THE SHOT HEARD 'ROUND THE WORLD
Treatment Advocacy Center Works to Promote COVID-19 Vaccination Among People with SMI
By Elizabeth Warner

TREATMENT ADVOCACY CENTER has been leading the charge to ensure that people with severe mental illness are not left behind in the fight against COVID-19.

Since the start of the ongoing pandemic, we have sent letters to state health directors to ensure that people with SMI were prioritized for vaccination. We have provided states, practitioners, community organizations and public health leaders with fliers to distribute to people with SMI who were hesitant and to providers to make it easier for people with SMI to get vaccinated. We also issued a statement, along with nine other mental health organizations, urging the federal government to provide a strategy to prioritize vaccination for people with SMI, followed up with an op-ed in The Hill.

We haven’t let up: The Office of Research and Public Affairs published a report on September 15 highlighting how community investment to facilitate COVID-19 vaccination can have a tremendous impact on promoting vaccination among people with SMI.

Our efforts to fight COVID-19 began in earnest in March 2020, when it became clear that people with SMI would again be marginalized in a public health effort. Director of Research Elizabeth Sinclair Hancq realized the importance of sharing research and information about how people with SMI and their families may be disproportionately impacted by the COVID-19 pandemic and the many barriers they face.

Sinclair Hancq started writing about the impact of the COVID-19 pandemic on people with SMI in the Office of Research and Public Affairs weekly research blog, Research Weekly. Just as COVID-19 vaccines started to become available, research was published in JAMA Psychiatry about the increased...
This is not the debut column I wanted to write as executive director of the Treatment Advocacy Center. I had hoped to be able to write that the pandemic was over and that, after enduring the worst economic and health crisis of our lifetimes, the Treatment Advocacy Center staff, the rest of the country and the world were able to return to normalcy.

But if there is anything we have learned from the pandemic, it is that people are resilient. Even in the midst of loss, doubt and uncertainty, the Treatment Advocacy Center staff I am privileged to lead have pivoted, adapted and found ways to push forward. We have learned how to operate in the new normal and imagine new ways to reach and serve our constituency.

As such, we are committed to doing things even better than before — to carrying out our mission to eliminate barriers to the timely and effective treatment of severe mental illness with the benefit of lessons learned from the ongoing pandemic.

The cover story in this issue of Catalyst is the perfect example of the creative thinking and entrepreneurial spirit of our work in these unprecedented and challenging times. In “The Shot Heard ‘Round the World,” you’ll read about how we partnered last spring with Magnolia Clubhouse, a free, community-based membership organization for people with mental illness, to educate their members about the dangers of COVID-19 and encourage them to get vaccinated against the disease.

Our Office of Research and Public Affairs surveyed Clubhouses worldwide to produce a new report showing that concerted community investment increased vaccination rates among people with SMI.

We broke new ground in another way this summer with the release of our first podcast, “The Way Forward” (“A New Way to Tell Our Stories,” p. 5). This limited-series podcast highlighted the success of assisted outpatient treatment in Ohio and helped introduce our work to a completely new audience online.

Our advocacy and AOT implementation teams made major progress in several key states by deftly pivoting to virtual testimony and appearances. In California, we were instrumental in the passage of SB 507, a law that will expand access to Laura’s Law programs for those who need them most by making key improvements (“Progress in the Golden State,” p. 7). Similarly, in Nevada, we helped to amend the state’s AOT law by persuading the legislature to relax the eligibility criteria and streamline the entire AOT legal process (“Treatment Advocacy Center Helps Improve Assisted Outpatient Treatment Laws in Nevada and Louisiana,” p. 9).

As this edition of Catalyst clearly shows, our work matters more than ever to the families we serve. Just read the moving personal essay (“I Didn’t Understand Mental Illness Until It Gripped My Son”, p. 10) by NAMI Santa Clara County board member Moryt Milo, who shares the story of how her son with schizophrenia was able to achieve his goal of graduating from college. Her story is a reminder that our work, while difficult, is neither quixotic nor hopeless, and that eliminating barriers to treatment is the way forward for our loved ones with SMI.

