatient psychiatric care.

Inpatient beds play an integral, underappreciated role in the continuum of care for the treatment of serious mental illness. Last year, our executive director, John Snook, and his colleagues on the Interdepartmental Serious Mental Illness Coordinating Committee urged the Centers for Medicare & Medicaid Services to address this disparity while strengthening quality and continuity of care to community services. Fortunately, their call was both heard and heeded.

Since the 1960s, Medicaid IMD law has prohibited such payments for adult inpatient treatment, undermining existing medical facilities and exacerbating a national bed shortage crisis—effectively denying medically necessary care. This longstanding

policy has disproportionately discriminated against adults with serious mental illness, many of whom are Medicaid beneficiaries, and many of whom have suffered terrible outcomes resulting from an inability to receive treatment.

That is why the Treatment Advocacy Center launched our #aBedInstead campaign—to bring light to this crisis and demand change.

Secretary Azar's announcement of the new waiver opportunity acknowl-

edges the negative outcomes that this policy, known as the IMD exclusion, has historically caused, and underscores the importance of both inpatient psychiatric care and connecting patients to robust community services to prevent the cycle of re-hospitalization.

States that decide to apply for these waivers will need to demonstrate their plans to bolster community services while integrating inpatient IMD care into their broader treatment system to better help people with serious mental illness. This new opportunity for collaboration between federal and state governments offers enormous potential to improve psychiatric care and rein in the costs associated with neglecting those most in need.

When the new waiver process was outlined, the Treatment Advocacy Center sprang into action. We held a telephone town hall-style conference, which we broadcast live on Facebook, to answer questions from people across the country. We then circulated a letter that advocates could send directly to the governors of their respective states to urge them to apply for IMD waivers as soon as possible. Hundreds of people have already taken this important step.

If you have not yet sent such a letter to your state's governor, please do so today. Click on the "What You Can Do" tab of our homepage, www.treatmentadvocacy-center.org and scroll down to the "Advocate" link to find the "Encourage Your

Governor to Seek an IMD Waiver" form among the list of action items.

We are excited about this potentially game-changing development and need your help to bring it to the attention of state governments.

LAST YEAR, OUR EXECUTIVE
DIRECTOR, JOHN SNOOK,
AND HIS COLLEAGUES ON
THE INTERDEPARTMENTAL
SERIOUS MENTAL ILLNESS
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FORTUNATELY, THEIR CALL WAS
BOTH HEARD AND HEADED.



National AOT Symposium

October 10-11, 2019 in Columbus, Ohio



Do you want to implement a quality assisted outpatient treatment (AOT) program in your community, or to improve the one you already have? Our upcoming AOT Symposium and Learning Collaborative may be the thing for you. Registration is now open!

This first-of-its-kind national event will be held October 10-11 in Columbus, Ohio. It will feature national and regional AOT experts, including judges, psychiatrists, mental health providers, advocates and a researcher. We are inviting teams from across the country to attend for free. Generally speaking, teams should include community leaders who are in a position to affect change, including judges; mental health system and agency directors; hospital and crisis center directors; attorneys and advocates.

Program highlights include:

- Remarks by Kevin Earley, Peer Support Specialist whose story is chronicled in *Crazy: A Father's Search Through America's Mental Health Madness* by Pete Earley.
- Workshops tailored to the various disciplines, and focused on the nuts and bolts of establishing, improving and sustaining quality AOT programs.
- Discussion with AOT judges and psychiatrists from around the country concerning their approaches to AOT and the lessons they have learned.
- Findings on the program's effectiveness from the latest research of Dr. Richard Van Dorn, a leading AOT researcher.
- Insights on the role of AOT in the continuum of care from Ron Honberg, NAMI's long-time Senior Policy Analyst.
- Guidance from the Treatment Advocacy Center's policy director Brian Stettin and policy advisor Betsy Johnson, and insight drawn from their experience implementing and assessing AOT programs across the country.

Most importantly, team members will come away with a blueprint for success for implementing, improving and sustaining AOT programs.

