

PUBLIC LIBRARIES:

Unintended Shelters

The Treatment Advocacy Center released a new survey in the March/April 2009 edition of *Public Libraries*, the journal of the Public Library Association. The survey results, based on responses from 124 librarians geographically representative of the U.S., included a finding that 9 out of 10 said that patrons with mental illness have disturbed or affected the use of the library by other people, with an almost equal number (85 percent) saying they have had to call the police as a result.

“Our nation’s libraries are turning into daytime shelters for people with severe mental illness who need to be in treatment,” said lead study author E. Fuller Torrey, M.D. “The fact that libraries remain safe havens from violence and life on the streets for people with mental illness is a sad commentary.”

The problems facing libraries are part of the larger issue of the lack of available treatment for people with severe mental illnesses, especially for

those who are discharged from mental hospitals without any follow up care. The result is an increase of people with mental illnesses who are homeless and turn to libraries and other public facilities because they just need somewhere to go.

Other findings include:

- 28 percent say they have witnessed someone with a psychiatric disorder assault a staff member;
- 58 percent report more library patrons who appear to have serious psychiatric disorders now than when they first started working in the library;
- 61 percent say library patrons with psychiatric disorders utilize a disproportionate amount of staff time; and,
- 66 percent say they have needed to change library rules because of patrons with mental illness.

The librarians surveyed reported very serious acts of violence including, “two librarians murdered by a mentally-ill patron in the early 90s’.” Others reported being punched, having chairs thrown, and stalking.



"Our nation's libraries are turning into daytime shelters for people with severe mental illness who need to be in treatment," said lead study author E. Fuller Torrey, M.D.

The librarians were frank in detailing the impact of untreated mental illness upon their facilities. Among the comments compiled:

“Many, many library customers don’t come downtown to our central library because they’re afraid of these customers... . They perceived the library to be a dangerous place and another homeless shelter and it has really lessened our stature in the community and is disheartening to our staff.”

“The libraries did not ask to become day programs for people with mental illness,” Torrey said, “but they are trying hard to accommodate these patrons. This should not be the job of libraries; it should be the job of mental health centers.”

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Keeping in Touch

Thanksgiving is a time for reflection and for appreciation of the bounty in this great country of ours. You plan to gather with family and friends. If you cannot gather in person you keep in touch with loved ones by phone or email.

Then there are those of our family, friends and fellow citizens for whom losing touch or being out of touch has a much deeper, even tragic meaning. For some it is episodic, coming and going, depending on the as-yet not fully known workings of the brain. Treatment helps many — at least those who can get it.

There are many barriers to keeping in touch for those with severe mental illness. Some are out of touch owing to incarceration or homelessness. Of course, in these severe

instances the term has a double sense: (1) physically separated from family and friends and/or (2) cognitively separated from reality by virtue of the condition *anosognosia*, or lack of awareness that they are even ill.

These are the people that we at the Treatment Advocacy Center are most concerned with: those who are haunted by delusions or hallucinations; those whose struggles have strained or broken relationships with family and friends; and those who are lost to suicide. The types of barriers to treatment that we focus on are principally legal in nature: rigid, outmoded state laws. But we also contend with the barriers of short-sighted thinking and fear of innovation.

Together, you and we (by which I mean our tireless staff and marvelous board) will make continued inroads. By next Thanksgiving, we will give thanks for adding more states to the 25 that have need-for-treatment standards or to the 43 that now have assisted outpatient treatment laws, and for better implementation of those laws where they do exist.

Do Keep in Touch,

Jim Pavle, Executive Director

ADVOCATE'S CORNER

Torrey Award Honors Those Who Turned "Tragedy into Treatment" for Mental Illness

The Treatment Advocacy Center announced the Webdale family of New York, Nick and Amanda Wilcox from California, Joe Bruce from Maine, and the National Sheriffs' Association as the winners of its annual Torrey Advocacy Commendation. This year's award recognizes heroic efforts that turned tragedy into treatment for people with severe mental illness.

"The heroes we recognize have done much to change the way society treats and views mental illness," said Stephen Segal, Treatment Advocacy Center Board President. "This award is just one way to recognize what they have overcome to bring care to those most in need."

