



Catalyst

EXPANDING RESEARCH: Generating Evidence for Reform

The emergence of serious mental illness treatment as a national issue has dramatically increased the demand for and reliance on the Treatment Advocacy Center's expertise and unique educational resources.

In particular, the public, policy makers and the press have discovered we are often the only organization examining the role severe mental illness plays in some of the nation's most significant issues and challenges.

To expand this vital public education activity, the Treatment Advocacy Center in 2015 established the Office of Research and Public Affairs – ORPA, for short.

"It was painfully obvious how appallingly and chronically the role of mental illness is overlooked as a factor in major public policy decisions," says John Snook, executive director. "We created ORPA to address this neglect by probing and illuminating those cracks and corners where severe mental illness has been swept out of sight."

ONE OF THE DEVELOPMENTS WE'VE SEEN IN THE LAST FIVE YEARS IS THE GROWING DEMAND FROM LAWMAKERS FOR EVIDENCE THAT PROPOSED POLICY REFORMS ARE EFFECTIVE AND ALSO FOR PROOF THAT THEY WILL BE COST EFFECTIVE.

One of the first studies released by ORPA, "Overlooked in the Undercounted," examined the role of untreated mental illness in fatal law enforcement shootings (page 6). Within 30 days of the report being released, it had been cited by more than 50 news organizations.

A THREE-PART FOCUS

Fixing a spotlight on overlooked topics is not new to the Treatment Advocacy Center. Founder E. Fuller Torrey, M.D., produced our first unique report in 1999 and continues to produce studies for us. The most recent is "Clozapine for Treating Schizophrenia: A Comparison of the States" (page 6).

ORPA continues to publish and build on Dr. Torrey's work, while carrying on three new activities from inside the Treatment Advocacy Center:

- Conducting, publishing and/or showcasing evidence-based research on critical issues in mental illness

that are ignored by other institutions and organizations – studies like "Overlooked in the Undercounted."

- Providing consumers, families and other stakeholders with reader-friendly summaries of news in the study of the brain, behavior and public policy: The public often has limited access to research being published by academic journals or presented at scientific conferences. In December 2015, we began to address this missing link through Research Weekly, a regular update that helps bridge the gap between inaccessible scientific journals and what you need to know. (See page 7 for a sample Research Weekly and subscription information.)
- Making sure our advocates and supporters have the most current facts, research findings and evidence they need to make the case for effective mental illness treatment: New studies and findings are published in the mental health field virtually every day. ORPA keeps us up to date.

"One of the developments we've seen in the last five years is the growing demand from lawmakers for evidence that proposed policy reforms are effective and also for proof that they will be cost effective," says Doris A. Fuller, chief of ORPA. "Developing and delivering this evidence gives the Treatment Advocacy Center another powerful tool for making the case to improve treatment access."

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A MESSAGE FROM THE
Executive Director

Welcome to the Revolution

Even a few years ago, the scope and sheer number of mental health reforms we have seen over this past year would have been unthinkable.

Now, our issues are the subject of meetings between the president and leaders of Congress, on the front pages of newspapers and in legislatures from Washington State to Florida. Finally, our leaders are recognizing what Dr. Torrey and the Treatment Advocacy Center have argued for years – an effective, functioning mental health system cannot ignore those with the most severe mental illnesses and hope to succeed.

These earthshaking changes are impacting the mental health system at all levels. In states and communities across the country, legislatures are embracing the Treatment Advocacy Center’s recommendations to restore needed inpatient hospital beds and make commonsense solutions like assisted outpatient treatment (AOT) more readily available.

OUR ISSUES ARE THE SUBJECT OF MEETINGS BETWEEN THE PRESIDENT AND LEADERS OF CONGRESS, ON THE FRONT PAGES OF NEWSPAPERS AND IN LEGISLATURES FROM WASHINGTON STATE TO FLORIDA.

