

Spring 2006: Community psychiatry

### TAC WINS 2006 APA PRESIDENTIAL COMMENDATION American Psychiatric Association president commends TAC for "extraordinary advocacy"

The Treatment Advocacy Center has won the American Psychiatric Association's Presidential Commendation for "sustained extraordinary advocacy on behalf of the most vulnerable mentally ill patients who lack the insight to seek and continue effective care and benefit from assisted outpatient treatment."

"One of the great tragedies of modern psychiatry is the large number of individuals with mental illnesses who are incarcerated or homeless," said APA President Steve Sharfstein, M.D.

# RECOVERY AND COERCION Reconciling two hotbutton terms

#### by TAC Executive Director Mary T. Zdanowicz, Esq.

Deinstitutionalization was a paradigm shift in treatment of patients with severe mental illnesses – and it was certainly a shift for the psychiatric profession who traditionally treated such patients in hospitals.

The "institutionalization" period stigmatized psychiatrists with the legacy of "forced treatment" that was so vividly portrayed in the movie "One Flew Over the Cuckoo's Nest." Along with deinstitutionalization came an expectation that community psychiatrists should be able to treat patients "voluntarily" in the community, despite the fact that before deinstitutionalization, many of these patients would have been hospitalized. One benefit of hospital treatment that was lost in the outrage during the "bedlam" debate is that an inpatient setting also provides an opportunity to leverage treatment in clinically appropriate ways for patients who otherwise would refuse care.

The shift of psychiatric treatment from hospitals to "the community" continues to accelerate. In the 1990s, the

#### Continued on page 4

#### unique advocacy is restoring the important balance between individual freedom and caring coercion." Assisted outpatient treatment allows courts to order people who meet specific criteria to receive outpatient mental

"This is the inevitable consequence of our reluctance to use

caring, coercive approaches, such as assisted outpatient

treatment. The Treatment Advocacy Center has been the

catalyst for many positive changes in our laws and a shift

in our perception of the importance of intervention. Their

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## **PSYCHIATRY'S HEROES**

#### by TAC President E. Fuller Torrey, M.D.



I have not had many heroes in my life.

When I was young, it was Gordie Howe, of the Detroit Red Wings. As a teenager, it was Albert Schweitzer, a mission doctor in West Africa. As an adult, it has been mental health professionals who have devoted their

lives to providing services for individuals with severe psychiatric disorders.

It is therefore very gratifying personally to be able to recognize psychiatrists who have done so. TAC award winners Drs. Jeffrey Geller, Richard Lamb, and Darold Treffert have made enormous contributions to improving care for severely mentally ill persons (profiled on page 8) and I have admired them for many years. My acquaintance with Dick Lamb even dates to 1968, when I was a psychiatric resident assigned to his unit at San Mateo County Hospital.

# **APA recognizes TAC's work**

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health treatment. AOT helps those who are the most ill and often unable to make informed treatment decisions. Results from states that use AOT show marked reductions in the incidents and duration of hospitalization, homelessness, arrests and incarcerations, victimization, and violent episodes. AOT also increases treatment compliance, promotes long-term voluntary compliance, and improves quality of life.

"Until we find the causes and definitive treatments for schizophrenia and bipolar disorder, we have an obligation to those who are suffering to try to improve their lives," said TAC President E. Fuller Torrey, M.D. "Except for biological chance, any one of us might today be there, living on the streets or in jail. TAC is the only organization willing to take on this fight, and I am very proud to be part of it."

TAC executive director Mary T. Zdanowicz will accept the award at the 2006 APA Annual Meeting in Toronto on May 22. The annual APA meeting is the world's largest gathering of psychiatric physicians. Past winners of the APA Presidential Commendation include Rosalyn Carter and U.S. Senator Pete Domenici and Nancy Domenici.  $\clubsuit$ 



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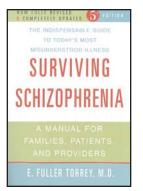
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And with special thanks to Peter Harms, an extraordinary volunteer.

#### JUST RELEASED!

Surviving Schizophrenia: A Manual for Families, Patients, and Providers (5th Edition)



Since its first publication in 1983, *Surviving Schizophrenia* has helped thousands understand this complex and often stigmatized illness. In clear, sympathetic language, this definitive book describes the nature, causes, symptoms, and history of schizophrenia, taking readers inside the minds of those living with the disease.

This completely updated fifth edition

includes the latest research findings, information about the newest treatments, and answers to the questions most often asked by families, patients, and providers.

"A comprehensive, realistic, and compassionate approach... Should be of tremendous value to anyone who must confront these questions." - *Psychology Times* 

"E. Fuller Torrey is a brilliant writer. There is no one writing on psychology today whom I would rather read." - *Los Angeles Times* 

#### About TAC

#### Spring 2006

The Treatment Advocacy Center (TAC) is a national nonprofit organization dedicated to eliminating legal and clinical barriers to timely and humane treatment for millions of Americans with severe brain disorders who are not receiving appropriate medical care.

Since TAC was launched in 1998, treatment laws in 17 states have improved. Today, we continue the fight for sustained and effective treatment for individuals touched by severe mental illnesses.

*Catalyst* is a free periodic hardcopy newsletter. TAC also produces a free weekly news roundup, sent via email to subscribers. To subscribe, send an email to info@psychlaws.org with "Enews subscription" as the subject.

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"Until we find the causes and definitive treatments for schizophrenia and bipolar disorder, we have an obligation to those who are suffering to try to improve their lives. Except for biological chance, any one of us might today be there, living on the streets or in jail. TAC is the only organization willing to take on this fight, and I am very proud to be part of it." - E. Fuller Torrey, M.D.

# **Psychiatry's heroes**

Continued from page 1

Drs. Geller, Lamb, and Treffert are three of a few dozen American psychiatrists whom I esteem highly. Others include John Talbott, past president of the APA, who worked at Manhattan State Hospital and then edited Psychiatric Services for many years to focus attention on the most seriously ill. Roger Peele, APA Area Trustee, devoted virtually his entire career to St. Elizabeths Hospital in Washington, D.C., where I was privileged to work under him. I think of old-timers, such as George Brooks in Vermont and Werner Mendel in Nebraska. In more recent years, some psychiatrists I have greatly admired include Tom Fox and Bob Vidaver in New Hampshire, Alberto Santos in South Carolina, Rohan Ganguli and Matcheri Keshavan in Pennsylvania, Mark Munetz in Ohio, Bill Knoedler in Wisconsin, Jose Santiago in Arizona, Pablo Hernandez in Wyoming, and Dave Cutler and Joe Bloom in Oregon. These and a few dozen others are psychiatrists who have devoted their careers to providing care for the sickest and most neglected patients, most of whom have schizophrenia, bipolar disorder, or severe depression.

The Treatment Advocacy Center (TAC) was created to facilitate treatment for these patients. Many are homeless or incarcerated in the nation's jails and prisons. Many have anosognosia and therefore are unaware of their illness. On any given day, less than half are under any treatment program. Victimization and violence are their frequent companions.

TAC can change laws and encourage treatment, but ultimately it is the mental health professionals who have to make it happen. Psychiatrists such as those mentioned above, psychologists, social workers, and psychiatric nurses who have a special interest in the severely mentally ill are the bedrock of the system. We would all do well to remember the 1885 words of the President of the British Medico-Psychological Association:

The reckless inhumanity which would condemn numbers of the helpless sufferers from brain disease to suicide or lifelong insanity might surely be avoided by simplifying, in place of complicating, the process of placing them under the treatment prescribed for them by their medical advisers.

It is therefore with great pleasure that TAC honors Drs. Geller, Lamb, and Treffert and the several dozen other American psychiatrists who have made care for

individuals with severe psychiatric disorders their life's work.

E. He Jon "

#### **Assisted Outpatient Treatment (AOT)**

In most states, treatment interventions are no longer limited to inpatient hospitalization. Most jurisdictions now permit assisted outpatient treatment (AOT). Assisted outpatient treatment is court-ordered treatment (including medication) for individuals who have a history of medication noncompliance, as a condition of remaining in the community. Typically, violation of the court-ordered conditions can result in the individual being hospitalized for further treatment.

Forty-two state statutes permit assisted outpatient treatment. (Only Connecticut, Maine, Maryland, Massachusetts, New Jersey, New Mexico, Nevada, and Tennessee do not.) Studies and real-world implementation show that AOT reduces arrests, incarcerations, violence, and homelessness. It also reduces hospitalization and improves treatment compliance.

**AOT reduces hospitalization.** A randomized controlled study in North Carolina demonstrated that intensive routine outpatient services alone, without a court order, did not reduce hospital admission. When the same level of services (at least three outpatient visits per month with a median of 7.5 visits per month) were combined with long-term AOT (six months or more), hospital admissions for those with schizophrenia and their psychotic disorders were reduced 72 percent and length of hospital stay by 28 days compared with individuals without court-ordered treatment. The participants in the North Carolina study were from both urban and rural communities and "generally did not view themselves as mentally ill or in need of treatment." Data from the New York Office of Mental Health on the first five years of implementation of Kendra's Law indicate that of those participating, **77 percent fewer experienced hospitalization**.

