Treatment Advocacy Center has been working across the country to ensure that those with severe mental illness who lack insight can access life-saving treatment. This includes Assisted Outpatient Treatment (AOT), the practice of providing community-based mental health treatment under a civil court commitment, as well as involuntary hospital care.

In Georgia, we worked on a bill to establish a three-year, five-site AOT grant program, which Gov. Brian Kemp signed into law in April. HB 1013 includes much of the language we drafted and follows many of the recommendations of the Georgia Behavioral Health Reform and Innovation Commission, which Policy Director Brian Stettin and DJ Jaffe Advocate Sabah Muhammad engaged with last year.

Stettin worked with the bill drafters this year to ensure both the inclusion of improvements to the AOT criteria and resources for implementation of AOT. The bill includes funding and technical assistance for the grant programs. The grantees will also have to collect data,
listening to a panel discussion hosted by the Manhattan Institute on April 7, titled “Crime and Mental Illness in New York City: Community Solutions,” I was struck by something my colleague Brian Stettin, Treatment Advocacy Center’s policy director, said in his remarks. “Assisted outpatient treatment is not handcuffing someone who is mentally ill, rather, handing someone the key to the handcuffs they are already wearing.”

Stettin’s evocative metaphor is a powerful paradigm for how proponents of AOT should be describing this form of compassionate, civil, court-ordered treatment for severe mental illness. Without treatment, people with severe mental illness lose their connection to reality. Lost in the throes of florid psychosis, they cannot be said to be free. In fact, they are imprisoned in their own minds.

An irony is that many are unaware that anything in their life is amiss. That’s because a neurological deficit known as anosognosia, estimated to afflict half of individuals with schizophrenia and 40% with bipolar disorder, prevents them from recognizing their illness and need for treatment.

That is why, as Stettin argues in a Jan. 23 op-ed in the New York Daily News, “any strategy to tackle untreated severe mental illness must unapologetically recognize the need to provide involuntary treatment to individuals in crisis, even those who are not yet violent or suicidal.”

In that spirit, Treatment Advocacy Center’s staff has been working hard to expand, strengthen and improve AOT laws all throughout the country (“Promoting and Improving Assisted Outpatient Treatment from Coast to Coast,” cover), including in New York, where Kendra Law’s as the state’s AOT statute is known, has saved countless lives in the 23 years since its inception. As the principal proponents of AOT, and the leading voice for people with severe mental illness and their families, our expertise is widely sought by leaders across the political spectrum, from Democratic New York City Mayor Eric Adams to Republican Georgia Gov. Brian Kemp.

Educating the public about SMI issues remains a key to improving access to lifesaving treatment like AOT, and we are constantly searching for new and better ways to do so. In “Lights, Camera, Action,” p. 9.) you’ll read about the new, animated explainer video that our Communications Department released with input from the entire staff, and which was included in a recent story about anosognosia in the Seattle Times. You can also read about how our Office of Research and Public Affairs recently debuted a live-video version of its indispensable product, Research Weekly, via our Instagram channel.

As helpful as these forays into video have been for getting out message out, we know that we cannot accomplish this task alone. That is why I am so grateful for Deborah Geesling’s story (“Personally Speaking: A Mother’s Story of Surviving Schizophrenia”, p. 11.) I hope that you’ll read her inspiring account of how her son’s life turned around after a successful experience in AOT.

I remain ever grateful to you, as well, our steadfast and loyal supporters. Without you, our work would truly not be possible. Thank you for your invaluable support.

Sincerely,

Lisa Dailey
which will be very helpful for future efforts to expand AOT statewide.

“For too long, Georgia’s excellent AOT law has been tragically underutilized. The grant program established under HB 1013 is a true breakthrough,” Stettin said.

“By starting up five new AOT programs and documenting their success in helping people with severe mental illness escape the ‘revolving door,’ Georgia will set the stage for statewide implementation in the near future. They are also pointing the way forward for many other states in the same boat.”

After the horrific subway killing of Michelle Go in New York City on January 15, Stettin published a two-page op-ed that month in the New York Daily News, in which he offered New York City’s new mayor, Eric Adams, a roadmap for a new era of refusing to accept the inevitability of untreated severe mental illness in New York City.