New Mexico passed a sweeping AOT bill this session, becoming the 46th state to embrace this lifesaving option (page 5). In Washington, legislators are finally addressing the state’s unacceptable elimination of psychiatric hospital beds by providing additional funding and making important reforms to their treatment standards. In Virginia, the Treatment Advocacy Center joined advocates from around the Commonwealth to successfully demand the rescission of a plan to eliminate even more inpatient beds from the state’s already struggling system. And active legislation in states like Kentucky, Wyoming, Oklahoma and Hawaii means that this year’s reforms have only just begun.

At the federal level, our issues have never had more currency. The first-ever federal AOT grant program is coming online this year, with full funding and the support of President Obama’s administration. The grants will help catalyze AOT state programs in communities that want to implement AOT but need assistance to get started.

AOT continues to be a hot congressional topic, with leaders such as Senate Majority Whip John Cornyn championing the program in legislation and hearings. Representative Tim Murphy’s Helping Families in Mental Health Crisis Act also continues to receive high-profile support from Speaker Paul Ryan highlighting it as one of the bills at the top of his 2016 agenda, to columnists Nicholas Kristof and Norm Ornstein lending high-profile media support.

IMD REFORM IS JUST ONE EXAMPLE OF HOW OUR ORIGINAL RESEARCH GOES HAND-IN-HAND WITH OUR ADVOCACY WORK.

But no issue has galvanized leaders on both sides of the aisle more than the tragedies that stem from the Institutions for Mental Disease (IMD) exclusion, the outdated rule limiting federal reimbursement for inpatient psychiatric beds. The Treatment Advocacy Center has long been a champion for IMD reform, and our groundbreaking research on the loss of hospital beds has made the issue one that decision makers cannot ignore. We are pleased to note that President Obama’s administration is currently in the final processes of considering a regulation to amend this rule and that every major mental health reform bill under consideration includes additional, substantial IMD reforms.

IMD reform is just one example of how our original research goes hand-in-hand with our advocacy work. The Treatment Advocacy Center champions those who are otherwise ignored by traditional mental health services, and our research is no different. Throughout this issue of *Catalyst*, you will read about how we are changing the national conversation about mental health reform with our cutting-edge research.

As I said in the last edition of *Catalyst*: Together, we have already accomplished so much.

But we’re not done.

Welcome to the revolution.

John Snook

PROFILES IN ADVOCACY: Ted Stanley

An Unrivaled Philanthropist for Reform

The Treatment Advocacy Center marked the passing of Ted Stanley in January 2016. Without the support of Ted Stanley and his late wife, Vada, there would be no Treatment Advocacy Center.

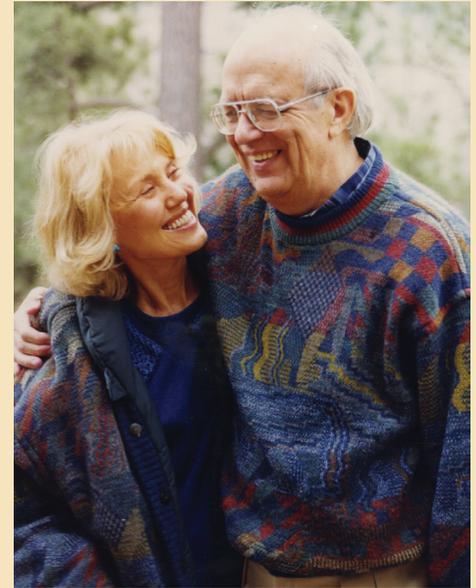
Inspired by the triumph of his son, Jonathan Stanley, over severe mental illness, Mr. Stanley committed his considerable vision, energy and wealth to reshaping the landscapes of mental illness research and advocacy in America.

Dr. E. Fuller Torrey tells the story: "In 1998, Vada called me after reading my book *Out of the Shadows* and asked, 'Isn't there something we can do now to help people who need treatment for serious mental illness?' We agreed that advocacy to improve access to treatment for individuals with serious mental illness – especially those who were not aware of their

illness – had the greatest potential. Vada and Ted then committed funds to get the Treatment Advocacy Center started."