AOT improves treatment compliance. In New York, the number of individuals exhibiting good service engagement increased by 51 percent, and the number of individuals exhibiting good adherence to medication increased by 103 percent. In North Carolina, only 30 percent of patients on AOT orders refused medication during a six-month period compared to 66 percent of patients not on AOT orders. In Ohio, AOT increased compliance with outpatient psychiatric appointments from 5.7 to 13.0 per year; it also increased attendance at day treatment sessions from 23 to 60 per year. AOT also promotes long-term voluntary treatment compliance. In Arizona, "71 percent [of AOT patients] ... voluntarily maintained treatment contacts six months after their orders expired" compared with "almost no patients" who were not court-ordered to outpatient treatment. In Iowa "it appears as though outpatient commitment promotes treatment compliance in about 80 percent of patients while they are on outpatient commitment. After commitment is terminated, about three-quarters of that group remained in treatment on a voluntary basis."

### Reconciling "recovery" and "coercion"

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inpatient capacity in state and county hospitals decreased by 40 percent. In 2003, more than half of states were expecting to close more hospital beds.<sup>1</sup>

Unfortunately, the barriers to community treatment seem to be accumulating as quickly as patients are being discharged – precisely what happened during the first phase of deinstitutionalization. But now there are new challenges.

- Medicare Part D implementation has presented significant challenges for the psychiatric community. In the early weeks of 2006, prescriptions for many patients with mental illnesses who previously received medications through Medicaid had not been filled. Instead, efforts to obtain much needed medicine were met with failures in the enrollment system, misapplications of deductibles, and miscalculations of co-pays.<sup>2</sup>
- Medicaid cost-containment strategies have severely impacted the availability of community treatment resources as states limit access to prescription medicines (through preferred drug lists, prior authorization, and limits on the number of prescriptions per month that a Medicaid recipient can have), eliminate optional services such as psychological counseling and psychosocial rehabilitation, cut eligibility for people with incomes above the federal poverty level, establish or increase co-payments, and restrict the use of case management services.<sup>3</sup>
- **Dual diagnosis programs** for those with co-occurring substance abuse or developmental disabilities are scarce.
- **Emergency rooms** are experiencing significant increases in psychiatric cases which emergency room physicians attribute to community psychiatric budget cuts and psychiatric bed closures.<sup>4</sup>

#### IN THE FIELD: "A productive and constructive tool"

Gilbert Gonzales, Director, Crisis Services/Jail Diversion, San Antonio, Texas

"In Texas, we refer to AOT as involuntary court-ordered outpatient treatment. AOT has been used as a clinical tool to assist in the continuity of care for persons whom we serve.

[AOT] has always been a productive and constructive tool. It is a proven clinical approach which has shown consistent benefits in the long term."

**CASE STUDY:** Patient is a 40-year-old female with repeated hospitalizations and encounters with law enforcement. A case review showed multiple hospitalizations and arrests in a 365-day period. After a year and active participation in our AOT program, this person showed a significant reduction in hospitalizations and encounters with law enforcement.

• Managed care "behavioral health care" for-profit companies frustrate physician's clinical goals by preempting their decisions based on cost-containment apparently without clinical considerations.

Despite these obstacles, there is a growing optimism in the mental health community. The chair of President Bush's New Freedom Commission on Mental Health said recently that "[o]ur main area of progress has been spreading a message of hope and recovery that has been grabbed onto by people around the country. In many states, people have been very actively working to improve resources, even while budgets are in trouble."<sup>5</sup>

#### What is "recovery"?

The American Association of Community Psychiatrists (AACP) Guidelines for Recovery Oriented Services note that "recovery has been variably defined" and that "[t]he use of coercive measures for treatment is not compatible with recovery principles."<sup>6</sup> On February 16, 2006, SAMHSA (Substance Abuse and Mental Health Services Administration) addressed both concerns by releasing its Consensus Statement of Mental Health Recovery. Sadly, the Consensus Statement defines recovery in a way that appears to foreclose the possible compatibility of recovery and the use of leveraged treatment.

The Consensus Statement identifies ten fundamental components of recovery, the first of which is self-direction:

"By definition, the recovery process must be self-directed by the individual, who defines his or her own life goals and designs a unique path towards those goals."

This perspective on recovery dashes all hope of rescuing those who are refusing treatment – it erects one more barrier to treatment for clinicians who are already facing too many obstacles. The most discouraging aspect of the SAMHSA formulation of recovery is that an organization that purportedly promotes an "evidence-based approach" has apparently ignored research demonstrating that the use of leverage is both necessary and beneficial for a small group of individuals with the most severe mental illnesses.

The debate about leveraged care, which promises to continue to rage, should be an informed rather than an emotional one. An informed review of relevant data shows that the practice of rescuing people with leveraged treatment can be entirely compatible with, and sometimes necessary for, recovery.

#### Is leverage necessary?

In a recent survey, researchers found the single most common cause of nonadherence to medications for patients with schizophrenia was "denial of illness" (35 percent) – significantly more common than "side-effects" (9 percent), "stigma associated with taking an antipsychotic" (3 percent), or "cost of the antipsychotic" (4 percent).<sup>7</sup> Half of nonadherence was attributed to denial or other symptoms of illness (paranoia, grandiosity, cognitive impairment).

In the survey, one third of nonadherent patients generally did not believe that they had a mental illness.<sup>7</sup> Patients with schizophrenia who lack insight have a much higher risk of nonadherence.<sup>8</sup> The reality is that "limited progress has been made in developing effective interventions to manage insight deficits and nonadherence among psychotic patients."<sup>7</sup>

A severe lack of insight into illness, whether caused by schizophrenia or other impairment, can "seriously interfere with [a patient's] ability to weigh meaningfully the consequences of various treatment options."<sup>9</sup> In such cases, it doesn't matter how ideal the treatment is – someone who does not recognize that they need treatment may never accept it voluntarily.

#### Widespread use of leverage

It is not entirely surprising that "leveraged treatment is ubiquitous in serving traditional public-sector patients."<sup>10</sup> The MacArthur Network on Mandated Community Treatment identified several forms of leverage used to facilitate people's acceptance of outpatient treatment.

- **Money as leverage.** Government disability benefits for people with a serious mental disorder are in some cases received and distributed by a family member or other appointed payee. Payees frequently use these payments as leverage to coerce treatment.
- **Housing as leverage.** People who depend on disability benefits often can't afford market-rate housing, so government-subsidized housing is used both formally and informally as leverage to ensure adherence to treatment.
- Avoidance of jail as leverage. For people who commit a criminal offense, adherence to treatment may be made a condition of probation. This long-accepted judicial practice has become more explicit with the recent development of specialized mental health courts.
- Avoidance of hospital as leverage. Under some statutes, judges can order patients to comply with prescribed community treatment, even if the patient doesn't meet the legal standards for in-hospital commitment. Failure to comply can result in hospitalization.
- Advance directives. In some states, a patient can attempt to gain some control over treatment in the event of later deterioration by specifying treatment preferences or a proxy decision maker.<sup>11</sup>

#### IN THE FIELD: "Excellent 'insurance' for patients"

Daniel Garza, MD, Director, Assisted Outpatient Treatment Program, Elmhurst Hospital Center, Queens County, New York State

"I was the original director once the state AOT law was passed. I use it often. Hard clinical research is indicated such that it can be readily perceived as a true, evidence-based, practice by physicians and physicians-in-training. [AOT is an] excellent tool for clinicians and excellent 'insurance' for patients. What most surprised me about using AOT was the patient's recognition of its value for them."

**CASE STUDY:** Patient is a Latino male in his 30s with schizophrenia, undifferentiated type, and marijuana abuse with history of multiple hospitalizations, mobile crisis unit interventions and periods of agitation and gross disorganization. He became **stable, sober, housed, and vocationally rehabilitated** after a series of court orders and [stepdowns to] voluntary agreements and has since graduated from the rolls of AOT successfully.

around the county revealed that 44 percent to 59 percent of patients had experienced at least one form of leverage. Housing leverage was the most common (23 percent to 40 percent of all patients). Outpatient commitment was experienced by half as many (12 percent to 20 percent).<sup>10</sup>

While saying in an earlier article that "mandating adherence to mental health treatment in the community through outpatient commitment is among the most contested issues in mental health law,"<sup>12</sup> several of the authors later concluded that the data "suggest that the focus of the current policy debate on one form of leverage – outpatient commitment – is much too narrow"<sup>10</sup> because the use of leverage abounds.

#### Perception is primary

Recently released data suggests another reason why the antipathy for outpatient commitment is misplaced. Surprisingly, individuals who experienced one form of leverage (either court ordered or other types such as housing) reported low levels of perceived coercion similar to individuals who had never experienced leverage. Most importantly, **those who had court-mandated treatment reported significantly higher treatment satisfaction that those whose treatment had been voluntary or leveraged by a means other than court order.**<sup>13</sup>

Additionally, those who experienced both court-mandated treatment and other forms of leverage had significantly higher perceived coercion and significantly lower treatment satisfaction than those with a court order alone.

These data suggest that when leverage is needed, reliance on the use of outpatient commitment for leverage in the community is preferable to other forms of leverage because the level of perceived coercion is comparable to voluntary care, but the

Interviews with outpatients from five sites in five states

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# Reconciling "recovery" and "coercion"

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treatment satisfaction is clearly higher than any other combination. More emphasis on outpatient commitment as the preferable from of leverage might help reduce the use of redundant forms of leverage that in this study resulted in such negative outcomes. The other benefit of outpatient commitment is that the Outpatient commitment ... is preferable to other forms of leverage because the level of perceived coercion is comparable to voluntary care, but the treatment satisfaction is clearly higher than any other combination.

patient's constitutional due process rights are protected by the courts, whereas such protections usually are absent from less formal methods of leverage.