Go to <https://aotconference.mightycrow.com> to register your team to attend the 2019 National AOT Symposium and Learning Collaborative. This event is being generously funded by Peg's Foundation.

The New York Times

Letter to Editor: When Mental Illness Goes Untreated *The Treatment Advocacy Center discusses the case of James Polite*

To the Editor:

Re "Man Accused of Anti-Semitic Vandalism Faces New Setback in a Life Full of Them" (news article, Nov. 4):

The tragedy of James Polite's defamation of the Union Temple of Brooklyn bears witness to the consequences of underusing proven solutions like Kendra's Law.

Kendra's Law, in New York State, provides court-ordered treatment for mental illness to help peo-

ple unable to maintain needed treatment voluntarily. Mr. Polite appears to have been an obvious candidate. He reportedly had a history of going off his medication, experiencing paranoid delusions and being hospitalized.

But as is too often the case, nothing was done. And now a community is reeling and left to ask why not.

Kendra's Law keeps those most in need from falling through the

cracks. But it can work only if it is offered before tragedy strikes. We can and must do more to ensure that it is able to prevent the inevitable next offender with a severe mental illness from being failed in the same way.

John Snook
Arlington, Va.

The writer is executive director of the Treatment Advocacy Center, a non-profit that works to eliminate barriers to treatment for severe mental illness.

A wide-angle photograph of the Illinois State Capitol building in Springfield. The building is a grand neoclassical structure with a prominent green and gold dome topped by a statue. The facade features a portico with tall columns and a series of arched windows. The building is set against a clear blue sky, and the foreground shows a paved plaza with some small figures of people for scale.

By amending the Pennsylvania Mental Health Procedures Act for the first time in over 40 years, the governor established a path to less restrictive community treatment. Now, families should no longer need to wait until their loved ones with severe mental illness become a “clear and present danger” to themselves or others; a threshold that often leads to arrest and incarceration instead of treatment.

and it received the unanimous and bipartisan support from the Pennsylvania legislature at every step of the two-year process.

“For too long, barriers to treatment have resulted in tremendous human and fiscal costs. So, I very much appreciate that the legislature and the governor are now providing a path to care for people who have the most difficulty accessing it, and who suffer the worst outcomes as a result,” said John Snook, executive director of the Treatment Advocacy Center. “As a Medicaid expansion state with well-funded and highly regarded community mental health services, the Commonwealth is well-positioned to implement strong AOT programs at the county level.”

The Treatment Advocacy Center is proud of Pennsylvania's progress and will remain active as counties move toward implementation of programs that the new law allows.

In February, the Treatment Advocacy Center released *A Promising Start: Results from a California Survey Assessing the Use of Laura's Law*. The report provides the first-ever county-by-county analysis of California's use of Laura's Law — a state program designed to provide assisted outpatient treatment to individuals with severe mental illness who struggle with voluntary treatment engagement.

with serious mental illness, and increasing participation. Given these results, the Treatment Advocacy Center recommends that every remaining county board of supervisors should adopt and implement Laura's Law, and that all counties should use the tools available in the law, including civil court orders, to their full extent.

Laura's Law is named after Laura Wilcox, a volunteer at a mental health clinic in Nevada County, who was a victim of a preventable act of violence at the hands of someone with untreated mental illness. Signed into law in 2002, it allows California counties to implement AOT programs.

A Promising Start applauds the much-improved outcomes of people who were enrolled in Laura's Law programs,

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PRESS HIGHLIGHT



America's Crime Problems Being Fed by a Broken Mental Health System

Variety and *Rolling Stone* published a package of stories last fall, arguing that “the criminal justice system needs fixing and there is bipartisan support for reform.” To make this point, the media outlets solicited perspectives from two dozen contributors offering insights and solutions in four main areas: the seeds of crime, the courtroom, prison, and the world ahead for everyone.

The submission of the Treatment Advocacy Center’s executive director John Snook is provided below.

By John Snook
NOVEMBER 14, 2018

A homeless woman freezes to death on a city sidewalk. A man with delusions is shot dead by police. A teen in psychosis murders his grandmother. These are all preventable tragedies.