The generous and unwavering commitment of the Stanleys made possible the Treatment Advocacy Center's emergence as a prominent national voice for mental illness policy reform.

In addition to supporting the Treatment Advocacy Center's achievements, Mr. Stanley emerged as a philanthropist without rival in the support of mental illness research. Through the Stanley Family Foundation, he donated almost \$600 million to the Stanley Medical Research Institute for more than 25 years to back research on the causes and treatment of schizophrenia and bipolar disorder. He also funded psychiatric research at the Cold Spring Harbor Laboratory in New



York, and, in 2014, he donated \$650 million to the Broad Institute to support genomic research of schizophrenia and bipolar disorder, bringing his total donations for mental illness research to more than \$1.2 billion.

The Treatment Advocacy Center celebrates the life and generosity of Ted Stanley. We all stand in awe of his contributions that promise to benefit humanity for generations.

A MAJOR BREAKTHROUGH!

Federal Grant Funds Soon to Be Available for New AOT Programs

A federal grant program to support local assisted outpatient treatment programs nationwide – a longtime goal of the Treatment Advocacy Center – has become a reality.

They said it couldn't happen! Thanks to the dedicated advocacy of the Treatment Advocacy Center and our supporters, the federal government has – for the first time ever – established and fully funded an assisted outpatient treatment (AOT) grant program. The \$15 million in annual funding will assist state and local mental health systems to establish new AOT programs beginning in 2016.

Key details:

- Applicants will compete for as many as 20 grants of up to \$1 million each.
- The program will be administered through the Substance Abuse and Mental Health Services Administration (SAMHSA).

- Communities without AOT programs already on the ground are eligible. This can include counties, cities, mental health systems, mental health courts or any other entity with authority to implement, monitor and oversee AOT programs.

What can you do?

- If your community is thinking about establishing AOT, push them to apply! Contact us for more details on the application process and deadlines.
- Support additional years of funding with your member of Congress. The Obama administration has already come out in support of funding the program in 2017, but Congress needs to hear from you!
- Monitor the Treatment Advocacy Center website for the latest on program developments.

Around the States

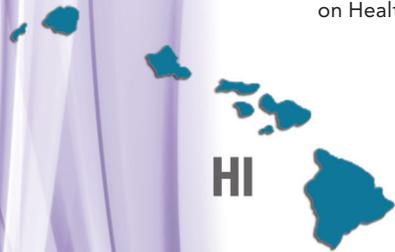


AK

CALIFORNIA

More than half of citizens of California now live in counties that have adopted Laura's Law, the state's assisted outpatient treatment (AOT) statute. Pilot programs are moving forward in Ventura, Alameda and San Luis Obispo counties, and numerous other counties are also considering adoption of the law.