The evidence indicates that the majority of real consumers' views on leveraged treatment, particularly AOT are that:

- **O** it helps improve quality of life;
- O its real benefits outweigh the potential disadvantage of perceived coercion; and
- **O** fear does not drive them away from treatment.

**Improves quality of life.** Assisted outpatient treatment (AOT), also known as outpatient commitment, refers to a

# IN THE FIELD: "I'm surprised at how tolerant and accepting patients are"

Jeffrey Stovall, MD, Medical Director, Adult Outpatient Services, Community Healthlink, and Assistant Professor of Psychiatry, and of Family Medicine and Community Health, University of Massachusetts Medical School, Massachusetts

"I am surprised at how tolerant and accepting patients are about having medication orders". Before I ever used them, I was hopeful that they would help but cautious that [these orders] would be overreaching into civil liberties. I've come to see it as an important and useful part of community based treatment.

If your state has AOT, educate yourself and families and use it. If not, advocate for it."

**CASE STUDY:** Patient is a 45-year-old man with a history of schizophrenia with associated hospitalizations, incarcerations, assaultive behavior, and homelessness. He has always declined to take medications outside of the hospital. About five years ago, a medication order was obtained and followed by 18 months of court-ordered injections of antipsychotics. After 18 months, the patient requested a switch to oral medications with lesser side effects. Now on oral meds with daily staff contact for over three years. Since the medication order, this patient has had only one hospitalization in the first few months, no arrests or incidents of violence, and stable housing.

\* Massachusetts does not yet have assisted outpatient treatment, but has the option for Rogers Orders. This is an excellent example of how clinicians can often find a way to help people even if their state has no AOT law or one that is weak or rarely used. court order mandating a person with a severe mental illness adhere to a prescribed community treatment plan, using the possibility of hospitalization for treatment noncompliance as leverage. The main goal of AOT is to enable more consistent adherence to treatment for people whose severe mental illnesses impair their ability to seek

and voluntarily comply with treatment.

More than 75 face-to-face interviews were conducted with participants in New York's AOT program (Kendra's Law). They were asked their perceptions of coercion or stigma associated with the court order and their quality of life as a result of AOT. Contrary to what AOT opponents speculate:

- 75 percent of recipients interviewed said AOT helped them gain control over their lives,
- 81 percent said AOT helped them get and stay well, and
- 90 percent said AOT made them more likely to keep appointments and take medication.<sup>14</sup>

A randomized control study of AOT showed similar results. Researchers assessed the impact of AOT on quality of life of people with severe mental illnesses, covering a range of areas including social relationships, daily activities, finances, residential living situation, and global life satisfaction. They found remarkable evidence that persons who underwent sustained periods of AOT had measurably greater subjective quality of life at the end of the study year. It appears that AOT exerts its effect largely by improving treatment adherence and decreasing symptomatology.<sup>15</sup>

**Real benefits outweigh potential disadvantage of perceived coercion.** In a survey of people with schizophrenia concerning preferences related to AOT, "being free to participate in treatment or not" was the least important outcome. When asked to rank their preferences, patients indicated that reducing symptoms, avoiding interpersonal conflict, and avoiding rehospitalization outranked avoidance of outpatient commitment.<sup>16</sup> Studies show a majority of people with severe mental illnesses who received mandatory treatment later agree with the decision.<sup>17</sup> A formal survey published in July 2004 found that a majority of consumers regard mandated treatment as effective and fair.<sup>18</sup>

One prominent advocate who has schizophrenia explained that those "who have been primarily interested in consumer rights and liberties ... focus ... on opposing the use of forced treatment. ... On the other hand, consumer advocates who place a high value on the need for psychiatrically disabled persons to receive treatment tend to support [AOT]."<sup>19</sup>

Fear does not drive consumers away from treat-

**ment.** Several studies contradict the theory that AOT deters people from seeking treatment. Among patients with schizophrenia who were asked whether various forms of mandated treatment would deter them from seeking voluntary treatment in the future, researchers found that outpatient commitment did not cause respondents to fear seeking treatment.<sup>20</sup>

The McArthur Coercion Studies revealed another very significant, yet counterintuitive, finding. **Legal status (i.e., voluntary versus involuntary treatment) does not necessarily correlate with perceived coercion.**<sup>21</sup> Two studies found no relationship between perceived coercion during hospitalization or outpatient treatment and future adherence with treatment.<sup>22</sup>

The study that is often cited for the proposition that AOT drives people away from treatment is the Well-Being Project.<sup>23</sup> In that survey, conducted with a clear bias against assisted treatment, a majority of people reported they never avoided treatment because of the fear of being involuntarily committed. A majority of people who had been involuntarily hospitalized reported that fear had caused them to avoid treatment at some time, but more than half of those were receiving treatment at the time and had overcome the fear.

#### Leverage is ubiquitous and necessary

Perhaps the apparent inconsistency between leveraged care and recovery can be reconciled in view of this evidence. Scholars suggest that "good clinical care requires a more assertive approach in situations of compromised autonomy" and propose broadening "the concept of patient-centeredness to include mandated care under certain circumstances. ... [U]sing incentives and disincentives to facilitate and promote adherence to treatment is patient-centered care to the extent that these interventions are experienced by patients as being grounded in a caring therapeutic relationship."<sup>24</sup>

As the MacArthur Coercion Studies demonstrate, a patient's beliefs that others acted out of genuine concern, treated the patient respectfully and in good faith, and afforded the patient a chance to tell his or her side of the story, are associated with low levels of experienced coercion.<sup>25</sup> The AACP Guidelines recognize this and advise that:

... when [coercive treatments] are unavoidable, they should be used with great care and circumspection. ... Individuals must be treated with compassion and respect during episodes of incapacitation and should be offered choices to the greatest extent possible with regard to their treatment plan.<sup>6</sup>

# IN THE FIELD: "It's just been a part of my choices for treatment"

Andrea B. Stone, M.D., Medical Director, Carson Center for Human Services, Assistant Professor of Psychiatry, University of Massachusetts Medical School, Massachusetts

"[Medication orders have] been helpful so often even though [they are] not truly enforceable [in Massachusetts]. I learned about it early on in my career, possibly during my training, so it's just been a part of my choices for treatment. It has been helpful in most situations when I have been able to get it."

**CASE STUDY:** Patient is a 34-year-old man with a diagnosis of schizophrenia. Frequent hospitalizations after stopping his medications. Several arrests related to drug use. Difficulties with assaultive behavior. After a hospitalization in a medium-length stay hospital he was begun on clozapine and a Roger's order\* was obtained. He has done quite well. No further drug use; no criminal charges. He is attending a two-year college and doing well. He, like several other of my patients, feel that the Roger's order is a "safety net." They do not want it dropped even though they have been adherent to their treatment, because of their feelings that it has been an important part of their recovery.

\* See the note in the box on the previous page.

Rather than wasting valuable resources on the question of *whether* leveraged treatment is consistent with recovery, we should be resolving the question of *how* leverage can best be used so treatment can rescue those for whom recovery is illusory without it.

As U.S. Supreme Court Chief Justice Burger once observed, "A person who is suffering from a debilitating mental illness, and in need of treatment is neither wholly at liberty nor free of stigma. It cannot be said, therefore, that it is much better for a mentally ill person to 'go free' than for a mentally normal person to be committed."<sup>26</sup>  $\bigstar$ 

#### NOTES

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# Treatment Advocacy Center honors three extraordinary community psychiatrists

#### National Torrey Advocacy Commendation awarded to psychiatry's heroes

The board of directors of the Treatment Advocacy Center (TAC) congratulates Dr. Jeffrey Geller, Dr. H. Richard Lamb, and Dr. Darold Treffert, the winners of TAC's annual national mental illness advocacy award.

The TAC award recognizes the courage and tenacity of those who selflessly advocate – despite criticism and opposition – for the right to treatment for those who are so severely disabled by severe mental illnesses that they do not recognize that they need treatment.

TAC's board of directors voted unanimously to recognize these three outstanding community psychiatrists. "These dedicated psychiatrists have devoted their careers to providing care for the sickest and most neglected patients, most of whom have schizophrenia, bipolar disorder, or severe depression," said TAC board secretary Dr. Fred Frese. "They each have spent a lifetime engaged in one the most difficult and underappreciated areas in psychiatry, and the world is a better place because of their selfless concern for those who most need intervention."

"TAC can change laws and encourage treatment, but ultimately it is the mental health professionals who have to make it happen," said psychiatrist and board president Dr. E. Fuller Torrey, for whom the award is named. "Psychiatrists such as Drs. Geller, Lamb, and Treffert, and psychologists, social workers, and psychiatric nurses who have a special interest in the severely mentally ill are the bedrock of the system. The battle for treatment is one that they wage every day in ways large and small. It is an effort and sacrifice that should not be ignored."

