



Catalyst

A Newsletter from the Treatment Advocacy Center

SPRING-SUMMER 2011

A PSYCHIATRIC CRISIS RESOURCE KIT: Help and Hope for Family Caregivers and Advocates

Your loved one is in a psychiatric crisis. Maybe he has stopped eating, bathing or dressing. Maybe he is responding to internal “voices” that are telling him to engage in deplorable acts. Perhaps you’ve begun to worry that he will hurt himself or someone else – or you. You’re afraid of what will happen if you leave the house ... or if you stay. If you do something ... or if you do nothing. You don’t know where to turn for help because nobody around you has been through anything like this.

The Treatment Advocacy Center’s mission is to eliminate legal and other barriers to treatment laws and public policies that encourage early intervention and sustained treatment. In pursuing this mission, we see and hear almost daily how

frightening, exhausting and frustrating it is for family members, friends and others to intervene effectively when a loved one is in psychiatric crisis. What rights do you have as a parent, spouse or friend? What rights does your loved one have? How do you get treatment if she resists help or, for that matter, doesn’t even seem to know she’s ill? How does someone get “committed” to a state hospital? Does your state have a law that could require your loved one to get treatment right away, before she gets even sicker or maybe even dangerous? Most importantly, who can you call for help *right now*?

To better equip families and advocates in circumstances like these, the Treatment Advocacy Center published a special “Family Advocate” issue of *Catalyst* in 2005. In the years since, the demands on families and friends of those with mental illness have only grown. State mental health budgets have plunged, fewer people with severe mental illness are receiving adequate treatment services, and more family members and friends are being called upon to fill the gaps.

With these needs in mind, the Treatment Advocacy Center presents this updated “Family Advocate” issue of *Catalyst*. With it, we also introduce our Psychiatric Crisis Resource Kit, a collection of tools and information for responding to – and helping others

respond to – psychiatric crisis. We are making the Kit available in three ways:

- In person to those attending our “CALM Approach to Advocacy” workshop at the 2011 NAMI Convention in Chicago
- Online in our Get Help section at TreatmentAdvocacyCenter.org
- On our new menued CD-ROM available at no cost (while supplies last)

The centerpiece of the Psychiatric Crisis Resource Kit is a user-friendly template that makes it easy for advocates and mental health professionals to develop a localized emergency resource guide. With the

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professionally designed template and access to a computer and printer, anyone can quickly and economically publish the most crucial information that family members and other caregivers in any community need in order to intervene when faced with a psychiatric crisis. The brochure layout

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SEVERE MENTAL ILLNESS: It's a Family Affair

Welcome to our updated and expanded family issue of *Catalyst*. The Treatment Advocacy Center has from its inception maintained a close connection to families of people with severe mental illness. The sister of our founder, Dr. E. Fuller Torrey, suffered from schizophrenia. Innumerable family members who have lost loved ones to mental illness have become active supporters. Parents and other family members struggling daily to take care of loved ones have been critical to our effectiveness in fighting for better laws and better implementation of those laws already on the books.

With this 2011 edition of our "Family Advocate" issue, we introduce still another resource for overwhelmed families and advocates – the Psychiatric Crisis Resource Kit, featured in our cover story. A project of the Torrey Action Fund, this collection of tools includes a new template that makes it easy for groups and individuals to create local resource guides for families dealing with psychiatric crisis.

Because we know that civil commitment may be necessary as a last resort in an acute crisis, the kit includes our fully updated and expanded "State Standards for Assisted Treatment," a guide to civil commitment criteria for each state and the District of Columbia. Our "State Standards" has long been a unique resource. Now we have expanded it to include standards for psychiatric evaluation (sometimes called "emergency hold") and state-specific details on who can petition the court for civil commitment.

We are emphatic about helping families get their loved ones into treatment because we know treatment works. In this issue's "Profile in Treatment Advocacy," Policy Director Brian Stettin tells how his involvement as a young attorney in the conception and drafting of New York's assisted outpatient treatment (AOT) law – "Kendra's Law" – changed his life and his career. Brian doesn't mention the impact of his achievement, but I will: Kendra's Law's dramatic success in reducing arrest, incarceration, homelessness, violence, victimization and other consequences of untreated severe mental illness has been widely studied and well-documented.

One of Brian's projects since joining us has been persuading counties in Texas to make full use of that state's existing AOT law. Exhibit A has been the remarkable results achieved through AOT in San Antonio. One of this issue's "Voices in Treatment" vividly embodies that achievement (please see p. 10).

The case of San Antonio brings me to a crucial point. Our middle name is "advocacy," and our advocacy takes many forms. We promote the passage and implementation of more progressive civil commitment laws. We educate the media and the public about barriers to treatment, the consequences of non-treatment, and the social and economic value of timely intervention through assisted outpatient treatment. We provide tools to equip family members to advocate for loved ones in crisis, as we have with our Psych Crisis Kit and this issue of *Catalyst*. As we carry on all these vital endeavors, we welcome and thank you for being part of our family.

Keep in touch,

Jim Pavle, Executive Director

TELL US ABOUT YOUR HERO

Nominations are now being accepted for the 2011 Torrey Advocacy Commendation Award, which rewards the courage and tenacity of those who selflessly advocate to eliminate barriers to treatment for severe mental illness. Entries must be postmarked no later than September 1, 2011, and sent by mail, email or fax to the Treatment Advocacy Center, ATTN: TAC Award Nominee. Contact information is located in the box to the right.

The Torrey Advocacy Commendation is awarded at the sole discretion of the Treatment Advocacy Center board of directors.

Previous Winners

- 2010: Randall Hagar, Barbara and Michael Biasotti
- 2009: The Webdale Family, Nick and Laura Wilcox, Joe Bruce, National Sheriffs' Assn.
- 2007: Jeanette Costello, Janice DeLoof, Karen Gherardini
- 2006: Dr. Jeffrey Geller, Dr. Richard Lamb, Dr. Darold Treffert
- 2005: Sheriff Donald Eslinger, Linda Gregory, Alice Petree
- 2004: Charles "Chuck" Sosebee
- 2002: Dr. Morton Birnbaum

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.