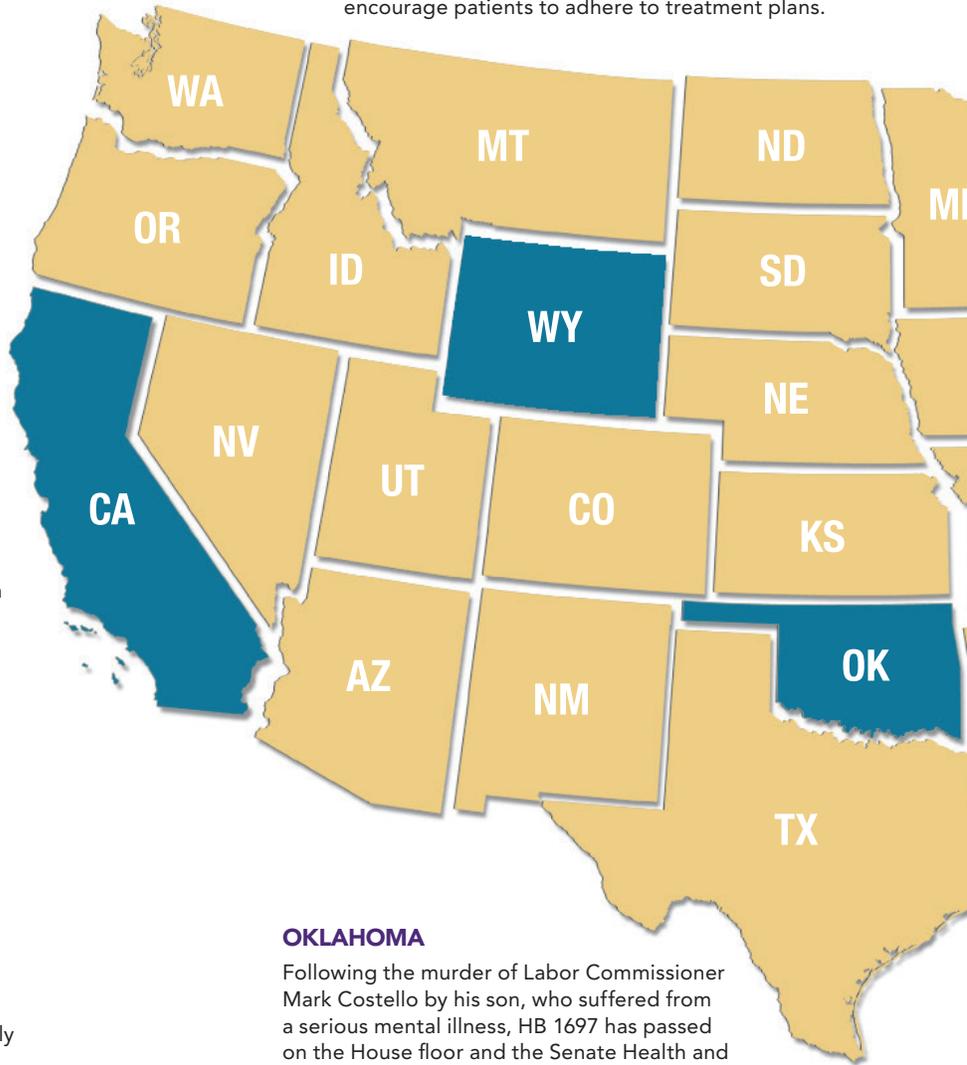
A bill (AB 59) extending Laura's Law through 2022 has passed on the Assembly floor and was sent to the Senate, where it is being considered by the Committee on Health.



HI

HAWAII

In 2020, Hawaii is set to adopt "gravely disabled" and "obviously ill" civil commitment standards.



WYOMING

The Wyoming Senate Health Committee will introduce a bill to address the state's high levels of emergency psychiatric holds through alternative treatment interventions, including encouraging broader use of AOT. The bill will address challenges to AOT implementation, including better commitment standards and mechanisms that encourage patients to adhere to treatment plans.

OKLAHOMA

Following the murder of Labor Commissioner Mark Costello by his son, who suffered from a serious mental illness, HB 1697 has passed on the House floor and the Senate Health and Human Services Committee. The legislation would significantly improve Oklahoma's AOT statute by allowing for earlier intervention and by clarifying criteria for eligibility for outpatient treatment within the community.

In order to provide up-to-date information at all times, we have moved Memorials and Tributes to our website. Visit treatmentadvocacycenter.org/honors to view all Memorials and Tributes gifts made this year.