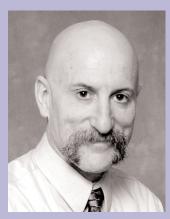
**About the award.** The Torrey Advocacy Commendation is named for TAC president and founder Dr. E. Fuller Torrey, M.D., a nationally known and respected psychiatrist, researcher, and advocate whose unflagging resolve to remove barriers to treatment for people with severe mental illnesses sparked a national reform movement. Recipients

#### Essays by TAC award winners start on page 10

make a substantial difference for their community through advocacy, awareness, research, or legislation in this field. To nominate someone for next year, visit our website at www.psychlaws.org.

#### **DR. JEFFREY GELLER (MASSACHUSETTS)**

Dr. Jeffrey Geller currently serves as the Director of Public Sector Psychiatry and Professor of Psychiatry at the University of Massachusetts Medical School. He still spends a portion of his time working directly with patients with severe mental illnesses. He takes advantages of creative opportunities for advocacy, serving as a consultant to pub-



Dr. Jeffrey Geller

lic institutions in 12 states and for the U.S Department of Justice, Civil Rights Division in another five states, and working as the book review editor for *Psychiatric Services*, where he has been instrumental in gathering personal accounts from people who have experience with mental illness. He is the author of numerous research papers and studies, as well as the book *Women of the Asylum*. Dr. Geller won the 1994 Effective Legislative Fellow Award from the National Alliance for the Mentally III, and was honored by the American Psychiatric Association as a Distinguished Fellow in 2002 and the Arnold L. van Ameringen Award winner in 2003.

In nominating him for this award, one of his colleagues notes: "In the 20 years I have known Jeffrey, he has been unwavering in his commitment to questioning assumptions about the needs of individuals with severe mental illness. Jeffrey's teaching and research, scholarly and service activities are guided by his belief that individuals with severe mental illness deserve access to the "right" treatment in the "right" time in the "right" place. To continuously question, test, speak, and write about the assumptions driving our field, as

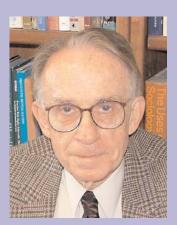
Jeffrey does, requires considerable courage and an unwavering commitment to an advocacy agenda guided by the belief in doing the best we can for individuals with serious mental illness."

Dr. Geller's "patients first" approach is well known. One colleague remembers NPR inviting Dr. Geller to speak about advocating for people with serious mental illnesses – but the taping date was also his patient clinic day. He declined the national exposure, saying, "How can I go on a radio show to speak of advocacy after canceling all my patients?"

#### DR. H. RICHARD LAMB (CALIFORNIA)

Dr. Lamb is professor of psychiatry and director of the division of psychiatry, law, and public policy at the University of Southern California. Prior to joining the faculty of the University of Southern California, Dr. Lamb worked for the Community Mental Health Services of San Mateo County, California. There, he developed and ran a large vocational rehabilitation service for persons with severe mental illness. In addition, he has run an acute psychiatric inpatient service, a day treatment and aftercare service, and psychiatric emergency services in Los Angeles. He has been a consultant to probation and police departments. He has also raised money from private sources in order to develop a range of supportive housing for persons with severe mental illnesses.

Dr. Lamb is active with the American Psychiatric Association. He chaired the Task Force on the Homeless Mentally III, served twice on the Editorial Board of *Psychiatric Services*, and was a member of the Committee on Rehabilitation, and Vice-Chair of the Council on Psychiatric Services. He chaired the Institute on Psychiatric Services Scientific Program



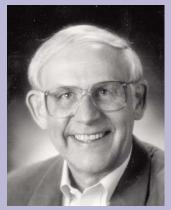
Dr. H. Richard Lamb

Committee. He currently serves on the Committee on Jails and Prisons. He is on the board of directors of the National Alliance for Mental Illness (NAMI).

His extensive research on the criminalization of people with severe mental illnesses has made him a sought-after speaker, and he has authored six books and over 180 other professional publications on these topics. His research and expertise have also made him a powerful advocate for tools like mental health courts, conservatorship, and more psychiatric beds. He also has been a vocal advocate for assisted outpatient treatment, noting that "Community treatment of severely mentally ill offenders who fall under the jurisdiction of the criminal justice system has important differences from treatment of nonoffenders. It is critical to identify a treatment philosophy that strikes a balance between individual rights and public safety and includes clear treatment goals."

Dr. Lamb received the NAMI 2003 Don and Peggy Richardson Memorial Award for Distinguished Service to Persons Afflicted With Serious Mental Illness. In 1998 he received the American Psychiatric Association's Arnold L. van Ameringen Award in Psychiatric Rehabilitation & Treatment of the Chronically Mentally III.

#### **DR. DAROLD TREFFERT (WISCONSIN)**



Dr. Darold Treffert

Dr. Treffert is a clinical professor at the University of Wisconsin Medical School and is on the staff of St. Agnes Hospital in Fond du Lac, Wisconsin. He completed both his medical training and psychiatric residency at the University of Wisconsin Medical School. He then joined the staff of Winnebago Mental Health Institute in Oshkosh, Wisconsin. He was named superintendent in 1964, a position he held for 17 years. For the next 12 years, he served as director of a community mental health system for a county of 90,000 people.

As the superintendent of Winnebego, Dr. Treffert spoke out early and often about the adverse effects of weak mental illness treatment laws. As early as 1973, he published an article titled "Dying with one's rights on," a phrase that has become part of the lexicon. Dr. Treffert blazed the trail of documenting preventable tragedies to help keep the focus on the results of lack of treatment; his vision inspired TAC's online database of preventable tragedies. Beginning in the mid-1980s, he began promoting Wisconsin's "Fifth Standard," which later became law and was unanimously upheld by the Wisconsin

Supreme Court. In numerous publications, he has clearly and forcefully described the consequences of failure to treat individuals with severe psychiatric disorders:

The "freedom" to be penniless, helpless, ill, and finally arrested, jailed and criminally committed is not freedom at all – it's abandonment. The "right" to be demented, agonized and terrorized in the face of treatment which cannot, because of legal prohibition, be applied is no right at all – it's a new form of imprisonment. The "liberty" to be naked in a padded cell, hallucinating, delusional, and tormented, is not liberty – t is a folie a deux between pseudo-sophisticated liberals and an unrealizing public. The delusion is that if one changes the name of something to something else, or if one substitutes a jail for a hospital or a preoccupation with legal rites for honest concern over patients' rights, he has done something significant, useful and important, or at least something. ["Legal 'rites" Criminalizing the mentally ill. Hillside Journal of Clinical Psychiatry 1982, 3: 123-137.]

# Voices of experience: Psychiatry's heroes

# A clear-eyed look at what we really need

# Three leaders in psychiatry on the humanity of coercion, the real need for inpatient beds, and a rational approach to funding

The three winners of the national Torrey Advocacy Commendation are each pioneers, revolutionaries, and stalwart advocates for those who are unable to advocate for themselves. They aren't slowed by petty ego or weighed down by inertia. Catalyst asked each of these leaders to share some thoughts on the state of community mental health.

# Dr. Darold Treffert: The human dimension to coerced care

For 17 years, I was Director of Winnebago Mental Health Institute, Wisconsin. Then for 12 years, I was director of a community mental health system for a county of 90,000 persons. Throughout those years, I was also in private practice with both outpatients in the office and inpatients in a general hospital psychiatric unit when such care was necessary. So my vantage point is that of a clinician and an administrator in a wide variety of public and private, hospital and community, outpatient, and inpatient settings. In each of those settings, the vast majority of patients were voluntary. But mental illness being what it is, in relatively few instances, involuntary or coerced treatment becomes necessary.

In the early 1970s, Wisconsin commitment law was changed to make coerced treatment virtually impossible until a patient was an imminent danger to self or others. It soon became apparent to me that too often, treatment came too late and patients were falling through the cracks.

In 1973 I wrote an article called "Dying With Their Rights On," in which I described a few of the hundreds of cases I catalogued. (TAC's online "Preventable Tragedies" database houses a similar collection.)

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Many of these "dying with your rights on" cases demonstrate graphically, and tragically, that freedom can be a hazard – or another form of imprisonment – for persons who are obviously ill and in need of treatment; who are not yet dangerous but well on their way to being so; or who, because of that obviously and permeating illness, are unable to care for themselves.

Civil libertarians and other critics refer to these cases as Treffert's "anecdotes." They dislike them. They are "out-liers,"

Coerced care need not be an oxymoron. To achieve that, coercion ... should always contain elements of procedural justice such as genuine concern, good faith, respect, listening to the patient's side of the story, and involvement of important persons in the patient's life in the decisionmaking process.

not common, and do not represent the mainstream circumstance, these critics say. But the instances are real. These persons, with such tragic outcomes, are not "anecdotes" to their families and loved ones, or to innocent persons or bystanders sometimes harmed by them.

So it was a relief when, in 1999 the MacArthur Coercion Studies systematically, dispassionately, and meticulously examined the nature of - and need for - coerced treatment in an overdue and enlightened fashion. These Coercion Studies provide studies in place of slogans, data in place of diatribe, and recommendations in place of recriminations.

The Coercion Studies revealed that involuntarily committed patients do not invariably deny their illness and protest the hospitalization process. Approximately one half (47 percent) agreed

> there was no reasonable alternative to hospitalization and 35 percent of patients who were legally committed did not perceive themselves as having been coerced into the hospital.