Kendra Webdale was a creative 32-year old full of promise when she was pushed off a New York City subway platform and into an oncoming

train by a man with untreated mental illness in January 1999. Her death led to the passage of Kendra's Law, one of the first fully-implemented assisted outpatient treatment laws in the nation. Without the passionate and courageous support of the Webdale family, Kendra's Law would not exist. Now more New Yorkers with severe mental illness are getting the treatment they need.

During her college Christmas break in 2001, Laura Wilcox was volunteering in a California county mental health clinic when an untreated client shot her. Nick and Amanda Wilcox have never forgotten that their daughter was at the clinic that day to help people with severe mental illness. Not only did the Wilcoxes see Laura's Law to passage in California, they continue advocating for the law's full imple-

mentation so that assisted outpatient treatment is available throughout the state.

In March 2006, Amy Bruce of Maine lost her life at the hands of the son that she and her husband, Joe, repeatedly tried to get into sustained treatment. Joe Bruce and his son William allowed their story to be told in a *Wall Street Journal* story in August 2008, raising awareness that family members are a critical voice in getting treatment for loved ones with severe mental illness. Maine made revisions to the state's treatment law and, with Bruce's support, is currently considering an assisted outpatient treatment law like Kendra's Law and Laura's Law.

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Catalyst

Catalyst is a publication of the Treatment Advocacy Center to update friends and supporters about our programs, activities and other news and developments affecting the treatment of severe mental illness.

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Profiles

IN TREATMENT ADVOCACY

Frederick J. Frese III, PhD is a member of the Treatment Advocacy Center's Board of Directors and is Associate Professor of Psychology in Psychiatry at Northeast Ohio College of Medicine.

Q. Fred, you were diagnosed with paranoid schizophrenia in the 1960s when you were a Marine Corps officer, and you had been a patient in 10 different hospitals over a 10-year time period. You are also a psychologist with decades of experience working with persons with severe mental illness, an educator, and a vocal advocate in the mental health movement. How does your own personal struggle with mental illness impact your professional work?

A. The experience of having been hospitalized, mostly involuntarily, between the ages of 25 and 35, provides me with first hand knowledge of what it is like to be on the receiving side of the mental health services system. I have vivid memories of events leading to my being subjected to court procedures that resulted with my being declared to be an insane person under the law and being remanded indefinitely to the state mental hospital system. Secondly, even though I am "in recovery" I am not fully recovered. My mind still has a tendency to function in a manner that reminds me that I am not entirely like the "chronically normal" folks. Finally, as an educator and an advocate, it is helpful to have had personal experience with these conditions. Most people know very little about what it is like to have a mind that is subject to psychosis.

Q. What are the most notable changes you've seen over your 40-year career?

A. First is the recognition that serious mental illnesses have, at least in part, a biological basis. Forty years ago, virtually everyone in the mental health professions believed serious mental illnesses were caused by childhood experiences. Second, consumer and family advocacy virtually were non-existent. NAMI, founded in 1979, has become very influential. NARSAD, founded a little later, has also become important as have many smaller consumer advocate groups. Third is the realization that recovery from serious mental illnesses is a possibility and increasingly recovery, to some degree, is being expected for persons with these conditions.



Frederick J. Frese III

Q. You live in a county that actively uses assisted outpatient treatment (AOT) to engage people in community services. Why do you think AOT can be helpful for people with severe mental illnesses?

A. When you are experiencing psychosis your mind plays tricks on you. Very often, a person in psychosis does not realize that they are sick. I have had many patients who said they did not want to be given treatment, particularly psychotropic medications. But, after they received the medicines, they expressed considerable appreciation that they were helped when they did not have an understanding of the state they were in. I certainly have been in that state myself several times in the past. I realize that this is not always the case, but it happens quite frequently.

Q. You have written articles on recovery. Do you think the notions of recovery and assisted treatment are inconsistent?

A. Absolutely not. I feel that for many persons with serious mental illness the opposite is the case. For many persons, the only way they will be able to recover is with the assistance of treatment. I often say that I am totally against any kind of forced treatment for persons who do not need it, but unfortunately many persons with serious mental illnesses are not capable of understanding that they need the treatment, so force becomes necessary if there is going to be recovery.