PENNSYLVANIA

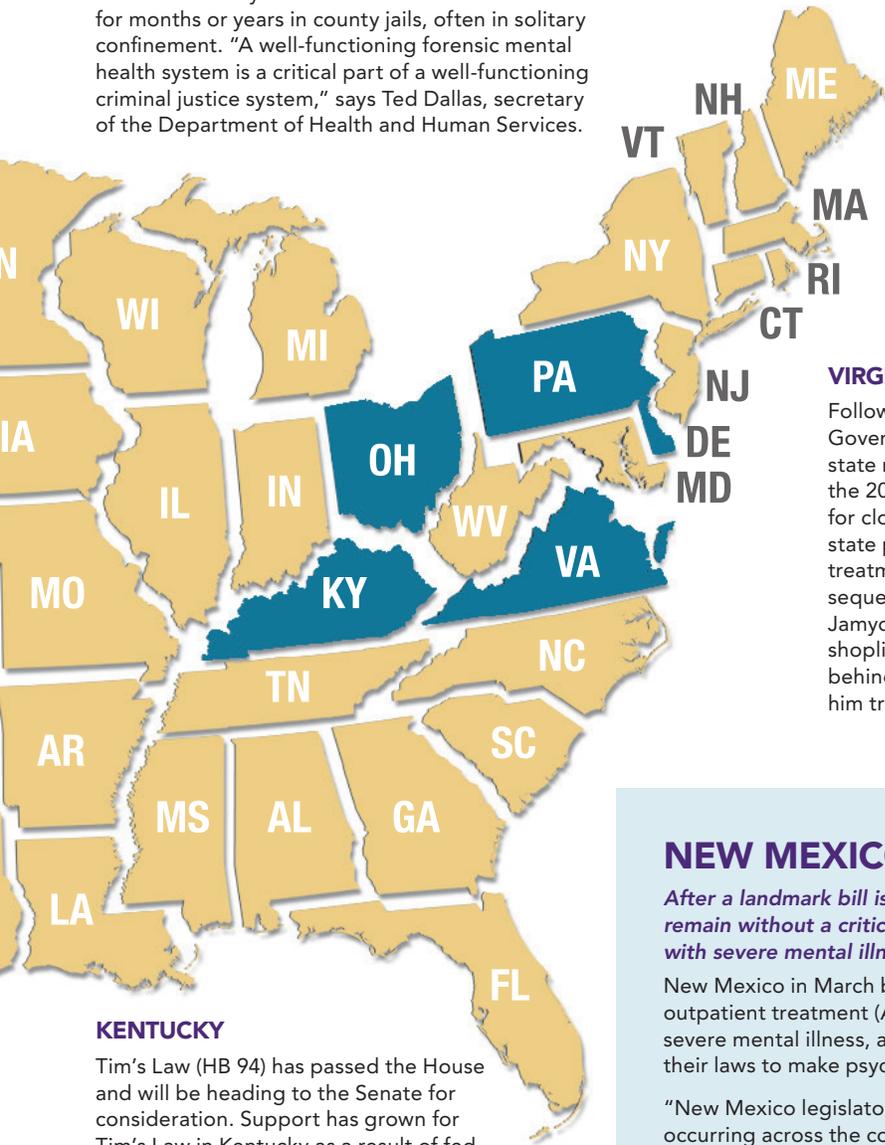
The success of the ACLU in bringing suit against the Pennsylvania Department of Human Services and two state hospitals brings renewed hope to efforts to reform the Commonwealth's outdated commitment criteria. The ACLU's suit focused on the treatment of mentally ill inmates who had been detained for months or years in county jails, often in solitary confinement. "A well-functioning forensic mental health system is a critical part of a well-functioning criminal justice system," says Ted Dallas, secretary of the Department of Health and Human Services.

OHIO

This spring, more than 20 counties will send teams made up of judges, board directors, law enforcement, providers and advocates to the "Developing an Effective Court-Ordered Outpatient Treatment Program in Your County" symposium in Columbus. The symposium will serve as an opportunity for teams across the state to come together to learn and share best practices for implementing AOT programs in their communities.

VIRGINIA

Following widespread protest over a proposal in Governor Terry McAuliffe's budget to close two state mental hospitals, Virginia will instead retain the 200 psychiatric treatment beds that were slated for closure. Virginia has a shameful history of closing state psychiatric hospitals, leaving a gaping hole in treatment services and leading to devastating consequences. Most notably, in April 2015, 24-year-old Jamycheal Mitchell, a mentally ill man arrested for shoplifting snacks from a 7-Eleven, died while behind bars, even as a judge repeatedly ordered him transferred to a nearby psychiatric hospital.