Thank you, as always, for your generous support of our work here at the Treatment Advocacy Center. Without you, none of our success would be possible.

Sincerely,

Lisa Dailey
The worldwide COVID-19 pandemic caused by the SARS-2 coronavirus has enormous consequences for virtually everyone living in the United States and most areas of the world. As is the case for almost all health issues, the effects are particularly profound for individuals with schizophrenia and other serious mental illnesses. Many studies have shown that individuals with SMI are more susceptible to a range of infectious diseases, particularly ones involving the respiratory system.

We found a number of years ago that this increased risk includes susceptibility to coronaviruses, the group of viruses that includes SARS-2. There are a number of reasons for this, most of which are related to environmental exposures that occur at an increased rate in individuals who are hospitalized, living in group housing or homeless. Underlying lung diseases associated with exposure to cigarette smoke and other pollutants also are likely contributors to this increased risk.

Several studies from the United States, Europe and Israel have indicated a higher rate of mortality and other serious complications due to COVID-19 in individuals with SMI compared with other populations. Some of these increases are related to the enhanced likelihood of infectious disease exposure for the reasons noted above. Furthermore, many individuals with serious mental illnesses have comorbid conditions that increase the risk of both SARS-2 infection and serious COVID-19 disease. These include cardiac disorder, hypertension, diabetes, obesity, emphysema and other pulmonary diseases. Lack of access to medical care, a common problem for individuals with SMI, can also contribute to an increased rate of mortality and other serious complications due to the subsequent underutilization of assisted ventilation and other interventions that have been shown to lower the rate of complications in infected individuals.

On the other hand, at least one study has suggested that individuals with SMI who are receiving adequate medical care and taking their medications actually have rates of COVID-19 infection similar to, and perhaps even slightly less than, other populations. One possible explanation of these findings is that some antipsychotic medications seem to have the ability to inhibit the replication of SARS-2 and other coronaviruses. It is also possible that individuals with SMI who are receiving adequate medical care may be under increased medical scrutiny during the pandemic and may benefit from early diagnosis and instruction about medical precautions. In any case, these studies emphasize the importance of continued access to medical care and medication compliance.

Immunization and infection control measures are the mainstay of COVID-19 prevention. However, the implementation of these interventions may face significant obstacles in the case of individuals with SMI. Lifestyle factors such as congregate housing can make social distancing more difficult, particularly for individuals who are homeless or living in substandard housing. In the case of immunization, limited access to medical care and the transportation required to attend clinics can be a significant barrier to vaccine access. One recent study found that much of the discrepancy between COVID-19 outcomes in individuals with SMI compared with others went away when comparing only individuals who were fully immunized, further underscoring the importance of immunization.

In addition to the direct effects of SARS-2 infection, individuals with SMI may be particularly vulnerable to the effects of having to live through the pandemic. Of particular importance may be the social isolation imposed by lockdowns with concomitant decrease access to caregivers, family members and other supportive individuals.

In order to examine the effect of COVID-19 on individuals with SMI, we interviewed 195 individuals, mostly living in the Baltimore area, who had a diagnosis of schizophrenia, bipolar disorder, or major depression, as well as individuals without a psychiatric diagnosis (see “Experiences of Persons With Serious Mental Illness During the Covid-19 Pandemic”). All individuals were previously enrolled in a cohort study and were interviewed before a COVID-19 vaccine was available.
risk of serious illness and death from COVID-19 for people with schizophrenia. Sinclair Hancq realized that Treatment Advocacy Center could play a major role in ensuring that there was a strategy to ensure that people with SMI were prioritized for the vaccine.

Our goals were to ensure vaccine eligibility for people with SMI as early as possible and to ensure resource provision so that targeted outreach and prioritization could promote vaccination among this vulnerable population. The Office of Research and Public Affairs sent letters last February to all state governors, state health directors and mental health commissioners, urging them to add people with SMI to those currently eligible to receive the COVID-19 vaccine and to conduct targeted outreach to those vulnerable populations.