“There is good reason to wonder whether Kendra’s Law is being utilized as frequently as it should be, but we must also recognize the limits of what can be accomplished through this one program. A top-to-bottom re-think of the entire mental health system’s priorities is overdue,” Stettin wrote.

The day the op-ed was published, Mayor Adams personally reached out to Stettin to praise the piece and pledge his administration’s support for the proposed reforms.

We didn’t stop there. Stettin drafted S 8508, a bill introduced on March 8 by New York State Sen. Diane Savino (D-NY23) that reduces barriers to inpatient treatment for those who need it most by expanding the definitions of “in need of involuntary care and treatment” and “likely to result in serious harm.”

Stettin is continuing to work closely with New York City officials and policymakers. In April, he participated in an online forum presented by the Manhattan Institute titled, “Crime and Mental Illness in New York City: Community Solutions.” At the event, Stettin argued for the need to use Kendra’s Law more effectively.

Our work expanding and improving AOT currently extends to several other states. Pennsylvania passed a law in 2018 to provide a statutory basis for AOT. However, to date, not a single county has taken advantage of the new law by implementing an AOT program. To remedy this, Treatment Advocacy Center’s AOT Implementation Team, Office of Research and Public Affairs partnered to call attention to this missed opportunity. As part of a multi-pronged strategy, Treatment Advocacy Center launched a social media-style video in July urging Pennsylvania county executives to implement AOT.

Responding to these efforts, the Pennsylvania Office of Mental Health and Substance Abuse Services offered counties an opportunity to use the state’s federal COVID relief block grant to launch AOT programs. There are now five counties in the planning stages of implementing AOT programs and our AOT Implementation Unit is providing each county with technical assistance to ensure their success.
In Washington, Gov. Jay Inslee signed HB 1773 into law on March 30, a bill that Treatment Advocacy Center helped draft and worked to help pass alongside partner organizations and legislators. The bill extends the duration of an AOT court order from 90 days to 18 months, opens up petitioning to a broader range of professionals, counts voluntary admissions (currently excluded) as qualifying prior hospitalizations for eligibility, and clarifies procedures and uses for AOT, all to make AOT more accessible.

We helped NAMI Alabama to improve their state’s AOT, inpatient commitment, and emergency detention laws by drafting HB 70 and testifying in support. The bill passed the legislature on March 17 and Gov. Kay Ivey is fully expected at press time to sign it into law. The bill will expand criteria for inpatient commitment, make it easier for people who are discharged from inpatient treatment to receive AOT, and remove a legal barrier to a law enforcement officer detaining an individual in crisis for evaluation.

In Kentucky, Gov. Andy Beshear signed HB 127 into law on March 25, a bill we have been working on for more than a year. The bill improves the criteria of Tim’s Law, Kentucky’s AOT law, by broadening how a person’s history of nonadherence with mental health treatment is considered, removing the requirement that a person be determined to have anosognosia, and correcting language ambiguities regarding clinical evaluations and timeframes.

Our staff engaged with the Severe Mental Illness Taskforce last year to help inform its recommendations to improve Tim’s Law. We also worked with Louisville’s AOT Judge Stephanie Burke to draft the bill and ensure Tim’s Law reflects the clinical realities of severe mental illness. Stettin testified to the Kentucky House Health & Family Services Committee on Jan. 13 on how desperately Kentuckians with SMI need these changes.

This was a legislative session without precedent for us, and we are so excited to see our work paying off. Everyone deserves the right to get treatment, and for so many, treatment comes in the form of AOT. But the fight doesn’t stop here. Next session we will continue to fight until everyone in this country has access to the lifesaving treatment of AOT.

Maryland is one of only three remaining states (along with Massachusetts and Connecticut) that have not passed a statute authorizing AOT. Our staff and board member Evelyn Burton made progress in changing that this year by working closely with the bill sponsors to draft HB 1017/SB 807, which would have established an AOT pilot program in Frederick County.