America’s mental health treatment system is broken, leaving those most in need to fall through the cracks. An estimated 8.3 million adults in the United States have a severe mental illness. At any given time, 3.9 million go untreated.

With medication and other support services, those with severe mental illness are no more dangerous than anyone else, capable of leading happy, productive lives. Without treatment, their prospects worsen.

Yet the odds are stacked against these individuals. Our health care system actively denies them care, and we criminalize the symptoms of their diseases.

When someone has a heart attack, an ambulance takes them to an emergency room. When someone is in the depths of

psychosis, however, police are called and frequently cart that person off to jail.

My organization is dedicated to eliminating barriers to treatment for people with severe mental illnesses—to root out systemic impediments to psychiatric care. It is a daunting challenge.

Families call us every day with heart-breaking stories. Many follow a familiar pattern. A parent notices a young adult child acting differently, growing paranoid and withdrawn. As the illness progresses, the child may hallucinate and become agitated or aggressive.

Troubled by these symptoms, parents reach out to doctors or crisis services seeking help on behalf of their loved one. However, if their child is too ill to understand the need for treatment, they are rebuffed, told that unless that child himself or herself seeks care, treatment is only available once the child becomes dangerous.

And so begins a cataclysmic cycle.

Without treatment, those with severe mental illness experience a host of negative consequences. Many take their own

lives. Others face a shortened life span due to a much-increased risk for other chronic health conditions. Ultimately, those with severe mental illness die, on average, 25 years earlier than their peers.

Others are lost to the streets. Conservative estimates suggest that one quarter of the homeless population suffers from a severe mental illness. In 2017, that amounted to 138,435 individuals on any single night. Also common are arrests for so-called “quality of life” crimes like loitering and public urination—behaviors that are triggered by illness, not criminal intent.

As a result, incarceration has become the norm for those with severe mental illness. Forty percent of them are incarcerated at some point in their lives. Two million are booked into jails each year. The Treatment Advocacy Center estimates that 383,000 individuals with severe mental illnesses were incarcerated in 2016, although many belonged in hospitals instead.

CONTINUED ON PAGE 10

Press Highlight

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But jails are the worst place to provide mental health treatment. Would-be patients are isolated. They deteriorate, are victimized and receive inadequate care. Their symptoms result in additional offenses and time behind bars. A 2018 national investigation revealed that since 2010, more than four hundred people with mental illness have died in our nation's jails.

Others die before ever reaching a cell. According to our report, "Overlooked in the Undercounted," at least one in four fatal law enforcement encounters involve an individual with severe mental illness. They are 16 times more likely to be killed in such an encounter than other civilians.

Law enforcement is taking steps to train its officers to defuse such situations whenever possible. But those laudable efforts are responsive measures, not preventative ones. They do nothing to answer the broader question we ignore: Why do we make law enforcement responsible for a public health crisis?

No matter how one looks at the challenges posed by untreated severe mental illnesses—whether from the perspective of would-be patients, family members, first responders or the general public—the status quo is untenable.

Yet opportunities to improve the existing mental health system abound.

First, we can and should increase the availability of psychiatric beds, now at a historic low. Even a modest increase would alleviate inhumane bed waits for people in need of inpatient care.

We must also fund a robust continuum of community support services that prevent the severely ill from reaching a crisis state, and reduce the need for a law enforcement response.

And we must make it easier to intervene on behalf of those in need. Family members and other caregivers are also victimized by the destructive symptoms of these chronic illnesses, and should have a right to seek treatment for their afflicted loved ones.

Untreated mental illness need not be an intractable problem. We can either continue to condemn families to predictable, preventable tragedies or we can provide necessary treatment to those who desperately need it. But first we must finally agree as a nation to take the treatment of severe mental illness seriously.

Collaboration in Ohio

In Ohio, Assisted Outpatient Treatment (AOT) monitors play an important role in their programs. They are responsible for tracking progress of the individuals enrolled in AOT and for ensuring that mental health treatment professionals provide services required by court order. Effectively, they serve as the court's eyes and ears, reporting on AOT enrollees' progress in meeting the benchmarks of their court-mandated treatment plans.