After receiving positive responses to the letter campaign from states like Rhode Island, Maryland and New York, we knew we had the leverage to push states to implement specific COVID-19 vaccination programs for people with SMI.

Treatment Advocacy Center partnered with Magnolia Clubhouse in Ohio, a community organization for people living with SMI, and Mental Health America to publish two flyers to try to maximize vaccination rates among people with SMI.

The first flyer was created for people with SMI and designed to ease doubts and concerns about the vaccine. The flyer listed myths and facts about the vaccine and the vaccination process and for every common myth about the vaccine, it provided an accurate fact. For example, one myth was, "You can get COVID-19 from the vaccine." The corresponding fact was: "You cannot get COVID-19 from the vaccine because it doesn’t contain the live virus."

The second flyer was created for providers and included tips for vaccine clinics to help people with SMI feel more comfortable about receiving the vaccine.

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Implementation Specialist Betsy Johnson helped us partner with Magnolia Clubhouse to make sure that people with SMI provided input for the flyers, from what myths and facts to include to advice on making the language more accessible.

The flyers were distributed to providers, Clubhouses, public health leaders, mental health commissioners and governors in all 50 states. Johnson even got Ohio’s Department of Mental Health and Addiction Services to include the flyers in their weekly email to people all over the state.

In April, when it was obvious that the federal government was still not addressing the threat that the pandemic posed to people with SMI, Treatment Advocacy Center partnered with nine other major mental health organizations to call for a national vaccination strategy to reach people with SMI.

That same month, Executive Director Lisa Dailey and Mental Health America President and CEO Paul Giovannetti penned a joint op-ed in The Hill arguing for a national strategy to maximize vaccinations for people with SMI. "COVID-19 and our nation’s response to it magnifies a sad truth: We have ignored our fellow citizens with severe mental illness," Dailey and Giovannetti wrote.
We asked the participants about their mental distress and suicidal thoughts, the impact of the pandemic and pandemic-related worries, their current tobacco and alcohol use, and their access to medical care. Compared with participants with no psychiatric disorder, individuals with schizophrenia were more likely to indicate that they felt overwhelmed or anxious, had difficulty concentrating, or were concerned about medical bills and having enough food; they also reported significantly increased tobacco use. Individuals with bipolar disorder also reported more COVID-19-related worries than did participants without a psychiatric disorder.

In a follow-up study, we found that, fortunately, most of the individuals in our study cohort received COVID-19 immunizations when they became available. Also, our laboratory evaluations indicated that most of the individuals who received immunizations developed a measurable immune response to the virus. The levels of antibody that were attained and their persistence over time are currently being evaluated in our research program. As the delta variant becomes dominant, questions arise about the susceptibility of individuals with SMI to this particular variant and about the need for booster vaccinations to retain immunity.

The pandemic also has consequences in terms of planning for future services relating to mental health and other services for persons with psychiatric disorders. Several studies indicate that COVID-19 infections have led to an increased rate of psychiatric disorders among individuals who did not previously have recognized psychiatric disorders. It is not clear if these findings represent the onset of new disorders or the worsening of symptoms in previously undiagnosed individuals. In any case, it is imperative that plans be made to provide adequate levels of care to the increasing number of individuals who are likely to need psychiatric treatment in the coming years.

It is difficult to predict the future of the COVID-19 pandemic or the occurrence of future epidemics caused by coronaviruses or other infectious agents. It is thus crucial that health care workers and stakeholders ensure that individuals with SMI are not left behind but are in a medical care system where they receive the highest level of evaluation and treatment.

The Stanley Medical Research Institute is a supporting organization of the Treatment Advocacy Center.

Dr. Yolken is the director of the Stanley Laboratory for Developmental Neurovirology at the Johns Hopkins School of Medicine. He is also a member of the Treatment Advocacy Center board. Dr. Dickerson is the director of the Stanley Research Program at Sheppard Pratt and collaborates closely with Dr. Yolken’s lab.