Stettin testified in support of the bill on March 9, extolling the success of AOT around the county. “The experience that other communities have had with AOT is that people really enjoy being a part of this,” said Stettin.

Unfortunately, the bill did not pass, but important groundwork has been laid to revive the effort in 2023.

Maryland Waives IMD Exclusion
The Maryland Department of Health gained authority, in January, to waive the discriminatory IMD exclusion in the state. Maryland will now be able to use federal Medicaid funds for inpatient treatment in psychiatric facilities. No longer will low-income people with severe mental illness be left behind. This will save countless lives of Marylanders.

Treatment Advocacy Center staff, with support from Board member Evelyn Burton on the ground in Maryland, fought tirelessly to obtain this waiver. We spurred 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.
One of the major emerging psychiatric stories of our time is the failure of genetic research on schizophrenia. For two decades the National Institute of Mental Health (NIMH) has invested the single largest share of its $2 billion annual research budget into genetic research, hoping that it would lead to the identification of genes which could, in turn, be targeted by new drugs to successfully treat the disease.

The problem is not that no novel genes have been found. The problem, instead, is that hundreds of genetic polymorphisms have been found, each having statistically a tiny effect. Such genetic abnormalities are most likely partial contributors to the true cause of the disease, such as an inflammatory process, or are predisposing genes, such as those that control the blood brain barrier prohibiting infectious agents and other pathogenic substances from entering the brain. Thus, at this point in time, there is no evidence that abnormal genes, by themselves, cause most cases of schizophrenia.

In retrospect, how did NIMH go so far down the wrong research road? The answer is twofold. First, the Human Genome Project to sequence the human genome was accomplished in the 1990s with $3 billion. To justify its cost its founders promised that it would identify the causes of most diseases for which the cause was not known, including schizophrenia, bipolar disorder and depression. Indeed, when you have a new $3 billion hammer, everything that is vaguely pointed looks like a nail.

The second reason why NIMH research got so far off track is confusion regarding the words “genetic” and “familial.” If you ask most schizophrenia genetic researchers why they think the disease is genetic, they will reply that it runs in families and cite various statistics for twin and adoption studies. They appear to have forgotten that many things run in families which are not genetic. Such things include infectious agents, such as those studied by SMRI over the last three decades. It also includes the internal microbes that make up the microbiome which also runs in families.

In summary, just because a disease like schizophrenia runs in families does not mean that it is necessarily genetic. Its familial pattern may also be caused by environmental factors. Just because a disease like schizophrenia runs in families does not mean that it is necessarily genetic. Its familial pattern may also be caused by environmental factors.

It has been known for many years that certain viruses as well as the spirochete causing syphilis can be passed from infected mother to offspring to offspring over three or more generations, appearing to look like a genetic disease. This ability, usually referred to as vertical transmission, is especially prominent in the parasite, Toxoplasma gondii, the subject of my recently published book “Parasites, Pussycats, and Psychosis: The Unknown Dangers of Human Toxoplasmosis.” In mice, this parasite can be passed from parent to offspring through 10 generations, mimicking genetic transmission. If and how often this occurs in humans is not known.

It is known that human mothers infected with this parasite can pass it to more than one offspring; human case studies have described the passage of Toxoplasma eye disease to two and three successive siblings. Siblings can also be infected by Toxoplasma gondii in other ways. For example, the parasite may be transmitted by eating undercooked meat from an infected animal; case studies have been published describing multiple family members becoming infected by sharing a meal.

Similarly, the parasite may be transmitted by an infected water supply, and family outbreaks of toxoplasmosis have been attributed to, for example, an infected well. Family outbreaks of toxoplasmosis have also been attributed to children playing together. In one such outbreak, seven preschool-aged children from an extended family became infected with toxoplasmosis after playing in sand piles contaminated by infected cats. In another outbreak, four children from one family became infected, presumably from exposure to the infected family cats.

In summary, just because a disease like schizophrenia runs in families does not mean that it is necessarily genetic. Its familial pattern may also be caused by environmental factors, such as infectious agents. NIMH made a fundamental mistake by forgetting this basic biological tenet and focusing almost exclusively on possible genetic causes measured in isolation from infections and other environmental exposures.