KENTUCKY

Tim's Law (HB 94) has passed the House and will be heading to the Senate for consideration. Support has grown for Tim's Law in Kentucky as a result of federal funding appropriated by Congress to implement new AOT programs. The law is named for Tim Morton, who was hospitalized for psychiatric treatment dozens of times over 36 years. Upon release, he would inevitably stop taking his prescribed medication and spiral downward until he became dangerous enough to require hospitalization again. The bill would broaden the state's outpatient criteria so that people like Tim can receive help before they hit rock bottom and require inpatient hospitalization.

NEW MEXICO LEAVES FOUR

After a landmark bill is signed in New Mexico, only four states remain without a critical outpatient treatment law for people with severe mental illness.

New Mexico in March became the latest state to authorize assisted outpatient treatment (AOT) for qualifying individuals with untreated severe mental illness, adding to the growing list of states reforming their laws to make psychiatric treatment more accessible.

"New Mexico legislators capitalized on the wave of treatment reform occurring across the country, offering AOT as a less-restrictive alternative to inpatient psychiatric hospitalization for people who are too sick to seek treatment themselves," says John Snook, executive director.

New Mexico is the 46th state to authorize a court-ordered assisted outpatient treatment (AOT) law. It will take effect July 1, 2016.

"The benefits of assisted outpatient treatment have long been championed by the Treatment Advocacy Center, advocates for people with severe mental illness, their families, mental health professionals and experts alike," Snook continues. "With New Mexico hitting this milestone, only Connecticut, Maryland, Massachusetts and Tennessee continue to be without this critical treatment option."

The Treatment Advocacy Center is especially grateful for the countless New Mexico families who spent years advocating and telling their stories. It is those stories and the relentless drive of advocates from across the state that made passage possible.



(ORPA), “Overlooked in the Undercounted” was cited in more than 50 national and regional media reports immediately following its publication. “The public, media and lawmakers have found the Treatment Advocacy Center to be a consistent, reliable source of evidence-based information about mental illness issues that are chronically overlooked by government agencies,” says Doris A. Fuller, chief of ORPA. “In this case, enormous public attention had been focused for more than a year on fatal police shootings and the lack of government data about them. But almost no attention was being paid to the role played by mental illness and its all-but-complete neglect as a driving factor.”

Like other research from the Treatment Advocacy Center, the study will be used to promote public policies that improve access to treatment for severe mental illness.

“Overlooked in the Undercounted: The Role of Mental Illness in Fatal Law Enforcement Encounters” was authored by Doris A. Fuller; H. Richard Lamb, M.D.; Michael Biasotti; and John Snook.

The full report is available online at TACReports.org/overlooked-undercounted.

Mental Illness in Police Shootings

People with untreated mental illness are 16 times more likely to be killed during an encounter with law enforcement than other civilians, according to the Treatment Advocacy Center’s newest original study.

Numbering fewer than 1 in 50 U.S. adults, individuals with untreated severe mental illness are involved in at least 1 in 4 – and as many as half – of all fatal police shootings, the December 2015 study found.

“Given the prevalence of mental illness in police shootings, reducing encounters between on-duty law enforcement and individuals with the most severe psychiatric diseases may represent the single most immediate, practical strategy for reduc-

ing fatal police shootings in the United States,” concludes “Overlooked in the Undercounted: The Role of Mental Illness in Fatal Law Enforcement Encounters.”

The first publication originating in our new Office of Research and Public Affairs

TREATING THE UNTREATED IS A PROVEN PRACTICE FOR REDUCING THE ROLE OF MENTAL ILLNESS IN ALL CRIMINAL JUSTICE INVOLVEMENT, INCLUDING IN DEADLY LAW ENFORCEMENT ENCOUNTERS.