A New Way to Tell Our Stories
Treatment Advocacy Center Launches First Podcast

Treatment Advocacy Center plunged into new waters this year, releasing our first podcast in an attempt to reach new audiences with our educational content. The four-part, limited series podcast, titled “The Way Forward,” was produced by Emmy Award–winning journalist Bill Retherford and covered the extraordinary success of assisted outpatient treatment in Ohio.

The first episode, “Assisted Outpatient Treatment: A Lifesaver?,” explained the history and purpose of AOT and how it can help people with SMI. The second episode, “AOT Champions,” introduced listeners to a local AOT advocate and taught how to start an AOT program at home. The third episode, “AOT: Inside the Courtroom,” brought listeners into a courtroom in Ohio’s Lorain County to demonstrate how an AOT program really works. The final episode, “AOT Success Stories,” highlighted people who have graduated from AOT programs and regained their independence. Reception to the podcast was overwhelmingly positive. The podcast was promoted by Ohio’s Department of Mental Health and Addiction Services in its monthly email and earned nearly 200,000 impressions on Treatment Advocacy Center’s Twitter page.

Guests included Butler County Judge Randy Rogers, the chief of psychiatry at Northeast Ohio Medical University, Dr. Mark Munetz, the executive director of NAMI Richland County, Mary Kay Pierce, Lorain County Judge James Walther and Columbus AOT team supervisor Jeanne Levy.

Listen to all four episodes on our website under the “Podcast” tab on the home page, or wherever you listen to podcasts.
Our advocacy on this issue continues. The Office of Research and Public Affairs published a new report on September 15 with Clubhouse International showing how well Clubhouses did in getting their own members vaccinated. Because local and federal governments failed to prioritize people with SMI, the work, as it so often does, fell to community groups like Clubhouses.

The good news: Clubhouses rose to the occasion. Our survey showed that estimated vaccination rates of U.S.-based Clubhouse members are higher than vaccination rates of the average U.S. population. Out of 105 Clubhouse responses from the United States, 64 estimated a higher vaccination rate for their members compared with the vaccination rate of their county at the time of the survey. In Floyd County, Ga., only 10.1% of the county’s population was fully vaccinated at the time of the survey, compared with an estimated 61%–80% of Clubhouse members.

The survey showed that one of the most effective tools for changing minds around vaccination was the sharing of experiences among peers.

At Putnam Clubhouse in Contra Costa, Calif., one member, Fred, was so inspired to help others get vaccinated that he shared his entire experience on social media and helped other members make the decision to get vaccinated. “Well, I thought if I could help other people get vaccinated that would be great because I believe that people need to be. I told other members, and I think it helped them,” he said. “There’s been a lot of fear about it.”

As humble as Fred was about his achievement, there is no doubt that he made a huge impact at his Clubhouse.

The survey also found that barriers to COVID-19 vaccination include not only hesitancy but also lack of access. To assist the efforts of member-influencers like Fred, Putnam Clubhouse staff also helped members get appointments for vaccination.

This made Putnam Clubhouse’s push to provide logistical support and transportation ever more important. “What scares me is the people who don’t belong to a Clubhouse because the government is still not worried about those with SMI,” said staff member Sandy Young.

Relying on our research, other organizations across the country also began advocating for better access to vaccines. Help in the Home, located in Rockville, Md., provides personalized care through support and community to help adults with serious mental illness, and in February 2021, cofounder Stacy Derrick used our research to advocate for the organization’s clients to receive the vaccine as early as possible. Derrick reached out to multiple state and local officials. While some officials responded, they did nothing concrete, but in one month, Help in the Home had got all of its clients vaccinated independently. Help in the Home also used our research to create its internal COVID-19 policies.