The Stanley Medical Research Institute is a supporting organization of the Treatment Advocacy Center.
The Assisted Outpatient Treatment (AOT) Implementation Team published a 74-page guide in May to help counties in Texas to effectively start and run AOT programs. AOT is the practice of providing community-based mental health treatment under a civil court commitment.

Policy Director Brian Stettin took the lead on drafting the Guide. “Texas has more statutes relevant to the practice of AOT than any other state. The Guide will be invaluable to those working to organize an effective AOT process that meets all legal requirements. It should also prove useful as a reference for established programs to consult when new issues arise – sort of a car manual in the glove compartment,” said Stettin.

The Texas AOT Practitioner’s Guide will support programs as they navigate the steps to implement a successful AOT program. Counties want to initiate their own programs, but they need help figuring out what the best practices are and how to build a program from the bottom up. Now that Texans have this manual tailored to their state, it will hopefully spur communities that have been thinking about implementing an AOT program to start the process.

The manual contains a step-by-step “how-to” guide for effective practice of AOT in accordance with the Texas Health and Safety Code, an explanation of Texas’s unique process for diverting eligible criminal defendants with mental illness out of the criminal justice system and into community-based treatment through AOT, and an exploration of the critical yet underappreciated role of families in helping AOT participants engage with treatment by suggesting ways to involve families in AOT implementation.

Texas Tech Law School Professor Brian Shannon, an authority on Texas criminal procedure and offenders with mental illness, wrote the section on pathways to AOT from the Texas criminal justice system. In that section, Shannon highlights the importance of coordination between court staff, attorneys and community service providers and other interested parties.

The exploration of the role of families in helping AOT participants was critical to the Guide’s success. Implementation Specialist Betsy Johnson saw how hard family member advocates fought for the passage of the AOT law and implementation and she knew that they must be included in the Guide. “Texas needs quality programs and quality programs include family members,” said Johnson.

For help publishing the Guide, Treatment Advocacy Center looked to a key partner, NAMI Texas, especially for the family engagement section. Greg Hansch, the executive director of NAMI Texas, emphasized how vital it is to have family members involved in the AOT program. “Family participation is critical to many aspects of AOT. A family member can provide invaluable insight to the judge and mental health provider during the development and implementation of a treatment plan.”

This is the second time the team has published such an AOT manual for a state. The first was for Ohio in 2017, published with the generous support of Peg’s Foundation. The implementation manual was a huge success and to this day, Johnson sees the implementation manual in AOT offices all over Ohio.

The AOT Implementation Team met with the Harry L. Willett Foundation in 2017 and the foundation decided to fund both an AOT symposium and the Guide. The foundation was looking to foster more AOT programs in Texas and our team decided to replicate what they did in Ohio with the help of the Peg’s Foundation.

First, they sponsored a statewide AOT symposium in 2018 in Austin to highlight the Substance Abuse and Mental Health Service Administration (SAMHSA) grants that could be used to start programs. At that time, there were only four AOT programs in Texas. After the symposium, programs had the knowledge and resources to apply for SAMHSA grants and by the Spring of 2020, there were 10 AOT programs in Texas.

Now that there are more programs it makes sense to help those programs grow and flourish by writing an implementation guide.

The Guide was published with a launch event featuring the authors. It is available for free on our website. Treatment Advocacy Center is also shipping free hard copies of the Guide to programs for a limited time only.

There will also be free hard copies available at our upcoming 2022 National AOT Symposium and Learning Collaborative happening this October in San Antonio, Texas. Register for the conference here: https://aotconference.mightycrow.com/.

WE HOPE TO SEE YOU THERE!
‘Waiting for Danger’
An Emotional Day of Testimony Regarding California’s Lanterman-Petris-Short (LPS) Act
By Clara Keane

The California Assembly Health and Judiciary committees hosted a full-day hearing on Dec. 15 on ways to improve the Lanterman-Petris-Short (LPS) Act, California’s statute governing civil commitment and conservatorship for grave disability. Treatment Advocacy Center staff and grassroots partners made sure the voices of family members of people with severe mental illness (SMI) were not ignored.