At their semiannual meeting in March, AOT monitors from throughout Ohio met for the third time. Clare Pettis, PhD, a Health Policy Services Specialist with the Office of Quality, Planning and Research at the Ohio Department of Mental Health and Addiction Services, walked the attendees through the state's new, easy-to-use AOT Data Collection program. The new program will enable AOT monitors to input data about program participants such as numbers of hospitalizations and lengths of stay, crisis contacts, arrests and more. Each county will be able to run reports which will eventually tell them how effective their programs are in improving outcomes.

Other items on the agenda included a discussion of common program obstacles and possible solutions,



including working with hospitals to ensure AOT participants are not inadvertently dropped from the program by voluntarily signing themselves in; and working with system partners to identify individuals who meet criteria for AOT.

In the spring, the AOT monitors will travel to two separate sites to observe the AOT programs in those communities.

Bringing Our AOT Know-How to Guam

The United States territory of Guam, an island in the western Pacific, is home to about 165,000 American citizens. About a third of Guam is covered by U.S. military installations, supplying a large contingent of service members and their families who mix easily with the local population. But four years ago, Guam's tranquility was punctured by a moment of shocking and senseless violence.

On New Year's Day of 2015, Yu Hua Han, a 44-year-old woman with schizophrenia, randomly approached a young Air Force Family in a shopping mall and punched 10-month-old Alexya Esser in the face. Thankfully, Alexya was not seriously harmed. But video of the terrifying incident went viral on the island, and public outrage reached a fever pitch when news reports revealed that Han had committed prior random assaults, including a 2009 knife attack on a toddler and her father.

Repeatedly, Han had been found incompetent to stand trial and charges were dismissed. Each time, Han was released after stabilizing in the hospital. Authorities had no legal basis to require her to adhere to treatment.

Faced with such clear evidence of system dysfunction, The Guam Legislature responded with the "Baby Alexya Law," establishing court-ordered "assisted outpatient treatment" (AOT) as a legal option for individuals with severe mental illness who are capable of living safely in the community but have demonstrated difficulty maintaining voluntary treatment engagement.

But after four years, the Baby Alexya Law has yet to be utilized. The reason is certainly not an absence of need; a recent review of records identified 24 patients at Guam's inpatient facility with multiple mental health hospitalizations over the prior 12 months. Rather, AOT in Guam has been stymied by the same forces that have inhibited implementation closer to home: the

unfamiliarity of collaboration between the treatment system and court, confusion over who AOT is intended for, and a mistaken perception of the need for "teeth" (serious consequences for court order violations).

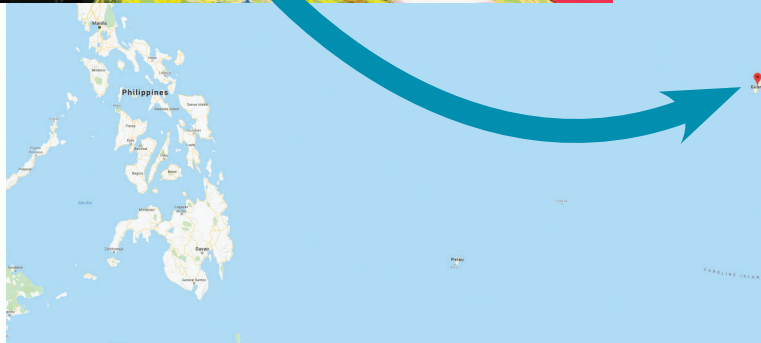
The Treatment Advocacy Center became aware of Guam's AOT law and implementation struggles in June of 2017, when a group from the Guam Behavioral Health and Wellness Center attended a two-day AOT training conference we conducted in Detroit. We have stayed in touch with that group since then and have been impressed by its determination to overcome the barriers and make AOT happen on their island. Needless to say, the 8,000-mile distance and 15-hour time difference have made it challenging to assist as we typically do in U.S. jurisdictions.