> They reinterviewed 270 of the patients in one sample of the study between four to eight weeks after discharge. More than 50 percent of the patients who said initially that they did not need to be hospitalized reported that, in retrospect, the decision for their hospitalization was the correct one. Thus, the patient's view of hospitalization, even when coerced, can

change in a positive direction over time and need not be a lingering deterrent to future care, should that become necessary. The Studies also found a low level of perceived coercion if:

- O persuasion and inducement are used, not threats or force;
- O others, including friends and family, are involved in the decisionmaking as a form of caring;
- **O** the patient believes others acted out of genuine concern;
- The patient believes he or she was treated respectfully and in good faith; and

• The patient was afforded a chance to tell his or her side of the story.

Thus, coerced care need not be an oxymoron. To achieve that, coercion, whenever it is used, must be the least intrusive possi-

ble, and should always contain elements of procedural justice such as genuine concern, good faith, respect, listening to the patient's side of the story, and involvement of important persons in the patient's life in the decisionmaking process.

Those elements remind me of the inscription above the door of a mental hospital in Europe: "To cure sometimes – to help often – to comfort always." These studies, and the concept of procedural justice, usefully remind everyone involved in the coerced care transaction that there is a vital human dimension to that stringent legal process. A variety of tools are being used as leverage ... to improve adherence to psychiatric treatment in the community, e.g., requiring adherence to medications or psychosocial treatment as a condition for living in a therapeutic residential community program, making the receipt of mental health services a condition of probation, and outpatient commitment.

It is frequently asserted that the increased availability of highquality community treatment, such as intensive case management and assertive community treatment, would result in very few persons with severe mental illness who needed intermediate or long-term psychiatric hospitalization. Moreover, a variety of

> tools are being used as leverage in the United States to improve adherence to psychiatric treatment in the community, e.g., requiring adherence to medications or psychosocial treatment as a condition for living in a therapeutic residential community program, making the receipt of mental health services a condition of probation, and outpatient commitment.

> More community treatment, such as intensive case management and assertive community treatment is clearly needed. However, there is no evidence that these treatments, even if they are accompanied by various forms of leverage, are sufficient to

# Dr. H. Richard Lamb: From hospital beds to prison beds

In a recently published article in the *Journal of the American Academy of Psychiatry and the Law*, my co-author Linda E. Weinberger and I estimate that at least 135 persons per 100,000 population, or almost 370,000 severely mentally ill persons, are currently in locked, 24-hour, involuntary, structured settings. This staggering number is derived by adding the number of persons in state hospitals in 2000 (22 per 100,000 population) and the number of severely mentally ill persons in jails and prisons in that same year (at least 113 per 100,000).

It is clear that the deinstitutionalization of persons with severe mental illness has amounted to far fewer persons than is commonly believed. Severely mentally ill people who formerly would have been psychiatrically hospitalized when there were a sufficient number of inpatient beds are now entering the criminal justice system. The reasons most commonly cited are:

- deinstitutionalization in terms of the limited availability of psychiatric hospital beds;
- O the lack of access to adequate treatment for mentally ill persons in the community;
- The interactions between severely mentally ill persons and law enforcement personnel; and
- **O** more formal and rigid criteria for civil commitment.

maintain all persons with serious mental illness in the community and can completely solve the problem of the very large number of seriously mentally ill persons entering our jails and prisons.

It is commendable that there are jails and prisons where the quality of psychiatric care is good. However, it is unfortunate that when many mental health professionals are asked whether the placement of severely mentally ill persons in criminal justice facilities that have quality psychiatric services is appropriate, the answer may be, "Sadly, these are the only places we have where we can give them the equivalent of good inpatient treatment." It has now been left to the criminal justice system to provide the high-caliber and humane level of services that was once the domain of the mental health system.

In recent years, there has been a reluctance on the part of society to fund additional mental health services or even to maintain existing ones, including community treatment, nonforensic state hospital beds, intermediate care facilities, and acute community inpatient beds. And within the mental health systems themselves, state and local mental health departments want to limit or reduce the few remaining state hospital beds in order to use scarce mental health funds for community outpatient programs.

The shortage of psychiatric beds in the mental health system is an extremely serious issue and has been one of the key factors contributing to persons with severe mental illness entering and remaining in the criminal justice system. Unfortunately, too few

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# **Voices of experience**

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people have advocated for establishing more nonforensic, longterm, intermediate, and acute psychiatric beds. Without such efforts, the criminalization of large numbers of severely mentally ill persons will continue.

# Dr. Jeffrey Geller: Budgeting people to death

We can talk about transformation, normalization, deinstitutionalization, medicalization and destigmatization; and we can bandy about whether to call persons who receive treatment for psychiatric disorders patients, clients, consumers, recipients or survivors; and we can debate the degree of restrictiveness or integration of supported housing, supportive housing, adult homes, state hospitals, general hospital psychiatric units, crisis/respite beds, jails, prisons and street corners; and we can ponder the extent of coercion in outpatient commitment, jail diversion, assertive community treatment, mental health courts, representative payeeships, treatment-contingent housing, probation, case management, managed Medicaid, and Medicare Part D; and we can pontificate about atypical versus typical antipsychotic medications, monotherapy versus polypharmacy, supportive psychotherapy versus dialectical behavior therapy, concurrent versus consecutive treatment for the dual diagnoses mental and substance abuse disorders, chemical versus mechanical restraints, multiple brief hospitalizations versus one longer admission, and whether psychologists versus pharmacists would injure more individuals if given prescribing privileges.

But the bottom line in providing care and treatment for persons with chronic mental illnesses with disabling consequences is the bottom line.

Essentially, major reforms in the structure and organization of services for persons with mental illnesses, whose services would

be funded by public dollars, have been fueled with the promise of saving money. Dorothea Dix, in arguing for establishing state hospitals, indicated hospital treatment would cure most mental illness, thus doing what's right while returning recipients of hospital-based treatment to the rolls of taxpayers rather than tax-dollar consumers. The rallying cry of the last quarter of the twentieth century – close hospitals and move everyone to the "community" – was predicated on

Community-based mental health services for persons with serious mental illness will continue to be a nonsensical, uncoordinated, fractured potpourri of purposeless activities confounding the beneficent efforts of those who work daily with this population until we have a rational scheme of funding.

the factoid that community-based care would be less expensive than hospital-based treatment.

More perverse than the fundamental question of absolute expense has been the Rube Goldbergesque maneuvers by states to cost shift from state coffers to the federal budget. This was predicted by former President Franklin Pierce who, on May 3, 1854 stated... "if the several States, many of which have already laid the foundation of munificent establishments of local beneficence, and nearly all of which are proceeding to establish them, shall be led to suppose, as, should this bill become a law, they will be, that Congress is to make provision for such objects, the fountains of charity will be dried up at home, and the several States, instead of bestowing their own means on the social wants of their own people, may themselves, through the strong temptation which appeals to the states as to individuals, become humble suppliants for the bounty of the Federal Government, reversing their true relations to this Union."

If there is any doubt that this has come to fruition, just look at what states sanction in order to move people to, and keep people residing in loci where they are Medicaid eligible: capping residences at 16 beds; having unlicensed, untrained staff administer medication; having those who own large residences subcontract for services of all kinds to be delivered in the residential setting so that the residential owner is not the service provider; creating one-bed, 24-hour/day, 7-day/week staffed residences; providing locked community residences with less professional staff time, physical space, access to outdoor opportunities, rehabilitation, and vocational opportunities than the locked hospital ward the individuals moved from; creating policy mandating acute hospital admission from scores to hundreds of miles from home rather than at the state hospital in one's neighborhood; and discharging from hospitals to shelters and street corners.

> Community-based mental health services for persons with serious mental illness will continue to be a nonsensical, uncoordinated, fractured potpourri of purposeless activities confounding the beneficent efforts of those who work daily with this population until we have a rational scheme of funding. While the states and the feds engage in cost-shifting exercises and budgeting slights of hand, persons who are disabled by the brain injuries we call psychiatric disorders are needless suffering and dying. \*

# **Voices of experience: Doctor/advocates**

# A New York psychiatrist on the realities of Kendra's Law

by Antonio A. Abad, M.D., President of the Association of Hispanic Mental Health Professionals, New York excerpted from testimony to the New York State Assembly Standing Committee on Mental Health, Mental Retardation, and Developmental Disabilities, April 8, 2005. Reprinted with permission.

I am familiar with Assisted Outpatient Treatment (AOT) since its inception in 1999, as well as with the Pilot Study Outpatient basis for AOT applications; indeed, I have witnessed how efficacious AOT results giving priority for the most needed individ-

Commitment Program (OCP) since 1996. In addition, I reviewed the New York State Office of Mental Health report on AOT. I have also gathered data regarding additional the Outpatient Commitment Program Pilot Program and AOT from experts within the AHMHP, NYU School of Medicine, and from various professional organizations and consumer groups ... I am also familiar with more than 100 AOT cases, and I have testified in more than 20 New York State Supreme Court AOT hearings.

AOT has been successful in providing

appropriate supervision and treatment to thousands of severe and persistent mentally ill (SPMI) individuals with a track record of danger to self or others due to noncompliance with treatment. AOT is viewed by providers as the "last resort" for patients with histories of repeated hospitalization and incarceration in order to avoid long-term inpatient treatment in state hospitals. As a forensic psychiatrist I can attest that AOT is viewed as an efficacious alternative to incarceration for many mentally ill individuals with criminal justice system contact. Many AOT patients have informed staff and judge alike "AOT was the glue that kept them together," attributing AOT to helping transform their lives.