Treatment Advocacy Center is a private, nonprofit, 501(c)(3) organization and does not accept funding from companies or entities involved in the sale, marketing or distribution of pharmaceutical products.

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Crisis Kit

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incorporates helpful language and headings along with space to insert local information about ... your state's standards for inpatient civil commitment ... the availability (or not) of civil commitment to outpatient treatment ("assisted outpatient treatment"/AOT) ... information about the local process for obtaining a psychiatric emergency evaluation... contact names and numbers for local mental health agencies, courts and others often involved in addressing a psychiatric crisis ... and more.

In addition to the template, the Kit provides these practical tools:

- "State Standards for Assisted Treatment: Civil Commitment Criteria for Inpatient or Outpatient Psychiatric Treatment" (2011) – a central and comprehensive guide to state standards governing civil commitment in all 50 states and the District of Columbia; newly expanded to include information about who can petition for court-ordered intervention and criteria for an emergency psychiatric evaluation
- Step-by-step guidelines for caregivers to use in collecting and storing the information that emergency responders, hospital personnel and other medical providers need in order to act quickly and appropriately in a psychiatric crisis
- Printable/downloadable single-page handouts containing suggestions for handling specific emergency situations, e.g., when a loved one is in danger, assaultive or suicidal

Coming to Chicago for NAMI 2011?

Don't miss our CALM Approach to Advocacy

Family members: How do you get the concrete, state-specific help you need to get through a mental health crisis with a loved one?

Advocates: How can you get involved in the legislative process and make your state laws work for you and others who need them?

Communicators: What is the best way to use old and new media to get your message heard quickly, easily and economically?

This year's Treatment Advocacy Center workshop is entitled "The CALM approach to Advocacy: Get through the Crisis, Advocate for Legislative Change, Make Media work for you." In it, our panel will —

- Share our new Psychiatric Crisis Resource Kit.
- Present techniques for using both traditional and new media to influence, educate and transform the mental health conversation.
- Show how to go from "our law that needs to be changed" to "our law gets it right."

Get through a mental health crisis armed with information. Make a difference and educate others. Influence legislators and get life-saving laws passed. The panel will feature Policy Director Brian Stettin, Legislative and Policy Counsels Kristina Ragosta and Aileen Kroll, and Communications Director Doris Fuller.

The presentation will take place Friday, July 8 from 3:30-4:45 p.m.

- "Eliminating Barriers: Tips for Advocates on Busting Through" – a two-page tip sheet on overcoming specific obstacles to getting treatment from a slow-moving or unresponsive health-care bureaucracy; includes an overview of HIPAA
- Crisis Glossary – definitions of key terms that often arise during or following a crisis, e.g., "conditional release," "psychiatric advance directive"
- A brief orientation video – a greeting from Dr. E. Fuller Torrey, founder of the Treatment Advocacy Center, and an overview of the Psychiatric Crisis Resource Kit by Aileen Kroll, legislative and policy counsel

The Psychiatric Crisis Resource Kit is a Torrey Action Fund project developed to benefit families, caregivers and those who support them.

Come to our CALM workshop at the NAMI 2011 conference and receive your copy of our new Psychiatric Crisis Resource Kit CD-ROM at no cost! And, please, drop by and introduce yourself at our booth in the conference exhibit hall.

Preparing for Crisis

The events that trigger the need for using mental health treatment laws are often harrowing and always stressful. When efforts to avert the crisis are unsuccessful, the emergency conditions typically require instant decisions and fast action.

Following are tools and information from the Psychiatric Crisis Resource Kit that are designed to help families and other caregivers prepare for emergency conditions beforehand - when there is still the time and presence of mind to do research, gather materials and otherwise prepare for an acute episode.

We suggest keeping the resources you gather in an electronic form that is accessible from a portable communication device or in a three-ring binder, file box or other easily transported container. It is also advisable to use letter-sized, one-sided paper that can easily be faxed or emailed to law enforcement, medical providers and mental health agencies.

Know your state standards for assisted treatment

The types of public psychiatric services available, the procedures for accessing them and pertinent legal provisions vary widely from state to state. To effectively advocate for intervention in a crisis, it is essential to know the standards that govern intervention locally.

“State Standards for Assisted Treatment” contains statutory language that governs civil commitment in each of the 50 states and the District of Columbia. Included are standards for court-ordered treatment and emergency evaluation. Find “State Standards” by clicking the link on any state page of our website.

Learn about the forms of crisis intervention

Three forms of psychiatric intervention may be available to address mental health crises in your state. Bear in mind that each of these are known by different names in different states.

- Emergency psychiatric hold or evaluation – typically a relatively short intervention of fixed duration (e.g., 72 hours) during which the patient is evaluated to determine whether further intervention is necessary
- Civil commitment
 - Inpatient – a process whereby a judge orders a person with symptoms of mental illness who meets the state’s legal criteria to be held beyond the emergency evaluation period in a hospital
 - Outpatient – a process whereby a judge orders a person with symptoms of mental illness who meets the state’s legal criteria to adhere to a mental health treatment plan while living in the community

Emergency contacts list

Having an up-to-date and complete list of key people, agencies and organizations to contact makes it faster and easier to get appropriate help if and when an emergency develops.

- Your standby support person(s) – the stable and reliable third party or parties willing to back you up in an emergency
- Mobile crisis team
- Psychiatric case manager
- Program of Assertive Community Treatment (PACT or ACT) team
- Local mental health center or county mental health department
- Telephone hotline numbers for different crises: mental illness, suicide, domestic violence
- Local hospital/emergency room
- Non-911 police/paramedic numbers that are answered 24/7 (e.g., local precinct)
- Crisis Intervention Team (CIT), if local law enforcement has one
- Local advocates who can advise or support you

- Sympathetic public official/elected official with whom you've established a relationship
- Homeless shelter(s)
- Friends of your loved one
- Employers or others who will need to be notified immediately if your loved one is hospitalized
- Legal Aid Services, public defender or private attorney familiar with mental health law

Provide copies of this list to your standby support person and anyone who might be called upon to act in your absence.