Q. What influence does your family — your wife and your four children — have on your work as a provider and advocate?

A. My family is a very major influence, and in many ways a guide to how I conduct my life's activities. I often point out that I have not been hospitalized since meeting and marrying my wife, Penny, when I was 36 years old. This does not mean that I have not had breakdowns, where I would have to take off from work, sometimes for several weeks. Penny has been very supportive of my mental health activities. She frequently gives presentations on living with mental illness in the family. When the children were young, they also gave presentations, appeared in the media, and were very supportive of their father during those times when I would experience relapses.

Thank you, Fred. Your dedication to the work of the Treatment Advocacy Center is greatly appreciated.

AROUND THE States

New York

The results of an independent evaluation of Kendra's Law are in and they continue to affirm the value of court-ordered "assisted outpatient treatment" (AOT).

In 1999, New York enacted landmark legislation to provide care and monitoring of persons with severe mental illness who have demonstrated difficulty complying with prescribed treatment. Dubbed Kendra's Law in memory of a woman pushed randomly to her death in a Manhattan subway station by a man whose untreated schizophrenia was well known to the mental health care system, the legislation was designed to bind such patients and the system to one another. It authorizes a judge, after finding a patient in need of AOT to function safely in the community, to simultaneously order county officials to ensure availability of the medication, services and case management recommended by doctors, and the patient to accept the same.

Kendra's Law was passed on a five-year trial basis over the objections of many "patient advocates" who deemed its approach punitive and draconian. They predicted that fear of "coercion" would drive people with severe mental illness further underground, and that the money spent on monitoring AOT patients would drain resources from the rest of the mental health system. When the original law

expired in 2005, these advocates were unmoved by early data collected over the first five years of the program, a survey of patients in the program, and by the anecdotal reports that patients had in fact found *greater* freedom by averting psychosis and hospitalization, and lobbied against making Kendra's Law permanent. In deference, the Legislature chose to extend the trial until 2010, and directed the state Office of Mental Health to contract for an independent study to evaluate the program's effectiveness and repercussions.

Another five years later, that evaluation has been released, and it leaves Kendra's Law critics with a stark choice: embrace the law (as many, to their credit, have), or find some new objections fast. A research team led by Duke Medical School faculty spent years analyzing data and interviewing hundreds of patients and providers. In the process, they found striking evidence to confirm the utility of AOT and debunk every familiar dire prediction. Among the researchers' key findings:

- AOT leads to a substantial reduction in a patient's number of psychiatric hospitalizations, the length of hospitalizations that occur, and the likelihood of being arrested. AOT patients were found to be far more likely to consistently receive effective medication, and case managers reported improvements in many areas of personal functioning.
- The claim of some that AOT only works because of the quality services attached is contravened by the evidence. After comparing results for AOT patients with those receiving identical services without court orders, the team concluded that "the AOT court order, itself, and its monitoring do appear to offer *additional benefits* in improving outcomes;"
- AOT patients feel no more "coerced" into treatment than do their non-AOT

counterparts, and after 12 months or more, AOT markedly *increases* patients' sense of active engagement in their treatment.

- Aside from an initial ramp-up period in which service expansions sometimes failed to keep pace with new demand, there has been no adverse impact on availability of services for non-AOT outpatients. On the contrary, thanks to added capacity driven by Kendra's Law, intensive community-based services increased since 2003 for individuals on AOT and those not on AOT alike.

At a time when many have lost faith in their lawmakers, Kendra's Law reminds us what is still possible. As noted in the independent evaluation, "New York's AOT program ... features more comprehensive implementation, infrastructure and oversight of the AOT process than any other comparable program in the United States." But one final imperative looms. Before Kendra's Law reaches its June 2010 expiration, the Legislature must make it a permanent fixture in New York's mental health care system. Though postponing the expiration date yet again might be the easier choice politically, the time has come to replace any question marks with an exclamation point. Kendra's Law works!

New Jersey

New Jersey became the 43rd state to adopt Assisted Outpatient Treatment (AOT) on August 11, 2009, when Governor Corzine signed Senate Bill 735 into law. Senator Richard Codey and countless advocates battled for years to give the state a better way to help those who refuse treatment because of incapacitating symptoms of illnesses like schizophrenia and bipolar disorder. "Our goal is to minimize time in the hospital and keep patients in the least restrictive environment that will help foster their recovery," said Senator Codey.

"The AOT court order, itself, and its monitoring do appear to offer *additional benefits* in improving outcomes."