“A piece of what the research did was validate what we were saying as non-scientists who were trying to advocate for our clients,” said Derrick. “Even if the people we sent this information to weren’t able to take action on it, it made us feel confident that what we were doing was worth the effort and we were justified in what we were asking for.”

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While government leaders have turned a blind eye to those with SMI during this unprecedented public health crisis, we continue to work to inform the public and hold leaders accountable. Sinclair Hancq summed it up best: “The Treatment Advocacy Center will always advocate for people with SMI. We have had to pivot our activities because of the pandemic and it is hard to anticipate what the needs are, but we will continually fight for the rights of people with SMI and to make sure they are not left behind.”
Progress in the Golden State
Nearly 8 in 10 Californians Now Covered by Laura’s Law

Calif. Gov. Gavin Newsom signed SB 507 into law September 30, 2021 to expand access to Laura’s Law, the state’s version of assisted outpatient treatment, in two key ways that will help ensure that anyone who needs AOT can get into a program.

First, the eligibility criteria have been modified by offering two separate bases for clinical determination regarding psychiatric deterioration. Either a finding that “the person in unlikely to survive safely in the community without supervision and that the person’s condition is substantially deteriorating,” or “that AOT treatment is needed to prevent a relapse or deterioration that would be likely to result in grave disability or serious harm to the person or to others” without continued treatment may be a basis for eligibility. Second, by eliminating a requirement that a person be actively deteriorating to qualify, AOT can now be used as a step-down option from hospitalization, allowing a safe return to community-based care.

These changes arrive not a moment too soon because, this past summer, California counties were required to decide whether to opt out of Laura’s Law. As a result, now nearly 80% of Californians have access to this lifesaving and effective tool for the treatment of severe mental illness.

Treatment Advocacy Center played an active role in helping to pass AB 1976, the bill that made county participation in Laura’s Law automatic unless a county formally opts out.

Treatment Advocacy Center board member Randall Hagar and Executive Director Lisa Dailey have established close ties with the people at the ground level in California who are getting things done to implement AOT. Through their membership in California Advocates, Hagar and Dailey talked to advocates in all 38 counties to make sure that counties knew that this was their opportunity and that they could always reach out to use to strategize, mobilize resources or simply ask us about the bill.

Under the law in California, for counties to opt out of Laura’s Law, they first need to go through a public process. We helped local advocates hold their local officials accountable by making sure that these public hearings were widely publicized and that there was genuine dialogue between those local officials and the community of people who would be served by AOT. With its knowledge, resources and bandwidth, Treatment Advocacy Center was the organization best equipped to make this happen.

“Without Treatment Advocacy Center I would have been by myself with maybe a couple of other people,” said Hagar. “But Treatment Advocacy Center coming in with its resources, its teams, its experience was critical to helping us garner in another eleven or so counties.”

One of those key resources was our own social work intern, Eric Smith. Smith, an AOT graduate and public speaker, was asked to testify to Sacramento County’s Drug and Alcohol Advisory Board, tasked with issuing a recommendation to the Board of Supervisors on whether to opt out of Laura’s Law.

One of the most effective moments in the hearing came when Smith used a vivid analogy to argue for the need for AOT in California. “Picture a building with stairs leading up to an entrance. Any building. Now picture this building as having no ramp for wheelchair access for the many people that need ramps to get where they need to go.”

Continued Smith: “Wouldn’t you find it irresponsible and faulty logic if anyone addressed this by saying, ‘don’t you see these people walking up and down the stairs? They are proof that we don’t need ramps.’ Opposition to Laura’s law is intricately intertwined with this type of logic. To be perfectly clear, some people can use the stairs, but that doesn’t mean we don’t need ramps.”

After his testimony, Judge Lawrence Brown, the judge who will be overseeing Laura’s Law in Sacramento, wrote a personal message to Smith. “Eric, thank you for just an inspiring presentation this evening. It was worth the price of admission. Thank you.”

Following Smith’s testimony, the board sent a unanimous letter recommending that the county start a Laura’s Law program, which was later influential in the Board of Supervisors’ decision to do so in May.