This February, our organization and theirs took a giant step forward together. Proving that the Treatment Advocacy Center will stop at nothing in its quest to make AOT available to every American that needs it, our Policy Director Brian Stettin traveled to Guam (19 hours each way) to conduct a three-day intensive AOT implementation training of the Guam Behavioral Health and Wellness Center clinical staff, judges and court staff, and other key stakeholders. Brian walked the group through every detail of the Guam AOT law, identifying several areas that might be improved to facilitate better practice of AOT. (We are now working on legislation incorporating these ideas.) He also guided the group through the development of specific implementation plans, which it will execute in the months ahead.

"It was a highlight of my career to visit Guam and get to know the amazing team working there to improve the lives of people with severe mental illness," Brian reports. "Wherever you go, mental illness is the same. Those who don't know they're ill tend to disengage with treatment. Good services, intensive case management, and the active oversight of a caring judge is our best formula to overcome that. It works in big cities, small cities, and rural areas. And soon, we're going to see it work on a tropical island in Micronesia."



Brian Stettin (back row in white shirt and tie) with the Guam Behavioral Health and Wellness Center clinical staff



Schizophrenia Claimed My Brother Skyler

By Heather Durham

My brother Skyler was a charismatic, loving, genuine person.

He was a star athlete and a class clown and really smart when he wanted to be. People were drawn to him, and he could make anyone laugh.

However, in his teens, Skyler was diagnosed with bipolar disorder and paranoid schizophrenia. He struggled with voices, hallucinations and delusions.

Occasionally, the “old Skyler” shined through, but the haze of his illness cast a cloud over him from which he could not escape.

His inability to reason or to rationalize led him through a revolving door of jails and hospitals such that many of our visits were conducted across a table or through a glass window.

The symptoms of his illness prevented Skyler from driving a car or going to work. He relied on SSI and Medicaid to cover medical expenses.

My brother’s monthly food stamp allotment was a mere \$64. Officials told us that he could eat at homeless shelters.

Unfortunately, Skyler was too unpredictable and aggressive to stay with my mother or me, and his run-ins with the law prevented him from finding public housing. He was forced to live in slum houses, with outrageous rent and no credit checks, alongside hardened criminals and others with severe mental illnesses.

Skyler would befriend just about anyone who was nice to him, so some of these people took advantage of him, stealing what little he had.

My mother and I tried to look out for him every way we could.

Mom encouraged him to take his medication. She helped him with laundry and other necessities on a nearly weekly basis.

In June, Skyler was a no-show. My mother’s instincts told her something was wrong. She sent my stepdad to check on him.



Heather and her brother, Skyler

My brother had passed away in his Louisville apartment four days earlier. He was 34 years old.

The coroner said the cause of Skyler’s death was a heart attack, but I would argue that schizophrenia is what claimed him. Research backs up this belief.

On average, people with severe mental illnesses die 25 years earlier than those without. These illnesses wear people down and exacerbate other physical conditions, such as diabetes and heart disease.

After Skyler’s death, I reached out to the Treatment Advocacy Center, a national nonprofit dedicated to eliminating barriers to the timely and effective treatment of severe mental illness. I wanted to memorialize my brother and bring awareness to the way we ignore, neglect and criminalize these diseases. I want to help the estimated 114,000 Kentuckians with schizophrenia or bipolar disorder, many of whom are untreated.

Surprisingly, Kentucky has laws to help the state’s most vulnerable citizens with severe mental illness—those individuals unable to recognize the severity of their

condition—it just refuses to implement the programs that these laws allow.

For example, in the interest of stemming the public health crisis posed by untreated mental illness and addressing the skyrocketing costs for public mental health services, bipartisan, veto-proof majorities in the Kentucky Senate and House passed Tim’s Law.

Tim’s Law authorizes assisted outpatient treatment in the community under court order, prioritizing those most in need—the same people who are already taxing public support services.

This approach makes sense. It recognizes that my brother did not belong on the streets, or in emergency rooms and jails; he just needed medical care. And addressing mental illnesses in this manner can reduce acts of violence as well as the costs of repeated hospitalization and incarceration.