“This measure provides another mechanism to treat that small group of people who are extremely ill and unable to seek treatment voluntarily,” said James Pavle, executive director of the Treatment Advocacy Center. AOT is a less restrictive, less expensive treatment alternative for people who need intervention but do not require inpatient hospitalization.

“You are giving hope to patients, their families and caregivers and to all New Jerseyans for a better way of life and a safer New Jersey,” said Cathy Katsnelson. The Katsnelsons have been advocating for years to improve the mental health laws after their son Gregory was killed by a man whose family had tried, unsuccessfully, to get him into treatment for schizophrenia. “[M]y family and I began this endeavor as victims feeling helpless to change what has happened to us, but after six years of working on this legislation, taking part in and playing an integral role in bringing about a positive change, we are survivors now.”

The law will be phased in over three years, with one-third of the state’s counties implementing assisted outpatient treatment each year. New Jersey counties must put this powerful tool to good use, to improve the lives

“Our goal is to minimize time in the hospital and keep patients in the least restrictive environment that will help foster their recovery,” said Senator Codey.

of individuals suffering from severe mental illness, and to prevent further tragedies caused by untreated severe mental illnesses.

Ohio

Treatment Advocacy Center staff visited Akron, Ohio last year to learn more about how Summit County has led the state with its effective use of assisted outpatient treatment (called “outpatient commitment”) since 1991. A study found that for individuals under court order, hospital admissions decreased from 1.5 per year before assisted outpatient treatment to 0.45 per year after assisted outpatient treatment was initiated. The orders increased compliance with outpatient psychiatric appointments from 5.7 to 13.0 per year, and increased atten-

dance at day treatment sessions from 23 to 60 per year. Approximately 80 patients on any given day receive assisted outpatient treatment.

Texas

Bexar County, Texas is setting an example for other counties in the state on how to implement existing law and use resources more effectively. The county started Involuntary Outpatient Commitment (IOPC) services in August 2003 to provide intensive case management and court advocacy to patients who have frequent emergency hospitalizations due to noncompliance with treatment. The IOPC program works closely with the civil court system to provide intensive case management services and monitor treatment adherence. Over a five year span, a total of 104 patients were in IOPC. Leon Evans, President & CEO of the Center For Health Care Services, estimates that the reduction in hospital days alone due to IOPC (not to mention fewer incarcerations, arrests, etc.) accounted for at least a \$2 million cost savings.

Montana

In March 2009, reformers in Montana gave compelling testimony to the House Appropriations Committee in support of HB 612, a bill designed to improve the state’s civil commitment law so that effective intervention can occur before a person reaches the point of “dangerousness.” Advocate Mitzi Anderson testified that the proposal was fiscally responsible: “HB 612 is concerned with people already in the system, so the cost should be minimal. In fact, it should save money by reducing pre-commitment costs, transportation costs and hospitalization. It is good medicine, good social policy and effective use of resources.”



Cathy Katsnelson, Assemblywoman Sheila Oliver and Senator Richard Codey look on as New Jersey Governor Corzine signs Senate Bill 735 into law.

Memorials & Tributes

(December 1, 2008 – October 15, 2009)

The Treatment Advocacy Center expresses our deepest appreciation to all who have supported our mission with a donation in memory of a loved one or a friend.

We are also grateful to those who choose not to make their donation public. Thank you.