Despite good intentions, gaps in the law and lack of state oversight to ensure consistent practice are largely responsible for often tragic outcomes. LPS must be reformed to broaden the definition of danger to self or others to include those who are unable to meet their basic needs or whose mental or physical health will deteriorate without needed care. Additionally, state-level oversight must be enacted to ensure that the survival of our loved ones is not dependent on which county they live in.

Treatment Advocacy Center distributed an action alert ahead of the hearing making it easy for our California grassroots partners to submit written testimonies in one click. More than 80 advocates shared heartfelt stories of their first-hand experience with the devastating impact this outdated law has on those California residents who need it most.

At the hearing, Treatment Advocacy Center staffers live-tweeted highlights. Senior Family Liaison Kathy Day, who attended the hearing in-person, live-tweeted about the emotional impact that the LPS Act has on families, caregivers and those with SMI, while Research and Policy Manager Kelli South live-tweeted about the policy impact the LPS Act has on Californians with SMI and their families.

During the nine-hour hearing, lawmakers heard from a lineup of over 30 speakers followed by 25 members of the public, including Treatment Advocacy Center board member Randall Hagar, who spoke from a provider’s perspective on policy changes necessary to make the LPS Act workable. “Our LPS system is crisis-driven and treatment failure-driven,” he said. “When we make a system that depends on waiting for danger, for many people, it’s too late.”

Family members and advocates Teresa Pasquini, representing National Alliance on Mental Illness Contra Costa, and Susan Shaw Goodman, delivered powerful testimony on the horrors their sons with SMI experienced within the California mental health system. “The criminal justice system is where we ‘house’ people with SMI in California,” said Pasquini. “There has been nothing civil or right about my son’s care in California.”

Family members protested outside the State Capitol during the scheduled lunch break.

As Gov. Gavin Newsom’s administration and the California State Legislature prioritize reducing untreated mental illness and homelessness across California, we are pleased to finally see a concerted effort to reform the LPS Act. We look forward to working with lawmakers on legislation to ensure that people with the most severe psychiatric illness in California can be served by the LPS Act.
As part of our ongoing author series, we were privileged to interview author and Treatment Advocacy Center founder Dr. E. Fuller Torrey about his brand-new book, published by Spring Publishing, “Parasites, Pussycats and Psychosis: The Unknown Dangers of Human Toxoplasmosis.”

Torrey’s latest book, his 21st, explores the connection between human psychosis in the United States and infection from Toxoplasma gondii, a parasite that humans can acquire from cats. The book is open access, ensuring that everyone will be able to read the book and understand the implications of this problem.

What follows are highlights from our conversation:

**How would you describe the book?**
The book is a summary of all the data that suggest that a parasite, *Toxoplasma gondii*, plays a role in causing some cases, not all the cases, of schizophrenia and bipolar disorder. It is a compilation of the data that’s been accumulated over the last 30 years.

**Can you explain the main takeaway of the book?**
In my book, I describe that if you owned a cat, that was outside, as a child, it’s a risk factor for later developing schizophrenia. I go into some length in the book describing what the data is on that and, it’s not uniform, there are some studies that don’t support this, but the majority of the studies do support this. Cat ownership in childhood is a risk factor. Therefore, the book concludes that having a cat in childhood, if the cat is allowed to go outside, is not safe. Cats that stay inside are safe.

**That is huge—what do we do about it?**
There is clearly a lot of work that needs to be done. First, we must research to develop an effective vaccine. There’s one that’s used in sheep and in some goats, but it’s not available for humans. Education is also important. Most people still are not aware of the risks involved with the parasite or how the parasite is transmitted. The parasite is transmitted in many, many ways, including even breathing the parasite in. That’s why pregnant women are strongly advised not to change cat litter. Because even if you don’t touch it, you could breathe it in and become infected that way.