Make multiple copies of the list, store it in your portable electronic device, and never leave home without it. Keep a copy at home, at work, in your car, in the briefcase you carry on trips – anywhere you might be when a crisis arises.

Revisit and revise your list regularly to make sure numbers and names are up to date.

Compile a psychiatric and medical history

A brief, easy-to-read summary of vital statistics, psychiatric history and medication records may help medical providers make informed choices during a crisis. Limit this page to key facts.

- Full name and date of birth
- Full address
- Psychiatric diagnosis (e.g., schizophrenia, schizoaffective disorder, bipolar disorder)
- Age at diagnosis
- Any other pertinent medical conditions (e.g., diabetes, allergies)
- Current symptoms
- Current condition (e.g., suicidal, homeless, missing, vulnerable, violent, abusing substances, other)
- Treating psychiatrist's name and number
- Local service provider's name and provider (e.g., mental health clinic, therapist)
- Current medication(s)
- Dates and locations of previous hospitalizations
- Any medication(s) that has/have helped in the past
- Any medication(s) that has/have **not** helped in the past
- History of symptomatic behaviors (e.g., running up huge debt, getting into car accidents, threatening family members, failing to care for basic needs)
- Date(s) and charge(s) of previous arrest(s)/incarceration(s)
- Current photograph
- Key physical characteristics: height, race, age, weight, hair color
- Full name, contact numbers and address for person to be contacted in an emergency

Leave space to add a description of clothing last worn in case that information is needed.

Collect forms and informational materials. Examples might include:

- Your state's standards for emergency psychiatric evaluation and for civil commitment
- Petition forms for civil commitment – multiple blank copies. Complete any fixed information ahead of time.
- Handouts, brochures, other materials supplied to you by hospitals, law enforcement, mental health agencies, others
- Authorization for release of information, already signed by your loved one, if applicable
- Advance directive, if applicable.



IN A CRISIS

General Guidelines

Your goal in a mental health emergency is to stabilize the situation and get the person professional help as quickly as possible.

- Do not try to manage the situation alone – Sometimes just having another party present or on the phone with your loved one will defuse a situation.
- Start at the top of your Emergency Contacts list and work your way down – If it is an evening or weekend and you cannot reach providers or agencies, call the most appropriate hot-line.
- Speak to your loved one in a calm, quiet voice – If it seems he/she isn't listening or can't hear you, it is possible that auditory hallucinations ("voices") may be interfering. Don't shout; raising your voice won't help and may escalate tensions.
- Keep instructions and explanations simple and clear – Say, "We're going to the car now," not, "After we get in the car, we'll drive to your doctor's office so she can examine you."
- Respond to delusions by talking about the person's feelings, not about the delusions – Say, "This must be frightening," not "You shouldn't be frightened – nobody's going to hurt you."
- Don't stare – Direct eye contact may be perceived as confrontational or threatening.
- Don't touch unless absolutely necessary – Touch may be perceived as a threat and trigger a violent reaction.
- Don't stand over the person – If the person is seated, seat yourself to avoid being perceived as trying to control or intimidate.
- Don't give multiple choices or ask multi-part questions – Choices will increase confusion. Say, "Would you like me to call your psychiatrist?" not "Would you rather I called your psychiatrist or your therapist?"
- Don't threaten or criticize – Acute mental illness is a medical emergency. Suggesting that the person has chosen to be in this condition won't help and may escalate tension.
- Don't argue with others on the scene – Conduct all discussion of the situation with third parties quietly and out of the person's hearing.
- Don't whisper, joke or laugh – This may increase agitation and/or trigger paranoia.

Print a copy of this list to keep with your list of essential telephone numbers.

Profiles

IN TREATMENT ADVOCACY

Brian Stettin is the Treatment Advocacy Center's policy director. In this role, he helps to lead state-level legislative reform and implementation campaigns and nurtures alliances between the organization and groups that share our goals.

WHAT BROUGHT YOU INTO THE WORLD OF MENTAL HEALTH ADVOCACY?

Unlike so many of the people who have worked at the Treatment Advocacy Center over the years, I was not pulled into this through the struggles of a loved one with mental illness. For me, it began on January 4, 1999, my first day of work as a policy aide to the New York State Attorney General, and the day after Kendra Webdale was pushed to her death from a New York City subway platform by a man with a long history of cycling in and out of treatment for schizophrenia.

On the commute to my new job that morning, I read the horrible early details of Kendra's death in the New York tabloids, like everyone else. A few hours later – before I even had an office – I was asked to prepare a memo to the Attorney General on what if any change in New York law might have prevented such a senseless tragedy. I furiously set about learning as much as I could about the New York mental health system. Before the day was out I had been introduced to the concept of “outpatient commitment,” and to a recently-minted organization called the Treatment Advocacy Center.

Over the months that followed – with much help from my new friends at the Treatment Advocacy Center – I crafted the Attorney General's original proposal for “assisted outpatient treatment,” met with the Webdale family to explain the proposal to them and secure their blessing to call it “Kendra's Law,” worked out some amendments with the governor and legislature, marshaled support among families impacted by mental illness and other stakeholders, and tried to beat back the tide of misinformation and frightful predictions that opponents had unleashed.

That summer, Kendra's Law was signed. At the time, I thought, “OK, that went well, bring on the next dragon to slay!” But the mental health issue had gotten further under my skin than I initially realized. I spent 10 more years in New York State government working on a host of important matters, but nothing that ever meant as much to me. When the opportunity arose to come to Washington and help promote the Treatment Advocacy Center's agenda nationwide, I jumped, and I've never been happier in my work.



Brian with his children Eva and Jeremy

WHAT IS IT ABOUT THE QUEST FOR ENLIGHTENED MENTAL HEALTH CARE THAT SO RESONATES WITH YOU?

There are hot-button issues in our society that will inevitably divide us, given our varying ideologies, upbringing, and orientations. We all know what they are, and we've all been in situations where we quickly realize the pointlessness in debating them.