Clozapine Use in Treatment-Resistant Schizophrenia

Clozapine is regarded as the “gold standard” for treating schizophrenia, a brain disease that affects an estimated 2.6 million adults in the United States. Often referred to by its trade name Clozaril, the drug is the only antipsychotic medication ever approved by the FDA for treating the 20 to 30 percent of people with schizophrenia whose symptoms are treatment-resistant. It has been found particularly effective in preventing suicide and violence.

In Germany, 20 percent of the population that could benefit from clozapine receives the medication; in China, 30 percent; and in Australia, 35 percent.

In the United States? Fewer than 5 percent nationwide, according to “Clozapine for Treating Schizophrenia: A Survey of the States,” published by the Treatment Advocacy Center in November 2015.

The report said 10 percent has been described as a “bare minimum” of clozapine usage for candidate patients. Based on an analysis of Medicaid and prescription data by Rutgers University:

- Only 6 states achieved the “bare minimum” of 10 percent use: South Dakota, Connecticut, Colorado, Washington, Vermont and Maine.

- Only 12 states used clozapine in 5 to 10 percent of the candidate population: Illinois, North Dakota, Massachusetts, New Hampshire, Wyoming, Kansas, Montana, West Virginia, Utah, Pennsylvania, Iowa and Michigan.
- In 9 states, fewer than 3 percent of the candidate population received the drug: Georgia, Kentucky, North Carolina, Mississippi, Alabama, Arizona, Louisiana, Nevada and Oregon.

Conclude the authors, “As the ‘gold standard’ antipsychotic for individuals with treatment-resistant schizophrenia, especially those individuals who are suicidal or violent, clozapine use can be regarded as a measure of a state’s effort to treat the sickest and most difficult-to-treat patients. This study has revealed a wide discrepancy.”

“Clozapine for Treating Schizophrenia” was authored by E. Fuller Torrey, M.D.; Michael B. Knable, D.O.; Cameron Quanbeck, M.D.; and John M. Davis, M.D. Funding for data analysis by Rutgers University was provided by the Stanley Medical Research Institute, a supporting organization of the Treatment Advocacy Center.

The full report is available online at TACReports.org/clozapine-for-schizophrenia.

Psychiatric Hospital Beds: A “National Disconnect”

The following is an excerpt from Research Weekly, a blog published as a public service of the Treatment Advocacy Center.

The Treatment Advocacy Center is a leader in tracking and reporting the declining population of state psychiatric hospital beds, a vanishing breed whose numbers have shrunk by at least 95 percent in the last half century.

Now a team of North Carolina researchers has created a simulation model to analyze how many non-forensic beds it would take to reduce the amount of time people in psychiatric crisis currently spend waiting for a hospital bed.

The results dramatically illuminate what the authors call a “national disconnect between increasing demand for psychiatric inpatient care and decreasing supply” and what practically might be described as the size of the cracks in the inpatient mental health system.

To develop their model, Elizabeth M. La et al. studied a 25-county region of North Carolina where 3.4 million people are served by a 398-bed state psychiatric hospital. This translates into 11.7 state hospital beds per 100,000 residents, significantly fewer than the 50 beds per 100,000 people considered the minimum number for adequate public psychiatric services.

What the Model Found

During the last six months of 2012, the authors found that an average of 520 adults in psychiatric crisis waited an average of approximately three days for admission to a hospital. (Not all patients on waiting lists were ultimately admitted.)

Running variables through the model found that dramatic increases in state hospital beds would be needed to significantly decrease wait times for psychiatric beds and improve access to inpatient treatment. Projections included:

- Adding 24 beds increased the number of admissions by 9 percent (115.2 patients) and decreased the average wait time by 6 percent (slightly less than four hours).
- Reducing average wait times to less than two days required increasing beds in the study hospital by 84 percent.
- Reducing average wait times to less than one day required increasing beds in the study hospital by 165 percent.