In addition to a reduction in rehospitalization and incarceration rates in AOT cases, a study at the NYS Psychiatric Institute at Columbia University showed that 75 percent of the cases reported that AOT helped them gain control over their lives, 81 percent said AOT helped them to stay well, and 90 percent said AOT made them more likely to keep appointments and take medication. In addition, various advocacy groups of consumers, advocates and families view AOT as the best approach to avoid the "criminalization" of mentally ill individuals.

AOT treatment plans have been appropriately matched to the needs of individuals. Enhanced services for psychiatric and substance abuse rehabilitation, as well as housing, have been correctly allocated to the most severe mentally ill individuals. These enhanced services have been made available on a priority

As a forensic psychiatrist, I can attest that AOT is viewed as an efficacious alternative to incarceration for many mentally ill individuals with criminal justice system contact. Many AOT patients have informed staff and judge alike "AOT was the glue that kept them together," attributing AOT to helping transform their lives. uals. However, deficiencies in the mental health delivery system, responsible for the existence of large underserved populations in the state of New York, have limited the efficacy of AOT for various underserved groups.

In this regard, the proportional overrepresentation of Latinos and African Americans in AOT court orders [in New York], in our opinion, is a good sign, indicating that AOT is effective in meeting the needs, and overcoming disparities, affecting many mentally ill Latinos and African Americans,

who are over-represented in the inpatient psychiatry system, as well as in jails and prisons. However, as in other areas of interest in mental health ... [we] still lack sufficient bilingual resources in the community, making impossible the development of proper AOT applications. As a consequence, this forces long stays in inpatient units, and jeopardizes the fiscal survival of community-based outpatient services, due to the financial burden created by the need of bilingual services and the short-*Continued on page 14* 

# IN THE FIELD: Hospital days reduced in local Texas program

Report from Crisis Care / Jail Diversion, The Center for Health Care Services, San Antonio, Texas

One year prior to beginning the outpatient commitment program, the average length of stay for the seven consumers reviewed was 131 days with the longest stay being 409 days and the shortest at 34 days.

One year after beginning the outpatient commitment program, 4 (57 percent) out of the seven consumers reviewed have not been re-admitted to a state inpatient facility. Of the three who were re-admitted, the average length of stay was 27 days. One of the three admissions did not have a psychiatric hospitalization during the first year. The longest stay was 48 days and the shortest stay was six days.

One Year Prior = 131 days average One Year After IOPC = 27 days, a reduction of 79 percent

# Kendra's Law in the field

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age of qualified bilingual mental health professionals capable to work with patients ... with limited English proficiency ...

Despite of deficiencies derived from the Mental Health delivery system identified, Assisted Outpatient Treatment demonstrates financial, legal, medical and emotional benefits to patients, family members and greater society. This is in accordance to the spirit of the law and evolving standards of social responsibility, as evidenced by the 1999 U.S. Supreme Court decision *In re Olmstead*, which upheld that mental health services should be provided in the community, whenever possible, as well as similar statutes in 42 states allowing the use of AOT ....

There is a school of thought that holds that psychiatric treatment is not even necessary, and that hospitalization and outpatient commitment is an infringement of their rights to liberty and free choice. However, in light of the strict criteria regarding the need of evidence for dangerousness to self and others secondary to non-compliance to treatment, and the comprehensive treatment planning utilized, the judicial decision of AOT orders seems to be consistent with the accepted legal principles. These include the concept of *parens patriae*, the duty of the government to protect those individuals who can not protect themselves, and police powers, the duty of government to protect society.

Unfortunately, as in the majority of states with court-mandated outpatient psychiatric treatment statutes, AOT is widely underutilized. In New York State, New York City accounts for a disproportionate number of the total orders ... the total numbers of AOT orders are less than the state originally projected. We need to assess from a therapeutic jurisprudence stance, why upstate rural and a number of suburban communities do not readily utilize AOT as an effective treatment modality.

In summary, the AOT program is a cost effective and promising practice ... balancing individual rights and the protection of society, ensuring the safe management of mentally ill individuals, who are otherwise potentially dangerous to themselves or others due to noncompliance with treatment.  $\clubsuit$ 

# A statement of madness: The new guidelines for treating mental illness need help

#### by Sally Satel, M.D.

Dr. Satel is a psychiatrist and resident scholar at the American Enterprise Institute. She is co-author of One Nation Under Therapy, which will be released in paperback in June. This article originally ran in National Review Online April 2006. Reprinted with permission.

Imagine your brother has schizophrenia. When he takes his medications, he can hold a part-time job in a mom and pop hardware store. When he stops the drugs — something he does every few years because he simply does not perceive himself to be sick — your brother becomes hostile, wildly delusional (believing the radios in the hardware store are pulling thoughts out of his head), and does not come home for days at a time, sleeping in the street and eating out of garbage cans.

Clearly, your brother is someone who needs to take those medications regularly. Unfortunately, like about one-half of all patients with psychotic illnesses, he lacks insight into his condition. In fact, he thinks the medications are for a bad cold he caught back in 1988, and unless watched closely by his psychiatrist and family (he lives with his parents who dole out the meds daily), he could easily neglect to take them.

Recently, the federal Substance Abuse and Mental Health Services Administration (SAMHSA), part of the Dept. of Health and Human Services, has released its Consensus Statement of Mental Health Recovery. It is a travesty of psychiatric care. In fact, if a psychiatrist treating patients with severe mental illness followed most of the ten "fundamental" principles of recovery elaborated in the statement, he would be at risk of committing malpractice. The statement, according to the press release, was "developed through deliberations by over 110 expert panelists representing mental health consumers [the politically correct term for psychiatric patient], families, providers, advocates, researchers, managed care organizations, state and local public officials and others." I wasn't one of them. Despite being a member of the Advisory Council for the Center for Mental Health Services (the arm of SAMHSA expressly devoted to the nation's mental health services), neither I nor several other members, nor the council as a body, was shown the document and asked to comment. Consider some of the "Fundamental Concepts of Recovery" from the Consensus Statement:

**Concept #1 Self-Direction:** "Consumers lead, control, exercise choice over, and determine their own path of recovery by optimizing autonomy, independence, and control of resources to achieve a self-determined life. By definition, the recovery process must be self-directed by the individual, who defines his or her own life goals and designs a unique path towards those goals."

**Concept #2: Individualized and Person-Centered:** "There are multiple pathways to recovery based on an individual's unique strengths and resiliencies as well as his or her needs, preferences, experiences (including past trauma), and cultural background..." Should we let him, and the

thousands like him, hit rock

bottom every once in a while,

as the Consensus Statement

seems to suggest?

**Concept # 3: Empowerment:** "Consumers have the authority to choose from a range of options and to participate in all decisions — including the allocation of resources — that will affect their lives, and are educated and supported in so doing. They have the ability to join with other consumers to collectively and effectively speak for themselves about their needs, wants, desires, and aspirations..."

**Concept #9: Responsibility:** "Consumers have a personal responsibility for their own selfcare and journeys of recovery. Taking steps towards their goals may require great courage.

Consumers must strive to understand and give meaning to their experiences and identify coping strategies and healing processes to promote their own wellness."

Reality check: How can a person like your hypothetical brother described above exercise full self-direction-empowerment-responsibility? His "choice" would be not to take his medication – a choice that leads to relapse rather than recovery. Should we let him, and the thousands like him, hit rock bottom every once in a while, as the Consensus Statement seems to suggest?

The list continues, rounded out by vague feel-good directives and descriptions. Recovery should be "holistic" yet it is a "nonlinear" process, says the statement. What? Also, patients should be treated with "respect," and, of course, there must be "hope." Reminding "providers" of the need to respect patients and instill realistic hope is patronizing.

Such principles are vital to good care, as we learn in medical school and residency. True, they are not always practiced, but this reflects the separate, real problem of the uneven quality of mental health treatment available.

This is déjà vu all over again. In 2003, President Bush's New Freedom Commission on Mental Health released its report, "Achieving The Promise: Transforming Mental Health Care in America." President Bush had charged the 22-member group with making a "comprehensive study" that would "advise [him] on methods of improving the system."

Though more detailed and somewhat more sophisticated than the Consensus Statement, the Freedom Commission report was also woefully incomplete. It, too, failed to take on the most difficult cases, and considered severe mental illness only in terms of a "recovery model." The model holds that sufficient therapy, housing options, and employment programs will enable people with schizophrenia or manic-depressive illness to take charge of their lives. Many will, but thousands won't.

The problem with the recovery vision is that it is a dangerous-

ly partial vision. It sets up unrealistic expectations for those who will never fully "recover," no matter how hard they try, because their illness is so severe and their dependence on medications so great. By neglecting the needs of the most severely ill – that is, the individuals whose very awareness of being sick is blunted – the Consensus recovery guidelines are applicable to only half of

> those with mental illness. Picture the outrage that would be aimed at the National Cancer Institute if it sent out "recovery guidelines" on breast cancer that ignored half the clinical population of women with the disease. What's more, exclusive emphasis on recovery as a goal steers policymakers

away from making changes vital to the needs of the most severely disabled.

Every few years, there are calls to abolish SAMHSA, which was created in 1992. It should be. The main task of SAMHSA is to allocate the state mental-health and substance-abuse block grants. It is a bureaucracy that could be absorbed by the Health Resources Services Administration. Discretionary grants for pilot programs, those that can actually survive a rigorous review, could be controlled by evaluation scientists at the National Institute of Mental Health and the National Institute on Drug Abuse.