But the question of whether to allow people with severe mental illness and lack of insight to refuse medical treatment has never struck me as one of those issues. When I first got involved with Kendra's Law, I was amazed to find any controversy around this at all. I still am! We are, after all, talking about diseases that totally overwhelm a person's ability to make rational choices, and about a set of consequences that couldn't be more dire. And I guess it's the way I'm wired, but nothing animates me more than the ringing of my “YOU'VE-GOTTA-BE-KIDDING!” bell.

I'm not talking about the small, vocal group who believe psychiatry is a sinister fraud. With them, our differences really do seem of the hopeless variety. But I'm interested in the people who should know better – those who actually make mental health policy and run mental health systems, and never think to question the prevailing dogma that the recovery process must be “self-directed” at all costs.

In my experience, the great majority are caring people who share our ultimate goals. When we engage them with common sense and our mountain of data, we get through to some, and good things happen.

AND HOW HAVE YOU ADJUSTED TO LIFE IN WASHINGTON?

Love it! Great place to raise kids. But I must say, I'm glad I didn't attempt the move before it became possible to watch Yankee games over the Internet.

AROUND THE States

In the landmark *Olmstead* case of 1999, the U.S. Supreme Court ruled that the Americans with Disabilities Act (ADA) prohibits states from indefinitely hospitalizing people with mental disabilities who have been deemed capable of surviving safely in the community and requires reasonable efforts to accommodate the needs of such patients for outpatient care. The Treatment Advocacy Center has been at the forefront of the movement to connect people with severe mental illness

to needed treatment, whether in a hospital or in the community. For some people, ensuring such connection requires government to do more than merely establish the services; those who lack insight into their illness also may need the benefit of assisted outpatient treatment (AOT) if they are to safely survive in the community and avoid the revolving doors of hospitals and jails. We are equally mindful that a person can't be court-ordered into community-based treatment that doesn't exist. Outpatients who need AOT and those who don't all have a stake in the dedication of state mental health systems to meeting their duties under *Olmstead*.

Justice Anthony Kennedy in his concurring opinion in *Olmstead* quoted at length from founder E. Fuller Torrey's book, *Out of the Shadows*. "For a substantial minority ... deinstitutionalization has been a psychiatric Titanic. Their lives are virtually devoid of 'dignity' or 'integrity of body, mind, and spirit.' 'Self-determination' often means merely that the person has a choice of soup kitchens. The 'least restrictive setting' frequently turns out to be a cardboard box, a jail cell, or a terror-filled existence plagued by both real and imaginary enemies." Eleven years after *Olmstead*, this remains the case for far too many.

We begin this edition of "Around the States" with dispatches from three of the states that are subjects of recent or ongoing Department of Justice actions for failure to comply with the ADA as interpreted in *Olmstead*. It is our sincere hope that these investigations culminate in meaningful change.



North Carolina

In 2001, North Carolina legislators approved a plan to bring the state's mental health system into compliance with *Olmstead* by downsizing state hospitals and creating a "Mental Health Trust Fund" to seed new community treatment programs. Unfortunately, the two linked goals were not pursued with equal zeal; the next year, the Trust Fund was raided to plug a hole in the state budget and was never replenished. Nonetheless, the hospital downsizing went forward. The predictable result was a severe statewide bed shortage that has only grown worse with subsequent rounds of budget cutting.

In late 2010, the Department of Justice announced a formal investigation into North Carolina's struggling mental health system and is currently reviewing the consequences of the state's "reform." With so few state hospital beds available, individuals with severe mental illness in crisis

must turn to unregulated and often squalid adult care homes, where warehousing is the norm.

The state Department of Health and Human Services was required to answer 31 detailed questions and submit extensive documents to the federal investigators. As we go to press, those submissions are still under Department of Justice review.



Georgia

A 2009 Department of Justice investigation found Georgia – the state from which the *Olmstead* case arose – continuing to warehouse people with mental illness in violation of the ADA. The new allegations led to a federal lawsuit, which ended in a comprehensive settlement agreement signed in October 2010.

A DOJ press release detailed the settlement terms: "[O]ver the next five years, Georgia will increase its assertive community treatment, intensive case management, case management,

supported housing and supported employment programs to serve 9,000 individuals with mental illness in community settings. The agreement will also increase community crisis services to respond to and serve individuals in a mental health crisis without admission to a state hospital, including crisis services centers, crisis stabilization programs, mobile crisis and crisis apartments."

The Treatment Advocacy Center is cautiously optimistic about this outcome. The community services that Georgia has agreed to build are wonderful when properly implemented but, in too many places, exist in name only. We urge the Department of Justice to vigilantly monitor the state's compliance. And, of course, we hope Georgia will seize this opportunity to effectively implement its assisted outpatient treatment law so that those who lack insight into their illness may claim their rightful share of the promised bounty.



Delaware

The Department of Justice has now completed an investigation initiated in 2007 into conditions and practices at Delaware Psychiatric Center (DPC), the state's sole public psychiatric hospital. In a November 2010 letter to Governor Jack Markell, the department detailed its findings that "the State's current mental health system fails to provide services to individuals with mental illness in the most integrated setting appropriate to their needs ... [which] has resulted in needless prolonged institutionalization of many individuals with disabilities in DPC who could be served in the community. It also has placed individuals currently in the community at risk of unnecessary institutionalization."

The letter reports that, at the time of one investigative visit, 85 patients – more than half of the hospital's total census – had been designated "clinically ready to leave the hospital." It was found that "[t]he most significant barriers to their discharge reflect not their individual needs, but rather, the level of [state] resources and categorical restrictions on these funds." As a result, the average length of stay in the hospital's non-forensic units – which the state itself has said should fall between three and six months – is approximately three years.

The Department of Justice further documents serious injuries and deaths at DPC attributable to the hospital's failure to identify and provide appropriate interventions and supervision and asserts that "utter failure to provide care amounts to deliberate indifference and is an egregious violation of ... constitutional rights."

The letter concludes with a not-so-subtle warning that if cooperative efforts to rectify the problems should fail, a lawsuit is likely.