Not far behind was Santa Clara County, which voted to proceed with Laura’s Law in late May. Soon thereafter, Riverside County joined them. As of this writing, 30 of California’s 58 counties have now chosen to make Laura’s Law an option for their residents.

Monterey County, unfortunately, chose to ignore the needs of its residents living with SMI by voting to opt out. But Smith remains hopeful for the future. “I don’t view the counties that opted out as permanent. If someone is saying ‘no,’ that’s just ‘no’ for now.”
Treatment Advocacy Center’s Office of Research and Public Affairs published a new fact sheet, “Racial Disparities in Individuals with Co-occurring Serious Mental Illness and Substance Use Disorders,” in May. The fact sheet builds on the report that was published last March about the prevalence of co-occurring serious mental illness and substance use disorders by demonstrating, with the use of graphics and research, how racial and ethnic minorities are disproportionately impacted by the negative effects of these disorders. These same populations also tend to have the least access to care.

There are stark differences in the level of treatment people of color receive compared to white Americans. For example, in 2019, 69% of white non-Hispanic people had received mental health treatment in the past year. In comparison, only 52% of Black/African American people received treatment and only 51% of Hispanic people received treatment, according to the Substance Abuse and Mental Health Services Administration’s 2019 National Survey on Drug Use and Health.

Cultural differences, associated stigma of these illnesses within communities, racial bias in health care and systemic racial disparities, including neighborhood segregation and poverty influence these differences in treatment and diagnosis.

The fact sheet also shares important statistics on how race is a compounding factor for criminal justice system involvement for individuals with co-occurring substance use disorder and SMI.

You can find and download the fact sheet and the preceding 33-page report on our website on the “Dual Diagnosis” page.

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

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

— PROFESSOR JAMETA BARLOW
Treatment Advocacy Center Helps Improve Assisted Outpatient Treatment Laws in Nevada and Louisiana

Treatment Advocacy Center provides technical assistance to assisted outpatient treatment programs across the United States. From time to time, these programs encounter challenges in implementation and operation resulting from defects in the state AOT laws they must follow.

Our experience assisting these programs often drives our legislative work. This year, Treatment Advocacy Center was able to help pass meaningful legislation to help AOT programs be more effective and treat more people in both Louisiana and Nevada.

Louisiana has had an AOT law ("Nicola’s Law") on the books since 2008, and in 2018 New Orleans finally implemented a program. But over its first three years, enrollment has been lower than the program’s organizers had hoped.

Nicola’s Law required anyone seeking AOT for another person to include a physician’s evaluation of the proposed patient with their petition to the court, provide documents showing that the proposed patient was hospitalized or violent twice in the last three years due to nonadherence to treatment, and pay a court filing fee.

These sorts of requirements are commonplace in other states, where petitions for AOT are typically filed by hospital administrators or public officials. But the New Orleans program is different, in that it relies on ordinary citizens — the families of proposed AOT participants — to file petitions with the court. As one might imagine, the procedural hurdles to petitioning have proven too high for many families to clear.

To address these and other issues, Janet Hays, president of Healing Minds NOLA and founder of the New Orleans AOT program, convened a work group last March consisting of herself, Orleans Parish Civil District Court Judge Kern Reese, other stakeholders involved in AOT across the state, and Treatment Advocacy Center Policy Director Brian Stettin.

Stettin provided guidance to the working group on the pros and cons of different ways to change the law and helped them refine the language of the bill.

As the product of a work group with extensive firsthand experience putting Nicola’s Law into practice, the bill was warmly received by Louisiana lawmakers and advanced through the legislative process with scant resistance.

Under the amended law, which passed in June and went into effect August 1, the court will appoint a physician to conduct the evaluation, relieving the petitioner of this responsibility. While a petitioner still has to prove history of treatment noncompliance, they no longer need to provide specific documentation. Filing fees are also no longer required.