The new Consensus Statement only fuels the well-deserved image of an agency that is often sorely misguided and naïve in its approach to the most vulnerable (and costly) of its constituents: the severely mentally ill.  $\clubsuit$ 

#### Anosognosia in psychiatry

Impaired awareness of illness is the single biggest reason why individuals with schizophrenia and bipolar disorder do not take medication.

In psychiatry, anosognosia usually connotes three overlapping dimensions: the failure to recognize that one has a psychiatric disease; the inability to recognize that one's unusual mental events, such as delusions and hallucinations, are pathological; and noncompliance with treatment. *[Anthony David, Insight and Psychosis,* 156 Br. J. Psychiatry 798, 805 (1990).]

Other researchers have added additional dimensions to the use of the term, including failure to perceive the need for treatment, lack of awareness of the benefits of treatment, and lack of awareness of the social consequences of having a psychiatric disorder. [Xavier Amador & Regine Anna Seckinger, The Assessment of Insight: A Methodological Review, 27 Psychiatric Annals 798 (1997).]

As used in neurology, anosognosia has been defined as "an impaired ability to recognize the presence or appreciate the severity of deficits in sensory, perceptual, motor, affective, or cognitive functioning." [Susan Kotter-Cope & Cameron J. Camp, Anosognosia in Alzheimer Disease, 9 Alzheimer Disease Assoc. Disorders 52 (1995).]

# "Recovery" and "coercion"

#### Continued from page 7

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#### IN THE FIELD: How I use AOT

Report from Tanya Feliz, MSW, Coordinator of Child, Adolescent Case Management & Adult ICM Programs, Family Service Association of Bucks County, Langhorne, Pennsylvania. Ms. Feliz' comments relate to her experience in New York state's AOT program.

"The goal of AOT is three-fold: to assure that persons with mental illness (who because of their illness might not seek needed treatment) get the treatment they need, to keep those clients who become violent (as a result of their untreated illness) out of jail/prison – where they do not belong and to keep the general public safe.

Once a client has received an AOT order – it has already been determined that there is a history of danger to self/other when the person is not adhering to their medication AND treatment regimen (it's very important that we understand that AOT is not only used to medicate people). Keep in mind that failure to adhere to medication and treatment recommendations in-and-of-itself does not guarantee hospitalization.

Intensive Case Management (ICM) clients are taken to the emergency room for an evaluation of danger to self/others. They may or may not be admitted depending on how they present. My experience is that it can take a few trips to the hospital before an admission. For example, Jane Doe has not taken her medication X3 days ,which is a concern due to her history of violence, but she is not yet symptomatic. By day 7, she may be more symptomatic and a return trip to the hospital ER would be appropriate to assess for danger to self/others and to treat presenting symptoms.

My experience with PACT Teams is that these hospitalizations almost always occur because they are usually requested by the Assertive Community Treatment (ACT) Team psychiatrist as opposed by an ICM and because ACT clients are generally higher risk and have more severe histories than ICM clients.

While PACT teams are 24 hour – I would never advise a worker to transport a client in need of hospitalization due to potential danger to self/others. It is always appropriate for the worker to contact local authorities to escort the client and for the worker to travel to the hospital separately. This way the worker remains safe while his/her presence assures the client of the worker/teams support.

AOT does not guarantee admission to the hospital but does guarantee an assessment of dangerousness by a psychiatrist."

# **Memorials and Tributes**

Our deepest appreciation to the people and organizations who sent in memorials and tributes since our last issue of *Catalyst*. We are grateful that you chose to support the Treatment Advocacy Center's mission in memory or in honor of someone very special to you. Your generous contributions allow us to continue our mission.

We are also grateful to all those who support our efforts but who choose not to make that donation a memorial. Your names do not appear below, but the result of your contribution appears in everything we do.

- The board and staff of the Treatment Advocacy Center

loop Cummingo and Jill Adolmon, Clop Ellyn, II	In honor of Michael Adelmon
Joan Cummings and Jill Adelman, Glen Ellyn, IL	In honor of Michael Adelman In honor of Nathan Stout
Joan Ariel, Santa Barbara, CA	
Frances Ashurst, Hemet, CA	In honor of Larry Erskine
Frances Ashurst, Hemet, CA	In memory of Jeanine Urbanski
Richard Avery, Denver, CO	In memory of David Teets
Thomas and Marcia Barnes, Williamsville, NY	In honor of Gregory Barnes
Gale Barshop, Boca Raton, FL	In memory of sister, Lynn Arden
James and Nancy Bollini, Oakton, VA	In honor of all mental health advocates
Hollis and Marilyn Booth, Inverness, FL	In honor of Joan Murphy
Kathleen Borge, Silver Spring, MD	In honor of Kristina Borge
Helen Brown, Gahanna, OH	In honor of Dr. E. Fuller Torrey
Alice Byrne, Franklin Park, IL	In memory of Jesus' birth date
A.J. and Jane Carlson, Westlake, OH	In memory of Christopher Carlson
Jeanette Castello, Newtown, PA	In honor of all the hard work TAC has provided for those with mental illness who are most vulnerable in our society
James Cayce, Black Diamond, WA	In honor of The Stanleys
James and Iva Chambers, Roanoke, VA	In honor of Dr. Torrey
Ron and Sunny Chandonais, Kila, MT	In memory of Patrick Coffer
Dave and Terry Clark, Tuscon, AZ	In honor of Eric Michael Clark (ADC# 180165)
Richard Cleva, Washington, DC	In memory of Henry Cleva
Susan Cleva, Bellevue, WA	In honor of Dr. Torrey and Mary
Susan Cleva, Bellevue, WA	In memory of Henry Cleva
Susan Cleva, Bellevue, WA	In memory of John L. Owen
Susan Cleva, Bellevue, WA	In honor of TAC
Melinda Cohen, Dove Canyon, CA	In honor of Jordan Y. Molina
Coliant Solutions, Sugar Hill, GA	In memory of Rebecca Giles
Carolyn Colliver, Lexington, KY	In memory of Scott L. Helt
Thomasine Cubine, Virginia Beach, VA	In honor of Dr. E. Fuller Torrey
Linda Davis, Holmes Beach, FL	In honor of Nathaniel
Frank and Janice DeAngelis, Amherst, OH	In memory of Elvis Ian Iskenderian
Ray and Linda Dellaero, Tampa, FL	In honor of Jason Dellearo
Jo Anne Dorgan, Orlando, FL	In memory of Mary P. Dorgan (Mom)
Beverly Edmon, Ventura, CA	In memory of Georgia Edmon
Isabel Ehrenreich, Flintridge, CA	In memory of Mark Ehrenreich
Ronald and Ann Eldridge, Santa Barbara, CA	In memory of Charles Skye-Campbell
Susan Embree, Davenport, IA	In honor of Andrew Conway
Judy Eron, Alpine, TX	In memory of Jim Siebold
Mildred Fine, Lynbrook, NY	In honor of The Friendship Network
David and Alice Fitzcharles. Media. PA	In honor of Sheriff Donald Eslinger, Linda Gregory, and Alice Petree
Laurie Flynn, New York, NY	In honor of Fuller Torrey, MD In honor of W.D. Frank
Karen Frank, Seguin, TX Harold and Joyce Friedman, Lake Worth, FL	
· · · · ·	In honor of Joyce H. Friedman
Anthony and Judith Gaess, Montvale, NJ	In memory of Kimberly Rose Gaess
Mark and Theresa Gale, West Hills, CA	In honor of Alex Gale
David and Lorraine Gaulke, Crosslake, MN	In memory of Scott Hardman
James Gladden, Alexandria, VA	In memory of my father and my brother David
Tom Glennon, Chicago, IL	In memory of Mr. S.
Nelson and Theresa Goguen, Ashby, MA	In memory of Rita V. Goguen
Nelson and Theresa Goguen, Ashby, MA	In honor of Isabelle McSherry on her 103rd birthday
Mary Ellen Gonzalez, Miami, FL	In honor of my son
Jean Gotchall, Waynesburg, OH	In memory of Glenn E. Gotchall