While Delaware has not issued a public response, a spokesman for the state Division of Substance Abuse and Mental Health reports that the agency is "working diligently and cooperatively" with the Department of Justice to address the concerns.



Arizona

A community forum entitled "A delicate balance: Creating a better, post-Jan. 8 system to protect the public and help the seriously mentally ill" was held on the University of Arizona campus in Tucson in April. The Schorr Family Foundation, the *Arizona Daily Star* and the Community Partnership of Southern Arizona (the regional provider of public mental health services) presented the event in the hope that a renewed focus on improving mental health care will help Tucsonians heal from the mass shooting by Jared Lee Loughner that left six dead and 13 injured in January.

Among the panelists assembled for the forum was Dr. Thomas Insel, director of the National Institute of Mental Health. The *Daily Star* reported that when "[s]ome speakers questioned the connection ... between violence and mental illness ...", Insel said it should not be taboo to discuss such links.

"We need to recognize that untreated people with mental illness are at greater risk for violence, particularly those with paranoia and command hallucinations," said Insel. "Denial will never reduce stigma. What we need is to understand all of the facts."



Iowa

On the morning of April 4, Keokuk County Deputy Sheriff Eric Stein, 38, was shot to death by Jeffrey Krier, 53, as Stein approached Krier's home to question him about recent vandalism of a neighbor's property. Three hours later, with his house surrounded by state police, Krier emerged brandishing weapons and was himself shot to death.

Later that day, Krier's heartbroken brother and sister released a statement to local media expressing their condolences to the Stein family and detailing their brother's 30-year struggle with bipolar disorder. Jeffrey Krier had not worked in 15 years. His

At least one panelist, University of Arizona psychiatry professor Dr. Joel Dvoskin, questioned whether expanded use of involuntary treatment mechanisms should be part of the reform equation. Dvoskin opined that "[r]ight now, we should be focusing on having enough mental-health services so that people who want services can get them."

With all due respect to Dr. Dvoskin, that strikes us as a false – and discriminatory – choice. The urgent need for adequate voluntary services is manifest. But to prioritize on the basis of whether a patient has sufficient insight to seek care, rather than on the severity of illness, is arbitrary and inhumane. Indeed, we wonder how such a system would have helped Loughner, who appears not to have sought treatment even after his college conditioned his return to campus upon it.

[T]o prioritize on the basis of whether a patient has sufficient insight to seek care, rather than on the severity of illness, is arbitrary and inhumane.

parents had lived with him on the family farm until March, when both parents moved to a nursing home. Shortly thereafter, Krier was taken to a local ER following an altercation and held for six days at a psychiatric facility in Des Moines. But, according to the family, their petition to have him committed for longer was denied by the court, and Krier was released to his isolated property. The *Des Moines Register* has reported multiple allegations of Krier threatening and menacing neighbors in the weeks between his release and the shootings.

The chronology leading up to the dreadful events of April 4 raises serious questions about the quality of mental health care in southeastern

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VOICES IN TREATMENT

Three Lives, Three Stories, Three Endings

Eric Smith was so gifted as a child pianist that local newspapers reported his accomplishments, the University of Texas at San Antonio asked him to play in a university production of *Die Fledermaus*, and he won a music competition as a seventh-grader.

Chris Weaver was so precocious academically that after a few months in first grade, school officials told his parents that he should move to

For Eric, the turn came as a teenager in Texas. After a childhood reveling and excelling in music, he lost interest in school, started using drugs and grew combative in his close-knit family. Scared and worried, his parents took Eric to a psychiatrist, who diagnosed the boy often called a musical prodigy with bipolar disorder.

Eric didn't accept the diagnosis. "When I was told I was bipolar and needed to be on medications, I said 'I don't need to be on any medication.' And they – the doctors and the counseling team – said, 'Well, you do.' And they were trying to spout statistics to me, and I said, 'I'm fine without medication. Medication is for people who are hallucinating, or this or that.' I was coming up with all these things I'd seen on TV. Little did I know that they would be me later on in life."

He eventually stopped using drugs, but the symptoms of bipolar disorder continued, and his life continued to unravel. He dropped out of school and lost his job, moved into his car and lived in squalor. His parents – Nancy and Bradley Smith – were baffled, heartbroken and often panic-stricken. After he threatened them, they called the police. Eric was arrested, jailed and ultimately committed to a Texas state psychiatric hospital. When it came time for his release, the Smiths were terrified anew – certain their son wouldn't stay on meds and fearful of a relapse and all the new consequences that would bring.

Chris Weaver's story starts much like Eric's. Chris's talents were in science and math, and he, too, dis-

tinguished himself early and often, his mother Cathy says. He was accepted to Stanford, Princeton and Cornell and became a Stanford freshman at the age of 17. At first, he excelled, but – in his junior year – began acting in ways that alarmed even his peers. One of them went to Cathy to say he was so worried that he'd asked his boss – a former therapist – about Chris's symptoms and was told Chris should see a mental health professional.

For a time, Chris returned to the university, went to a psychiatrist and stayed on medications, says his mother, but eventually he stopped accepting treatment, and his life, like Eric's, swiftly deteriorated. He dropped out of school to write a book he believed would save the world and took Cathy's camper on a cross-country trip but kept getting lost. He developed delusions that the FBI and CIA were after him and made a plan to disappear in Latin America. Eventually he was hospitalized and diagnosed with paranoid schizophrenia. Six times in all, he was hospitalized and released, each time rebounding for a while before going off his meds and relapsing.

Curt Bauer sailed through the ages where Eric and Chris began to



The Smiths before Eric unraveled (L-R): Father Brad, Eric at age 11, David at age 14 and mother Nancy.

second grade immediately. As a high school senior, he won a national writing competition and was accepted by two Ivy League universities and Stanford.

Curt Bauer was so motivated that, after earning a bachelor's degree in philosophy, he earned a master's degree in psychology and became a certified respiratory therapist – all while being a husband and involved father.

And then came the onset of severe mental illness.