**Why does the book matter?**
The book matters because if in fact I’m right and having a cat in childhood is a risk factor for schizophrenia and bipolar disorder, that’s very important. That’s a risk factor that we can control. There is a way to decrease the risk. Also, it’s important because if this is true, and one of the estimates in the book is that these parasites cause 20% of cases, that would open up treatment for people that we don’t have available now. If we could treat 20% of the cases of schizophrenia with a more effective medicine than we have now that would be a big step forward. So, this has real implications for both preventing and treating the disease.

**Do you believe cat owners will agree to a vaccine?**
I think that people will get a vaccine because they want to keep cats as pets. People feel very strongly about cats. And people who are cat lovers will, I think, do whatever is necessary to make their cats safe pets. There are cat people and there are dog people, in my experience, both feel very strongly about their pets. And if they understand the risk of having a cat, they will do whatever is necessary to minimize that risk. Cats make nice pets!

**What is your favorite kind of cat?**
I spent two years in Ethiopia with the Peace Corps and I started to like lions. One of the women who was in the Peace Corps with me had two young baby lions. I spent a lot of time with the baby lions. I’m partial to lions. The baby lions made very nice pets.

**Why was it important for you to make this book public access?**
The book is open access, which means that it can be downloaded by anybody for free because there is a lot more interest in this research in middle income and lower income countries. It’s available free online and I did it purposely to make it available widely.

**You’ve written a staggering 21 books. What advice do you have for younger writers aspiring to write a book?**
My advice for young writers is that it’s most important to write something that you’re interested in. And to not take on too much at once. Start modestly with something that you can handle.
LIGHTS, CAMERA, ACTION!
Reaching and Educating More People Through Video

An essential part of Treatment Advocacy Center’s mission is to educate the public and policy makers on issues affecting people with SMI and their families. We are always trying to expand our audience and reach new ones. This year, we have been accomplishing that goal by producing exciting new video content.

We published an animated explainer video in December on anosognosia, a symptom of severe mental illness (SMI) experienced by some that impairs a person’s ability to understand and perceive their illness. Anosognosia is the single largest reason why people with schizophrenia or bipolar disorder refuse medications or do not seek treatment. The video garnered 3,286 views on our YouTube channel, 1,108 views on Twitter and reached 8,624 people on Facebook.

Anosognosia remains one of the most misunderstood symptoms of SMI, and it’s critical that policy makers understand how anosognosia acts as a barrier to treatment for some of the most vulnerable among us.

The strategy worked: The Communications Department worked directly with the Seattle Times in January to include our video in the paper’s story on anosognosia.

As Executive Director Lisa Dailey is quoted in the article as saying, “If you are building a system that is based on the idea that anyone can and eventually will recognize that they need treatment... it means the population of people who literally can’t because they have anosognosia are just invisible to the system.”

The video will continue to be used to make people with anosognosia less invisible. You can watch the full video on the anosognosia webpage on our website or on our YouTube page.

We redubbed the video in Mandarin and Cantonese in April to reach an even wider audience. With this new video, we hope to grow ties with Mandarin and Cantonese speaking advocates in the Bay Area and all of California. The two newly dubbed versions of the video are also available on our website and YouTube channel.

In collaboration with the Communications Department, Director of Research Elizabeth Sinclair Hancq, Research and Policy Manager Kelli South, and Research Intern Nina Robertson launched a new iteration of the Office of Research and Policy Affairs’ Research Weekly on Instagram in February.

Research Weekly is a weekly public service of ORPA to make sure the public is up-to-date on recent research published in the severe mental illness field. Instagram, a picture-sharing platform, allows us to post pictures and videos.

Every week in February, the research team published a short video on our Instagram, in which that week’s Research Weekly author discussed the blog, how advocates could understand and use the data, and why understanding severe mental illness is critical to implementing lasting policy change.

The research team broadcasted live to our Instagram followers on the last Wednesday of the month to discuss that month’s most impactful research and to answer questions from the audience, in an event moderated by Communications Associate Elizabeth Warner.