Carol Ager, Cardiff, CA	In honor of my daughter	Phyllis Garvey, Indianapolis, IN	In memory of Kevin Garvey
Mary D. Alexander, Millis, MA	In memory of Ralph Roberts	Jeffrey Geller & Merle Brandzel, Holden, MA	In honor of the work of Rosanna Esposito
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John & Maude Boerger	In honor of Susan Boerger	David & Mary Kay Hershberger, Greenwood, IN	In honor of our son, Mark
Bonita Bowman, Arlington, TX	In memory of Esther Miller Bowman	John and Jacquelyn Herum, Ellensburg, WA	In memory of Beth Skahill
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Constance Cereola, Greenlawn, NY	In memory of my father, John Barracco	David & Jean Kelly, E. Providence, RI	In honor of all persons with mental illness
Constance Cereola, Greenlawn, NY	In honor of Dr. & Mrs. Doug Richards	Adrienne Kennedy, Austin, TX	In memory of Ann Patrice Kennedy
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Katherine Garner, San Luis Obispo, CA	In honor of Treatment Advocacy Center	Robert & Mary Ellen Molinaro, Waterloo, IA	In memory of our son, Henry Irwin Molinaro, a true hero
	In memory of Jay Garner	Frances Moon, Plant City, FL	In honor of Ted Urbanski
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		Mary Morrow-Bax, Alexandria, VA	In honor of Dan Morrow
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In memory of Marie Zeigler
In respect for Dr. Fuller Torrey &
in memory of Hanna Schusheim
In honor of Stephen Segal's birthday
In memory of Mark Seifter
In honor of David Shoup
In memory of George Hacker
In honor of Dr. Susan Thornsley
In memory of Judith Gourniak
In honor of A.J. Supino
In honor of Daniel Moschelli
In memory of Chaplain Lee
In honor of Tim Pedon
In honor of Eric Livingston
In memory of Kendra Webdale —
10 year anniversary
In memory of Alex Wier
In memory of Laura L. Wilcox
In honor of Ted Wilkinson
In memory of Sara Michelle Bladen
In honor of James Pavle's association
with Treatment Advocacy Center
In honor of Dana York
In honor of Rosanna Esposito
& Sharron Day Johnson

Stanley Medical Research Institute Update

By E. Fuller Torrey, M.D.

A major research initiative of the Stanley Medical Research Institute (SMRI) is investigating infectious agents as a possible cause of schizophrenia and bipolar disorder. An infectious agent of great interest is *Toxoplasma gondii* (*T. gondii*), a protozoan parasite that is carried by cats but that also infects many other animals, including humans. Previous SMRI research has established in many studies that individuals with schizophrenia have more antibodies to *T. gondii* than controls.

Recent research has added a new and interesting twist to this research. It has been known for many years that individuals with schizophrenia appear to have an excess of dopamine. Most antipsychotics, in fact, are thought to be effective because they block dopamine. However, despite numerous studies, nobody has been able to figure out where the excess dopamine comes from.

Recently, two SMRI-funded studies independently reported that the parasite *T. gondii* has genes that allow it to synthesize dopamine. Thus, it is possible that the excess dopamine in individuals with schizophrenia is being introduced from the outside by the parasite rather than being made by the person. This would be a radically different way to look at the disease. One research group reporting this is Dr. Glenn McConkey et al. at the University of Leeds in England; their report was published in the online journal *PLoS ONE* in March. The other research group is under Robert Sapolsky, Professor of Biological Sciences and Neurology at Stanford University. Dr. Sapolsky reported his findings at a February talk at NIMH.

The finding has obvious implications for new treatment approaches, and SMRI has underway some treatment trials using drugs that block *T. gondii*. A more detailed account of SMRI's research on *T. gondii* can be found on the SMRI website, www.stanleyresearch.org (click on Laboratory of Developmental Neurovirology, then on Toxoplasmosis-Schizophrenia Research).

Dr. Torrey continues to serve as Executive Director of SMRI where he oversees groundbreaking research on the causes of, and treatment for, schizophrenia and bipolar disorder.



Treatment Advocacy Center
200 N. Glebe Road, Suite 730
Arlington, VA 22203
www.TreatmentAdvocacyCenter.org

Torrey Action Fund CONTRIBUTORS

(December 1, 2008 – June 30, 2009)

We are very grateful for your generous donations to the Torrey Action Fund. These gifts greatly honor our founder, Dr. E. Fuller Torrey, and allow the Treatment Advocacy Center to continue his vision. We will recognize donations received after June 30, 2009 for the Torrey Action Fund in our Spring Catalyst.

Mary D. Alexander, Millis, MA
Judge James Cayce, Black Diamond, WA
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Mildred Fine, Lynbrook, NY
Gordan & Lucy Gay, Shenandoah Junction, WV
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Torrey Awards

CONTINUED FROM PAGE 2

The National Sheriffs' Association is the first organization to win the Torrey Advocacy Commendation. The group was one of the first national organizations to courageously support assisted outpatient treatment laws. The NSA also issued training materials to its members on how to safely and responsibly respond to and help people with mental illness in the community.

The Torrey Advocacy Commendation, named in honor of Dr. E. Fuller Torrey, is presented annually by the Treatment Advocacy Center's Board of Directors. Award recipients make a substantial difference in their community through advocacy, awareness, research, or legislation in this field.