The AOT programs operating in Clark County (Las Vegas) and Washoe County (Reno) often seek AOT for individuals who are about to be discharged from a hospital stay. These patients are eligible for discharge precisely because they have been stabilized and are not currently dangerous. From the perspective of an AOT program, it is illogical for an individual who checks every box for high risk as an outpatient to be disqualified from AOT simply because they are coming out of the hospital in a stable condition.

For this and other reasons, the time had come to rethink the Nevada AOT law. Starting last fall, Stettin participated in weekly meetings of a small group of stakeholders from the two Nevada AOT programs, including both presiding judges. The group spent months perfecting a bill draft. In addition to relaxing the eligibility criteria, they sought to streamline and clarify the entire AOT legal process. When they had a draft to share, they held a series of meetings with the full array of mental health stakeholders statewide, making compromises when necessary and securing broad support.

The reward for this groundwork was a bill that moved swiftly through the Nevada legislature. The AOT reforms were incorporated into an expansive mental health bill signed into law in June 2021.

We are optimistic that the new and improved AOT laws in Louisiana and Nevada will enable AOT programs in both states to expand their reach and impact in the years ahead.
Personally Speaking:
I Didn’t Understand Mental Illness Until It Gripped My Son

By Moryt Milo

My son reached a milestone in his life on May 27, 2021. He graduated from college. He had hoped to achieve this goal in 2014, but his mind had other plans. His dream of becoming a video game writer plunged into chaos when his concentration betrayed him and invisible voices overpowered him.

His mind raced, and he fell prey to delusions, unaware they had supplanted reality. He lost his college friends, who slinked away out of fear, and he hid his problem from me because he didn’t know how to explain the unexplainable. The truth was exposed on December 26, 2012, when his mind broke.

The next day, I flew up to Spokane, Wash., where he attended college, and ran through the hospital emergency department doors to hear my 21-year-old son shout, “You are not my mother!” This became my first encounter with a mental health crisis. I understood none of it other than the panic and pain that engulfed me.

Mental illness had erupted in my universe, but in reality it had been lurking for years. My son’s psychotic break had been preceded by early warning signs going back to middle school. I beat myself up. I pondered how I, a news reporter and editor who prided myself on keen observation skills missed the most important story of my life — my son’s struggle with severe mental illness. Simply, mental illness had never touched me directly.

Over the next two years my son’s fixed delusion of me not being his biological mother perched in his brain through six hospitalizations and three residential treatment facilities that ultimately dumped him into homelessness. During the worst of times when he disavowed me, verbally abused me, and berated me for controlling his life, I knew that was not my son. I knew schizophrenia had twisted his brain. I knew his neurotransmitters were overreacting. I knew none of it was his fault. Frustrated, I had no solution to his horrific situation.

Still, I refused to listen to those who told me to let my son hit rock bottom. My son was filthy, hungry, penniless and homeless. If that didn’t qualify as rock bottom, what the hell did? He wouldn’t have even been in this situation if California’s mental health system hadn’t tossed him to the curb. Who in their right mind would want that life? My son wouldn’t have traded his dreams of being a video game writer for homelessness. It became clear early on in my efforts to save him that the real definition of insanity was our country’s mental health system.

So, I left my position at the newspaper and went searching for my son. Through luck and good timing I managed, after nine months, to get him off the streets of San Francisco and, eventually, into treatment in California. The hospital was able to get him conserved because he had a strong history of noncompliance. In other words, he needed to be in the gutter to qualify. After close to six months of treatment — hospitalization, residential treatment programs and intensive outpatient care — my son’s genuine self started to reemerge.

He returned home because success required a strong support system coupled with clinical care. He wanted to return to college. This meant staying local and enrolling in a two-year school to test the pressures of academic life. It meant taking his time. Life was too precious. Our priorities had changed. Each accomplishment without any assistance — passing a class, running an errand, seeing a doctor — was a win, and over time my son found his confidence. Through it all, my son taught me the meaning of perseverance and patience, the value of life, and to never give up.