Each life took a drastic turn, and each turn led to a different destination – one assisted by court-ordered outpatient treatment (AOT), one assisted by court-ordered inpatient treatment, one in rejection of treatment.



Chris Weaver



Curt Bauer

have symptoms of mental illness. He completed not one but two degrees, including a master's, and married. He loved spending time with his boys. "I would go do things with them," he recalls now. "We'd go shopping. I'd go run the dogs with them. I'd make sure I didn't miss any of their events." A certified respiratory therapist, he worked in ICUs and trauma units and provided neonatal care in hospitals. His work was "very interesting, very stimulating and very rewarding," though meeting the financial needs of a young family meant he often worked two jobs at once.

Eventually the pressures took a toll. "Things my wife Debbie and I used to do as a family, we no longer did," he says now. Debbie suggested he was depressed, but he rejected the idea. "I know the clinical signs of depression and this just didn't fit" is how he saw the situation. To appease his wife, Curt finally went to a psychologist but didn't accept her diagnosis. "I did the questionnaire and all this, and we talked a little bit, but the impression I got from her, from the way she talked about depression, was that she was more depressed than I was. So when I came home, I said 'I don't think this is the problem.'"

Curt was wrong. He stopped eating and taking showers. He stayed in bed 16 hours a day, crawling out just long enough to go to work and come back. One night, he brought home a bag of medications from the hospital, called his wife at work and told her not to come home. She

ignored his admonition and saved his life. With this, because he had become a danger to himself, Curt met the criteria for court-ordered hospitalization, which enabled Debbie at last to get her husband the treatment he needed, first in a rehabilitation center and – when his insurance ran out – in the state hospital in Harrisburg, Pennsylvania. He remained there for two years, until the state shut the facility down.

Curt today is 56 and lives in a group home in Harrisburg. His marriage did not survive the strain of his illness. "When it's all said and done, I lost 24 years of a marriage, I've lost the connection I had with my two sons, I lost my job and pretty much everything that would ever say who I was," he says. Nonetheless, court-ordered hospitalization saved his life, and he is steadily rebuilding. He works for NAMI-Pennsylvania and eloquently advocates for reform of his state's overly restrictive assisted outpatient treatment law with its narrow requirement that a person present an

imminent danger. With improved access to AOT, Curt sees "a future where a lot of suffering can be averted, where a lot of families don't have to be destroyed, a lot of children don't have to see their parents go through the terrible side effects or the terrible damage a mental illness can cause."

For Cathy Weaver, the time for hope is past. Shortly after Christmas in 1999, Chris drove away from her home and took his own life. He was 28. After he died, family members found a plastic bag the size of a soccer ball filled with the prescriptions he had not taken.

Cathy today lives in Austin, is active in the local NAMI affiliate there and advocates for local implementation of Texas's AOT law. Her advocacy is driven by her belief that Chris would have survived his illness had the option of court-ordered outpatient treatment existed for him. "If there had been an outpatient commitment applied to him that kept him on his meds, he would be here working for an engineering firm," she says. "Does this make me angry? It makes me want to chew nails."

Eric Smith is 28, the same age Chris was when he died. He lives about 70 miles from Cathy Weaver, in San Antonio. After his release from the hospital, Eric was court-ordered into his county's assisted outpatient treatment program. His mother Nancy says, "This is the first time since Eric was diagnosed that he has ever been compliant for any period of time. And it started with the program." Eric, now in college earning nearly straight A's and planning a career, says simply, "It saved my life."

The dramatic, full story of these "voices in treatment" and the families that fought for them is now available online and in our new 30-minute documentary, "Stopping the Revolving Door - A Civil Approach to Treating Severe Mental Illness." Poignant, inspiring and instructive in equal measure, the video is appropriate for community meetings, law enforcement training, legislative information and other educational, or awareness and advocacy activities. To view the video online, visit the Video Library on our website. To request a free DVD (subject to availability), email Info@TreatmentAdvocacyCenter.org or telephone 703-294-6001.

Understanding and Navigating HIPAA Privacy Restrictions

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) created a national standard for the protection of certain types of health care information. The U.S. Department of Health and Human Services issued a “Privacy Rule” in 2002 to implement the requirements of HIPAA. The Privacy Rule limits the circumstances in which individually identifiable health information can be used and disclosed by covered entities (health care insurers, providers and clearinghouses).

When a loved one has severe mental illness, family members and other caregivers need to understand what kind of information they can obtain regarding the diagnosis, treatment plan, medications, etc. HIPAA establishes *minimum* protections for the release of such protected health information (PHI). Generally speaking, when a state law and HIPAA conflict, HIPAA preempts the state law. However, state laws that prohibit or *further restrict* the disclosure of protected health information will prevail even if HIPAA would permit the disclosure. Many states have their own laws governing confidentiality – several of which are more stringent than federal law. When faced with a HIPAA hurdle, it’s important to find out what your state’s law says.

IMPORTANT: Providers are not precluded under HIPAA from accepting information from families or others who are knowledgeable about the individual and his or her treatment needs. A good medical provider will want to know all the relevant information available. If your loved one’s provider refuses to listen to your information, contact a supervisor such as the hospital administrator, insist that you be heard, and/or submit written information. An annotated version of this chart with source references is available on the Treatment Advocacy Center website.