Why Kentucky is failing to put its treatment laws into full effect is beyond me. Why compound the pain and suffering of families across the state when appropriate psychiatric treatment can restore both sanity and stability?

Sadly, I will never know how much better or longer my brother’s life could have been if he had received the care and support he deserved. But I maintain hope that we will step up to prevent anyone else from that nagging, unanswerable question.

I understand that mine is but one voice. However, it seems clear that providing more timely treatment to individuals in psychiatric crisis could help thousands of people and improve the health and safety of our communities. So, for the sake of people like my brother and their loved ones, I pray that those in positions of power hear me.

Heather Durham lives in Louisville, Kentucky.

Competency Restoration versus Psychiatric Treatment

By Frankie Berger, Director of Advocacy

The process of competency restoration may be unfamiliar to most, but it is important because it overlaps the mental health treatment system and the criminal justice system. It is a process that we highlighted in our report, *Emptying the 'New Asylums'*, which focuses on the tremendous backlog of people in jails who require competency restoration — that is, people with mental illness acute enough to render them unable to face their charges. This backlog is a symptom of a terrible public health crisis, reflecting both an inadequate and misdirected treatment system and an unjust criminal justice system. In a nutshell, there are practically no psychiatric treatment beds, and states are struggling to meet the demand for those that do exist.

Starting on Christmas Eve, Colorado joined a growing list of states that, either by policy or by practice, have made the choice to deny civil patients access to state psychiatric hospitals. Instead, these states are reserving those beds for the overwhelming number of people with mental illness who have been arrested and charged, and who require competency restoration. The mental health system failures we have warned against have now become a matter of administrative fact: one must commit a crime to receive a treatment bed.

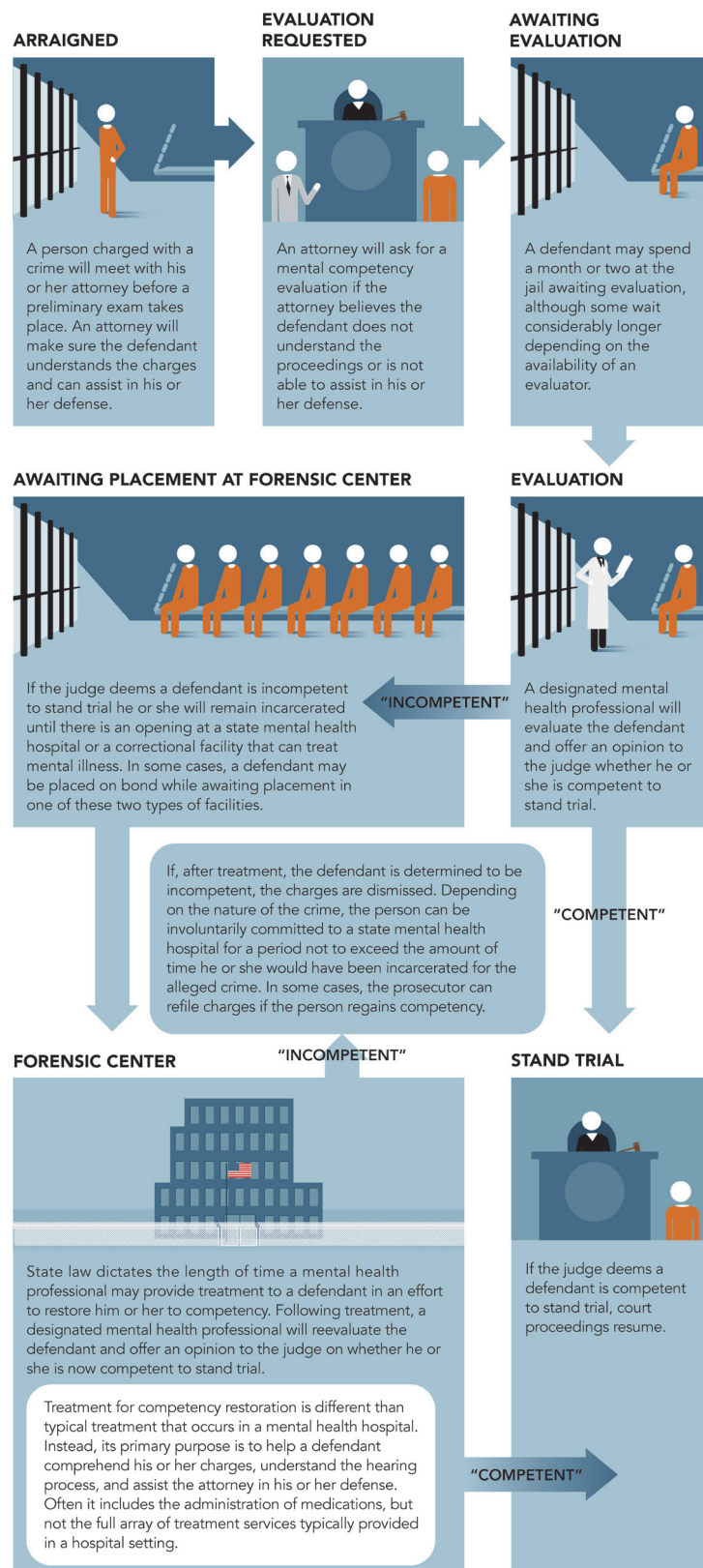
Why? Because a person charged with a crime has a constitutional right to a speedy trial. To legally stand trial one must be found to understand the nature and purpose of the legal proceedings and be able to effectively cooperate with one's own counsel. If the person does not meet this standard, his or her competency must be restored as quickly as possible. When states fail to meet this legal obligation—due to too few psychiatric beds—resulting lawsuits compel them to act. Unfortunately, the remedy they are choosing is to refuse admission to patients who are not in the criminal justice system, just to maintain minimum compliance with the law.