When my son graduated from college, several of my friends said, “It couldn’t have happened without you.” I didn’t see it that way. My son and I were a team. Yes, I helped guide him. I provided him with the tools. But it was up to him to pick up those tools and follow through. As his brain grew stronger, he did just that.

With the right medication, proper tools and support in the mental health system, those with SMI can succeed. My son proved it. But his story should not be the exception, his story should be the norm. There is still much work to be done.

Moryt Milo is a writer and NAMI Santa Clara County board member who can be reached at www.morytmilo.com.
JUDGE PAT WOLKE is a judge for the 14th Judicial District in Josephine County, Oregon. He has presided over the Josephine County Mental Health Court since 2009, giving him over a decade of experience on the ground with mental health law. Judge Wolke is also an outspoken advocate in the Oregon legislature for better treatment and services for people with severe mental illness. He is a longtime donor to Treatment Advocacy Center and is committed to the fight to remove the barriers to treatment for people with SMI.

Q: Why did you get involved in mental health advocacy?
Wolke: My son developed schizophrenia when he was a freshman at the University of Oregon and had to drop out of school. That took my wife and I from being totally ignorant about SMI to being immersed in it. Ultimately, after about a couple of years, Billy had to be civilly committed, which really led to his ongoing recovery. He’s doing fine now, but I think that civil commitment was really necessary for him to begin his recovery.

Q: Why is Treatment Advocacy Center’s work so important?
Wolke: It’s extremely important! I’ve relied on Treatment Advocacy Center in so many different ways. The website, first of all, is a great source of information about civil commitment and assisted outpatient treatment laws across the country. I’ve invited Brian Stettin [policy director of Treatment Advocacy Center] to come out and talk to all of the Oregon circuit judges about civil commitment laws. Lisa Dailey [executive director of Treatment Advocacy Center] has been a member of the work group to decriminalize mental illness and has come out to Oregon multiple times to attend meetings. She has been absolutely instrumental in moving the work group forward. I also relied on Treatment Advocacy Center for research I needed to do for some testimony. The research department really helped me a lot with my research and my testimony. Treatment Advocacy Center’s just a great resource, and one that’s not really duplicated elsewhere. You really can’t find another group that has the same type of information — the type of resources — needed to reform treatment for people with SMI as the Treatment Advocacy Center.

Q: Why are you a donor?
Wolke: I started donating right after Treatment Advocacy Center was so instrumental in getting the 21st Century Cures Act signed. It expanded AOT and other resources for people with SMI. I continue to donate because Treatment Advocacy Center is unique in its ability to focus on SMI. It’s so important since better treatment for the severely mentally ill is kind of a blind spot in our legislation, so I’m happy to be donating.

Q: Do you have anything you wish people knew about SMI?
Wolke: I consider the way the severely mentally ill are treated, not only in court but in society as a whole, to be the new blind spot in America’s head. In my mind, the treatment of people with SMI is a civil rights issue. People should not be deteriorating out on the streets, having shorter lifespans and being involved in the criminal justice system just because they’re unfortunate enough to have SMI.

Q: Do you have a specific case you have presided over or heard that sticks out to you the most?
Wolke: I’m thinking of someone right now who has SMI in mental health court. He was really the terror of his neighborhood. He lived in a pretty nice neighborhood, but he was psychotic and untreated and was tearing up the neighborhood. All the neighbors were ringing their hands, so he entered into mental health court and is now really recovering. He fixed up his house, got a job, and is taking medicine as prescribed. It just shows that somebody can go from being psychotic and out of control to having a real, meaningful life. And that’s what I think treatment is all about. That’s what Treatment Advocacy Center is all about: taking people who are just having a horrible time and getting them on the path, so they can have a good life.

Q: Do you have a motto that you live by?
Wolke: Our motto in mental health court is “trust the process.” Our whole team has it on our coffee cups. By trusting the process, I’ve seen many young people, or just people in general, involved in the criminal justice system get out of the criminal justice system forever and go on to have good lives.