“However, many community facilities are not currently staffed to care for the most acutely ill psychiatric patients and those who become violent,” the authors note. “Thus, although buying community hospital beds may initially be less costly than adding state hospital beds, making community beds the sole solution would change community hospital staffing requirements, possibly increasing total costs for North Carolina.”

THE AUTHORS FOUND THAT AN AVERAGE OF 520 ADULTS IN PSYCHIATRIC CRISIS WAITED AN AVERAGE OF APPROXIMATELY THREE DAYS FOR ADMISSION TO A HOSPITAL.

In economics, equilibrium is what occurs when supply and demand for products or services are equal. Consumers are getting the goods or services they want; sellers are selling the goods or services they produce. Demand is met, and supply is consumed.

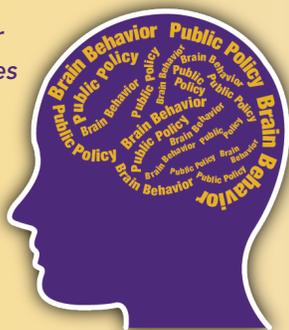
Equilibrium in psychiatric hospital beds was lost long ago. Elizabeth M. La et al. have developed a tool for mapping the disequilibrium. As grim as the map is, the authors have also demonstrated that it is possible to analyze demand and project the supplies needed to meet it.

REFERENCES

- Torrey, E. F., et al. (2012). “No Room at the Inn: Trends and Consequences of Closing Public Psychiatric Hospitals.” Treatment Advocacy Center.
- La, E. M., et al. (December 1, 2015). “Increasing Access to State Psychiatric Hospital Beds: Exploring Supply-Side Solutions.” *Psychiatric Services*.

Research Weekly, a weekly digest of brain, behavior and public policy research from journals, conferences and other expert sources not readily accessible to the public, is the newest public service from the Treatment Advocacy Center.

If you are interested in reading about research from peer-reviewed journals in everyday language, sign up to receive Research Weekly at treatmentadvocacycenter.org/sign-up.





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Stanley Medical Research Institute Update *E. Fuller Torrey, M.D.*

THE ANATOMICAL BASIS OF ANOSOGNOSIA

One of the most important, but difficult to understand, aspects of serious mental illness is the fact that approximately half of all people afflicted with schizophrenia and bipolar disorder do not realize that they are sick – a condition called anosognosia. They really believe that they are being followed by the CIA, or that God is speaking to them through the voices they hear. They believe there is nothing wrong with them; therefore, they see no reason to take medication.

This lack of awareness of illness is seen in most cases of advanced Alzheimer's disease and Huntington's disease. Neurologists have known about it for more than 100 years, but psychiatrists just became aware of it about 25 years ago. The question has been, why do some people with schizophrenia and bipolar disorder have anosognosia, while other people with schizophrenia and bipolar disorder are fully aware of their illness?

The answer to this question is now very clear: the brains of people who have and do not have anosognosia are different, and there are now more than 30 studies supporting this conclusion. The Stanley Medical Research Institute (SMRI) has been very interested in this research because it has such important implications

for medication adherence – for this reason, SMRI supported one of the early studies.

The most recent studies are using sophisticated techniques, and the results have become increasingly interesting. Two of them are from Toronto and Moscow. A research group at the University of Toronto in 2014 published a study using the newer functional MRI technique and reported that people with schizophrenia who have anosognosia show evidence of connectivity problems between specific brain areas. Another exciting study was carried out by researchers in Moscow using postmortem brains from the SMRI brain collection. The researchers found fewer glial cells – part of the white matter connectivity system of the brain – in people with anosognosia.

In summary, new techniques for studying the brain are yielding new and exciting findings for understanding the anatomical basis of anosognosia. Many of these studies are summarized on the Treatment Advocacy Center website.

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

Dr. Torrey serves as associate director of SMRI, where he oversees groundbreaking research on the causes and treatment of schizophrenia and bipolar disorder.