Type of disclosure	Rights	How disclosure can help	Restrictions
To patient	An individual has the right to review and obtain a copy of his/her protected health information (PHI). Covered entities such as hospitals and physicians must provide PHI to the individual who is the subject of the medical record.	If family members can convince their relative to request a copy of his/her medical records and share the records with them, they will be informed of their relative’s condition and treatment.	There are a few exceptions to this rule. An individual does not automatically have the right to review or obtain psychotherapy notes, information compiled for legal proceedings or medical records from correctional centers. A health care professional can deny an individual access to his/her own records if the professional believes access could cause harm to the individual or another. Also, some state laws limit the rights of individuals with mental illness to act on their own behalves and to have free access to their protected health histories.
To personal representative	A personal representative is someone legally authorized to make health care decisions on behalf of another individual.viii If you have a power of attorney or guardianship/ conservatorship, you are considered a personal representative. Health care providers are required to treat personal representatives as they would the patient, i.e., personal representatives are entitled to <i>full access</i> to the individual’s medical records.	The personal representative may access the individual’s medical records, speak with the individual’s doctors and make treatment decisions on behalf of the individual. State law controls who can act as a personal representative to make health care decisions on behalf of the individual. Guardianship or conservatorship require a court order. Power of attorney requires the loved one’s authorization.	If the treating physician suspects the personal representative of abusing or neglecting a person with mental illness, the health care provider is not required to share information with the personal representative. Disclosure is also limited when a personal representative only has authority to act on behalf of the person in limited or specific health care decisions. Also, a health care provider may refuse to share information with a personal representative if the person with mental illness objects to the disclosure, and the disclosure is permitted but not required under the Privacy Rule. Conversely, entities must make disclosures to personal representatives that are required under the Privacy Rule, even if the individual objects.

Type of disclosure	Rights	How disclosure can help	Restrictions
To families and others with “formal authorization”	A covered entity – generally a health care provider - must obtain written permission (“formal authorization”) from the person with mental illness for any use or disclosure of protected health information that is not for treatment, payment or health care operations, or otherwise authorized by the Privacy Rule. This written permission constitutes the authorization for disclosure. The individual making the authorization must be told that he/she can revoke it at any time.	Families of persons with mental illness can access specific information about a relative if the relative is willing to give authorization.	In a psychiatric crisis, this is not often a practical choice because it requires that a loved one – who may not even believe he/she is ill – be willing to give authorization. Even so, it is always worth trying to obtain. If a provider withholds information from you because there’s no release, insist that he/she at least ask your loved one if he/she would be willing to sign an authorization.
To families and others where an individual has an “opportunity to agree or object”	A covered entity can provide family members with information if the entity obtains <i>informal</i> permission from the person with the severe mental illness by either asking the person outright or by circumstances that clearly give the person the opportunity to agree or object to the disclosure.	As long as the individual is present and does not object, a provider may disclose information to the family.	This disclosure must be made according to the professional judgment of the covered entity – in most cases, the treating physician. An individual’s doctor may feel it is inappropriate to disclose information to the family in front of the patient. Disclosures of this type are permitted, but not required. Under the concept of “minimum necessary,” providers must limit unnecessary or inappropriate access to an individual’s protected health information. But this is not an absolute standard; providers can make their own assessment of what part of the protected health information is reasonably necessary for a particular purpose.
To families and others in “best interest of the individual”	When an individual is incapacitated, in an emergency situation or not present, providers may use their professional judgment to make disclosures determined to be in the “best interest of the individual.”	The Privacy Rule allows the disclosure of some protected health information where, “the opportunity to object to uses or disclosures ... cannot practicably be provided because of the individual’s incapacity or an emergency treatment circumstance.” A provider may determine that, in certain circumstances, severe mental illness qualifies as an emergency and that it is in the best interest of the individual for family members to be given information.	Because health care providers are not required by HIPAA to share a patient’s information, “best interest” disclosure is limited by the professional judgment of the health care provider. In short, family members cannot depend on getting information in this way.
To individuals who may prevent or lessen a “serious threat to health or safety”	The Privacy Rule permits use and disclosure of protected health information – without an individual’s authorization or permission – for 12 national priority purposes. One of those is the prevention of a serious threat to health or safety. According to Health & Human Services, “[providers] may disclose PHI that they believe is necessary to prevent or lessen a serious and imminent threat to a person or the public, when such disclosure is made to someone they believe can prevent or lessen the threat (including the target of the threat).”	The disclosure of health information under the public interest exception could help to prevent harm to individuals – including families and loved ones.	Because these disclosures are not required, they are made at the discretion of health care providers. Again, family members cannot count on obtaining health information about a loved one through this exception.

Around the States

CONTINUED FROM PAGE 9

Iowa. The state's civil commitment standards are not unduly stringent so it remains unclear why Krier's commitment was denied. But regardless of whether Krier's hospital release was unwarranted, tragedy might also have been averted if Iowa's assisted outpatient treatment law had been implemented to its full potential. No system can prevent all mental illness-related violence. But as Iowa mental health officials look for lessons in the senseless deaths of Eric Stein and Jeffrey Krier, they might begin by considering

whether existing laws have been appropriately utilized.

New York



New York's highest court has issued a ruling that appears to add an additional hurdle to the process of securing court-ordered outpatient treatment for severe mental illness under the state's assisted outpatient treatment (AOT) law, known as "Kendra's Law. The Treatment Advocacy Center is currently analyzing the opinion and will report in a future issue of Catalyst

[A]s Iowa mental health officials look for lessons..., they might begin by considering whether existing laws have been appropriately utilized.

about its implications and potential remedies, if warranted. To receive news and developments in the meantime, please visit our website and use the **Sign Up** button on any page.

Stanley Medical Research Institute Update

By E. Fuller Torrey, M.D.

For the past decade, the Stanley Medical Research Institute (SMRI) has supported trials of repurposed drugs as ancillary treatment for schizophrenia and bipolar disorder. Repurposed drugs are those already approved to treat non-psychiatric conditions, including drugs available over the counter and in health food stores. SMRI has supported approximately 200 such trials and currently has 50 active trials.