There was a novel development in Minnesota—one that struck me as both radical and an absolutely necessary step towards change. As Minnesota Public Radio reported on December 19th, the state's Department of Human Services is ending a program designed to restore criminal defendants with mental illness to competency to stand trial. With that action, the agency is effectively saying: *No more—we are not in the business of stabilizing people to stand criminal trial or face sentencing. Our mission is to help people experiencing psychiatric crises to stabilize and recover.*

I applaud their principled stand.

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How Courts Determine Mental Competency to Stand Trial



To view a larger image, go to <http://tinyurl.com/yyeuctmo>



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A Promising Start

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including decreases in psychiatric hospitalizations, crisis contacts, incarcerations and homelessness. However, the report finds that fuller implementation of Laura's Law, including the use of more effective court-ordered supervision of treatment, would better serve the population the law was created to help.

With recent action by Solano County, 20 California counties have now approved implementation of Laura's Law, representing roughly 65 percent of the state's total population.

More robust use of Laura's Law is needed to improve access to treatment for the approximately one million Californians with severe mental illness, as many as half of whom are untreated on any given day. Without programs like AOT, these individuals cycle through the various public service systems, become entangled in the criminal justice system and take up residence on the streets and in dangerous encampments.

A Promising Start's assessment of existing Laura's Law programs in California, and specific recommendations for improved implementation of the treatment law, is available at <TACreports.org> or <www.treatmentadvocacycenter.org/a-promising-start>.

Competency Restoration

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Restoration to competency so one may face criminal charges **is not the same** as adequate and appropriate mental health treatment to manage illness, provide care, and improve a person's condition. The goals are fundamentally different: competency restoration serves the criminal justice system; treatment serves the individual who is ill.

Of course, if Minnesota's Department of Human Services will not restore competency, then they must step up their work to keep people out of the criminal justice system in the first place. That means exercising options to redirect people from arrest or jail into meaningful treatment—particularly for low level misdemeanors and quality-of-life crimes. And if treatment supervision is necessary, then they must make the deliberate choice to supervise treatment through non-punitive civil courts. This is particularly critical to those who are too lacking in insight to seek treatment themselves, and who so often end up incarcerated because of untreated mental illness.

I am hopeful that the actions of Minnesota's Department of Human Services will result in a sincere assessment of the current competency restoration system and that all states explore alternatives to redirect people who need it into real treatment. Enough is enough.