You can watch the weekly videos and the full live event on our Instagram page.
ON THE ROAD
with the Implementation Team

Treatment Advocacy Center’s Assisted Outpatient Treatment (AOT) Implementation Team hit the road this month. Policy Director Brian Stettin, Project Manager Amy Lukes and Implementation Specialist Betsy Johnson traveled to El Paso, Texas and two cities in New Mexico, Las Cruces and Albuquerque, 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 saw hearings in the afternoon. The hearings took place partially in Spanish to accommodate AOT participants and their loved ones. There, Treatment Advocacy Center trio was lucky enough to witness at 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 thanked them for giving her her son back.

Our trio conducted trainings in both Las Cruces and Albuquerque. Judges, attorneys, treatment providers and evaluators came together to hear from the Implementation Team 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.

They were also able to have some fun on the road. When you see a town named Truth or Consequences, you must stop and check it out!

To get in touch with the Implementation Team and learn more about AOT, visit our website.
Personally Speaking: 
A Mother’s Story of Surviving Schizophrenia

By Deborah Geesling

My husband Matthew and I have four adult sons. Our third son has battled schizoaffective disorder for the past 12 years. He has all of the symptoms of schizophrenia and bipolar disorder. For almost a decade, he lacked insight into the extent of his illness, a condition called anosognosia.

Our son needed the compassionate use of assisted outpatient treatment (AOT), thankfully available in our state and county. He did not understand that he was ill and therefore would not take his medications without this tool. When he had his first psychotic break at the age of 18, he went through a mental health court process that determined he should comply with treatment to remain in the community for one year. If he failed to take his medications, he could be placed back into the hospital. Our son was given legal representation and had the right to appeal this order every 60 days.

He was released from the hospital after he was placed on AOT to our home and was assigned to a clinic with an ACT Team for individuals with higher needs. This support was crucial to our family as our son was still symptomatic and we were learning how to care for him. However, after the court order ended, our son stopped taking his medications. Things went from bad to worse. He quickly decompensated and he had to be hospitalized once again and was eventually placed back on AOT.

The following year proved very difficult as he tried new medications. He was not stable and was stuck on a dangerous roller coaster ride.

What if he never gets better? What if he continues to decompensate further into psychosis and loses more cognition? I felt terrified and helpless.

Eventually he would need to be on AOT for eight years in a row, something unheard of in most states. Because our son did not want to go back into the hospital, he took his medications. He also did not object to the last four years of the assisted outpatient treatment renewal because he began to see the benefits. He was no longer going in and out of the revolving door of hospitalizations and he was starting to feel better.

Three years ago, he began a part-time job at a wood-fire pizza restaurant. He continues to work there faithfully and rarely misses a day of work.

When COVID lockdowns began I was concerned that my son would lose ground. The restaurant closed temporarily and he and the men at his group home had nothing to do all day, their days and nights were mixed up. We went from our weekly routine of shopping, having lunch together, going to church, and spending time with family, to zero visits, random face-time calls, and Instacart grocery deliveries.

There is nothing I enjoy better than my son proving my fears wrong. As the COVID restrictions began to lift, he returned to work slowly.

Since that time, I have seen noticeable improvement in my son’s cognition. He continues to struggle with symptoms of his illness, but he is gaining insight. For the past eight years, he has been consistently taking medications and has remained in the community with no further hospitalizations. Assisted outpatient treatment gave him the platform and structure to begin to heal. So many people in our country don’t have that opportunity. So many people aren’t offered this kind of chance of a life filled with hope and dignity. They are forced to accept the lie that “this is as good as it’s going to get” because the necessary tools are not available to them. But I know it’s possible, I’ve seen it. My son has proved it over and over, despite setbacks and a system that’s not friendly toward those with severe mental illnesses. He beat the odds and showed me and everyone else that it can be done.

Assisted outpatient treatment is the right thing to do if needed, even if it doesn’t feel right at the time and you think your loved one may hate you. He or she may certainly hate you in that moment you sit in that courtroom and testify, but maybe they’ll just prove all your fears wrong someday, prove everyone wrong.

Deborah Geesling is an advocate for individuals and families living with serious mental illness in Arizona where she works with state leaders to enhance the system of care.
Treatment Advocacy Center invites you to the

2022 National AOT Symposium & Learning Collaborative

SAVE THE DATE

OCTOBER 13–14, 2022
SAN ANTONIO, TEXAS