Out of such trials, several drugs have emerged that, when used in conjunction with the person's regular medication, show some promise for improving the symptoms of schizophrenia and/or bipolar disorder. In order to make these results more widely known, we have summarized the clinical trials data on 10 such drugs and have submitted the summary for publication. These drugs are:

- **allopurinol:** Used to treat gout. May be useful for selected cases of schizophrenia and is being tested for the treatment of mania.
- **aspirin:** Appears to be useful for some patients, especially those with increased serum level of inflammatory markers.
- **celecoxib:** Used for arthritis and inflammatory conditions. Promising results for recent-onset schizophrenia, but major side effects (heart, GI tract) suggest it should be used only when other drugs have failed.
- **estrogen and raloxifene:** Used to ameliorate postmenopausal symptoms. Has shown promise for improving symptoms of schizophrenia in women.
- **folate:** This is a B vitamin that may be useful in schizophrenia, especially for individuals with a low folate level.
- **minocycline:** This is a tetracycline antibiotic that has shown promise in improving the negative symptoms of schizophrenia, especially in recent-onset cases.
- **mirtazapine:** This is an antidepressant, now available as a generic. Has also shown promise for the treatment of the negative symptoms of schizophrenia.
- **omega-3 fatty acids (fish oil):** Some evidence of efficacy for both schizophrenia and bipolar disorder, especially if the omega-3 contains at least 50 percent EPA.
- **pramipexole:** Used to treat Parkinson's disease. Appears to be helpful for bipolar depression.
- **pregnenolone:** A naturally occurring neurosteroid sold in health food stores. May be useful for a subset of patients with schizophrenia and for bipolar depression.

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

Memorials & Tributes

January 1 – April 30, 2011

The Treatment Advocacy Center extends its appreciation and thanks to all who have supported our mission with donations in memory of a loved one or a friend, including to the many who give anonymously.

William & Christine Albinson, St. Louis, MO	In honor of Charlotte Albinson	NAMI-Moore County, Pinehurst, NC	In honor of NAMI - Moore County
Carolyn & Paul Baker, Atlanta, GA	In memory of Brooks Dorn	Joseph & Tammy Napoli, Middletown, NJ	In honor of Robert Napoli
Gale Barshop, Alexandria, VA	In memory of my sister, Lynn Arden	Nancy Navin, East Falmouth, MA	In honor of Arnold Hanawalt
Melvin & Gillian Clough, Murrells Inlet, SC	In honor of Michael Clough	Maura O'Connell, New York, NY	In memory of Sheila O'Connell
Carolyn Colliver, Lexington, KY	In memory of Scott L. Helt	Fred & Carol Olson, Langley, WA	In honor of Margot
Robert Coffman, New York, NY	In memory of Ken Steele	Charles Pisano, Enola, PA	In memory of Jean Pisano
Betty Corsaro, Morongo Valley, CA	In honor of my son, Robert Corsaro	Ginny Rather, Atlanta, GA	In memory of Brooks Cameron Dorn
Wink Davis, Jr. & "The Bible Study Group", Atlanta, GA	In memory of Brooks Dorn	Ralph L. Crisp Realty, Andrews, NC	In memory of Brooks Dorn
Cecelia Diggins, Providence, RI	In memory of her son, Joseph Diggins	Mary Sue Riggs, Westfield, IN	In honor of Gabrielle Giffords and in memory of Arizona victims
Judy Eron, Alpine, TX	In memory of Jim Siebold	Dewitt Sage, Greenwich, CT	In honor of DeWitt Sage and in memory of David Taggart
John W. Fite, Clarkesville, GA	In memory of Brooks Cameron Dorn	Louise Schnur, Auburn, CA	In memory of Teddy Jack Jones
Fred & Penny Frese, Hudson, OH	In honor of Dr. E. Fuller Torrey	Suzanne Serbin, Fullerton, CA	In honor of James Serbin
Philip Friedman, Silver Spring, MD	In honor of Dr. E. Fuller Torrey	Hilary Silver, Stockton, CA	In honor of Aram Silver
Marguerite & Bill Hodges, Petersburg, IL	In honor of Amanda Arnold	Sandra Smallwood-Beltran, Miami, FL	In honor of consumers and caregivers
Stacy Kinnison, Alexandria, VA	In honor of Eric Fargo, my son	Joan Tanchek, Pasadena, CA	In memory of Tom Shatford
Allison Koenig, Atlanta, GA	In memory of Brooks Dorn	Ernest & Kathy Tharpe, Atlanta, GA	In memory of Brooks Cameron Dorn
Anne Lange, Norfolk, NE	In honor of the Taylor family and in memory of Thor Taylor	Mary Ellen Tormey, Sewickley, PA	In memory of Tucson, Arizona, victims
Amanda LaPera, Laguna Hills, CA	In honor of my loving father	Jeanne Walter, Sumner, WA	In memory of Jan Geary
Roy & Leanore Lembke, Havre, MT	In honor of Paul Campanella Jr.	John Wright, La Jolla, CA	In memory of Christina Green and Laura Wilcox
Neal & Naomi Lonky, Yorba Linda, CA	In honor of Jeff Hoblin	WTI-Molinaro Charitable Foundation Waterloo, IA	In memory of Henry Molinaro
Brian Marcum, Tulsa, OK	In honor of Mary Kay Marcum	Stephen Zeliff, Atlanta, GA	In memory of Brooks Cameron Dorn
Mary Morrow-Bax, Alexandria, VA	In memory of Ray and in honor of Dan		
Elisabeth Murawski, Alexandria, VA	In memory of Christina Green		

The Psychiatric Crisis Resource Kit and "Stopping the Revolving Door - A Civil Approach to Treating Severe Mental Illness," our documentary about how assisted outpatient treatment saves lives, were made possible entirely by donations to the Torrey Action Fund, an annual campaign in honor of our founder E. Fuller Torrey, M.D. Thank you to all who made these projects possible. To support the next Torrey Action Fund project, please visit **Donate** on our website.

Do you know a small foundation with a mental health focus that might be interested in supporting our mission? Please telephone Executive Director Jim Pavle at 703-294-6001 to share your thoughts, or send us an email through the **Contact Us** function on our website.



Treatment Advocacy Center
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Arlington, VA 22203
www.TreatmentAdvocacyCenter.org

Get Help Online

No matter where you are or what time of day or night, you will find links, tools and tips for responding to psychiatric crises on the Treatment Advocacy Center website. Every element of our new Psychiatric Crisis Resource Kit can be found under the **Get Help** tab, along with other information to help you —

- Know the laws in your state
- Be prepared for an emergency
- Find out about the options
- Respond in a crisis

Staying Up to Date – As Easy as 1-2-3

1. **By email** – Receive periodic emails about major news and updates. Click on **Sign Up** on our website to provide your email address, or telephone us at 703-294-6001.
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