# Memorials and tributes (continued)

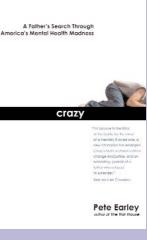
Linda Gregory, Jacksonville, FL	In memory of Deputy Sheriff Eugene Gregory
Richard Gross, Johnstown, PA	In honor of NAMI staff at DC office and their good work
Claire Hedgcock, Fruitland Park, FL	In memory of William Linden
Ron Honberg, Rockville, MD	In honor of Mary Zdanowicz
Roderick and Betty Hooper, Double Springs, AL	In memory of Virgil Davis
William and Sylvia Hughes, Albuquerque, NM	In honor of Kevin Hughes
Pattie Hunt, St. Augustine, FL	In honor of David Hunt
Jordan and Sarah Hymowitz, San Francisco, CA	In honor of Sandy Hymowitz
Pam Jackson, Titusville, FL	In honor of Steve Jackson, brother
Carla Jacobs, Tustin, CA	In honor of Randal Hagar
Dale and Carmen Johnson, Taos, NM	In memory of Jay L. Johnson
Ronald and Barbara Johnson, Lewes, DE	In memory of Sharra Taylor
Matthew and Angela Greiling Keane, Washington, DC	In honor of Jim Greiling
Matthew and Angela Greining Rearie, Washington, DC	In memory of Bonnie R. Picard
Merry Kelley, Hiawatha, IA	In memory of Bonnie R. Picard
Marilyn Kendrick, Wake Forest, NC	In honor of Kimberly Johnson
Lil Kenny, Hopelawn, NJ	In honor of Mary Zdanowicz
Ted and Martha Kitada, Alta, CA	In honor of our son Ted Jr.
Kenneth Kress, Iowa City, IA	In honor of the contributions of Mary Zdanowicz, Jonathan Stanley, Rosanna
	Esposito, and John Snook to TAC's <i>amicus brief</i> in the U.S. Supreme Court in Clark v. Arizona
George and Nina Lacombe, Salt Lake City, UT	In memory of Vicki Cottrell (Executive Director-NAMI, Utah)
Bert Latran, Oberlin, OH	In memory of Elvis Ian Iskenderian
Dale and Trude Lawrence, Rockville, MD	In honor of Hans Lawrence
Raymond and Florence Lemke, Milwaukee, WI	In memory of Kristin Epperson
John and Linda Lewis, Davenport, IA	In honor of Patrick Lewis
Mary Lou and Alan Lowry, Glen Ellyn, IL	In memory of Joanna Lowry
Sue Marlowe, Columbus, GA	In honor of NAMI Columbus
Michael and Marcia Mathes, Orlando, FL	In memory of Deputy Eugene Gregory
Michael and Marcia Mathes, Orlando, FL	In memory of Alan Singletary
Martin and Terry Mc Cue, Red Bank, NJ	In memory of Joan T. Mc Cue
Janet and Albert McSweeney, Seabrook, NH	In honor of son, Stephen J. McSweeney
Paul and Nancy Merola, Austin, TX	In honor of Tod Christian Merola
Paul and Nancy Merola, Austin, TX	In honor of our son, Tod Christian Merola
Sheila Miller-Shugerman, Birmingham, AL	In honor of John M. Miller, IV
Erin Moriarty, Long Beach, CA	In honor of Ms. Jean S. Lancaster
Charles and Charlotte Mueller, Ormond Beach, FL	In honor of Marianne Mueller
Kathleen Murray, Windsor, CT	In honor of Kara Anne Murray
Ruth Pace, Saint George, UT	In honor of Deborah Carver
Dottie Pacharis, West River ,MD	In honor of Scott C. Baker, son
Cheryl Pachinger, Newark, CA	In honor of Jeffrey Pachinger
Doreen Parks, Oro Valley, AZ	In honor of Matt Parks
Sherilee Parsell, Vero Beach, FL	In honor of Bo Gelsimino
Philip Pearlstein and Connie Yetter, Cinnaminson, NJ	In memory of Barbara Yetter
Bill and Alice Petree, Sanford, FL	In memory of Alan Singletary
Cheryl Phillips, Omaha, NE	In memory of Michele Rawson
Larry and Colleen Phipps, Chico, CA	In honor of Donovan Phipps
Alan Pierce and Linda Van Broeke-Pierce, Austin, TX	In honor of our cousin, Everett Drake
Holly Pressman, Greenwich, CT	In honor of Dr. Bruce Waslic
Ram and Sheela Ratan, Redlands, CA	In honor of Philip Ram Ratan
A.E. and Helen Ridolfi, Auburn, CA	In memory of Robert Neal
Marie Royce, Alexandria, VA	In honor of St. Jude
Roger Russell, Silver Spring, MD	In memory of Michele Russell
Mary Ryan, Hastings, FL	In honor of Alexa Markiewicz and Susan Shacklock
Marsha Ryle, Emeryville, CA	In memory of Albert Turk
Heidi Sanborn, Sacramento, CA	In honor of Joyce Peterson
Glory Sandberg, Wilmington, DE	In memory of Sharra Taylor Hurd
Kenneth and Suzanne Schneider, Amherst, OH	In memory of Elvis Ian Iskenderian
M & Louise Schnur, Auburn, CA	In memory of Jack Jones (my brother)
Joy Scoble, Clifton, NJ	In honor of George Scoble
Fred and Bernice Seifter, Matawan, NJ	In memory of Mark Seifter
Sylvia Sheldon, Miami, FL	In honor of Ben Sheldon
Todd Sherbacow, Washington, DC	In honor of support for TAC
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# Memorials and tributes (continued)

Hilary Silver, Stockton, CA	In honor of Aram Silver
Mary Silverstein, Philadelphia, PA	In honor of Jane Silverstein
Ingrid Silvian, Groveport, OH	In honor of Deborah Gleeson
Eleanor Slater, Pittsburgh, PA	In honor of Laura Nowakowski
Jane Smith-Decker, Millersburg, PA	In honor of Dr. Susan Thornsley
Jane Smith-Decker, Millersburg, PA	In memory of Judith Gourniak
Jane Smith-Decker, Millersburg, PA	In honor of Rahn Smith
Harding and Marion Sortevik, Amherst, NH	In honor of son, Paul
Shari Steinberg, New York, NY	In honor of Mary Z.
Henry and Nadine Stevens, Westbury, NY	In honor of Charles E. Stevens
Vic and Linda Taggart, Seattle, WA	In honor of Alicia Taggart
The Rogers Family, Deptford, NJ	In honor of Lauren Rogers
Dorothy Thorman, Altadena, CA	In memory of Carol Thorman
Elizabeth Tobinski, Salt Lake City, UT	In memory of Vicki Cottrell
Fuller and Barbara Torrey, Bethesda, MD	In honor of Ted & Vada Stanley
Donald and Judith Turnbaugh, Palm Harbor, FL	In honor of Daniel Moschelli
Ed Turner, Dumfries, VA	In honor of Geraldine Weeks
C.M. and Judith Valentine, Pigeon, MI	In honor of Laurn Valentine
Robert Vance, Kendallville, IN	In honor of Colin Vance
Susan Warren, Albuquerque, NM	In honor of Eric Livingston
Ralph and Pat Webdale, Fredonia, NY	In honor of 7 years of missing Kendra, and supporting her legacy
Edit White, Chicago, IL	In honor of Christopher J. White
Robert and Joyce White, York ,PA	In honor of David A. White
Donald Wickes, Marina Del Rey, CA	In honor of Mary M. Wolff
Joel and Diane Wier, Columbia, SC	In honor of Dr. Tom Mercer
Nick & Amanda Wilcox, Penn Valley, CA	In memory of Laura Wilcox
Kevin Wilkinson and Francine Levine, Montpelier, VT	In honor of Max Levine-Wilkinson
Michele Wollert, Vancouver, WA	In memory of Jonathan Woller
Joyce Wood, Auburn, CA	In honor of Douglas P. Wood, diagnosed paranoid schizophrenic
Susan and Richard Wuhrman, Bellevue, WA	In memory of Mike Robb
Marilyn Wyatt, Columbia, SC	In memory of Joseph Wyatt
Jill Zaheer, Riverdale, NY	In honor of Rebecca Zaheer

# Riveting new book on the fight for treatment

Pete Earley had been a journalist for over 30 years – but he had always been on the outside looking in. When his son Mike was declared mentally ill, Earley was thrown headlong into the maze of contradictions that is America's mental health system. His new book is an intense look at what he found. Author Bebe Moore Campbell says "Earley takes us on his compelling journey through psychiatric wards, jails and urban streets in search of his son's sanity. In the process, this courageous journalist gives us a blueprint for saving minds, healing spirits and making the mental health system accountable to those it purports to help ... *Crazy* is both a clarion call for change and justice and an enthralling portrait of a father who refused to surrender." And Senator Pete and Nancy Domenici say "A book as riveting to read as it is important it be read .... Many of the tragic situations he uncovers were preventable. Maybe, with this book, they can be."



My son was so out-of-control that a nurse called hospital security.

I was glad. Maybe now they will medicate him, I thought.

But before the security guard arrived, Mike dashed outside, cursing loudly .... Meanwhile, the doctor told my ex-wife that it was not illegal for someone to be mentally ill in Virginia. But it was illegal for him to treat them unless they consented. There was nothing he could do.

"Even if he's psychotic?" she asked. "Yes."

Mike couldn't forcibly be treated, the doctor elaborated, until he hurt himself or someone else.

Crazy: A Father's Search Through America's Mental Health Madness, by Pete Earley 374 pages, April 2006, G.P. Putnam's Sons; ISBN0-399-15313-6

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"TAC can change laws and encourage treatment, but ultimately it is the mental health professionals who have to make it happen. They are the bedrock of the system. The battle for treatment is one that they wage every day in ways large and small. It is an effort and sacrifice that should not be ignored." - E. Fuller Torrey, M.D.

Why support the Treatment Advocacy Center? We fight hard. For a small organization, we have tremendous successes in getting messages about the value of assisted outpatient treatment and the consequences of lack of treatment out to the audiences who most need to hear them. Already in 2006, TAC has reached more than 10 million readers in newspapers nationwide, from *The New York Times* to the *Santa Fe New Mexican*.

The president of the American Psychiatric Association calls what we do "extraordinary advocacy." We need your help to sustain this campaign for treatment, especially against the well-funded opposition. TAC is firm about not accepting funding from pharmaceutical companies, so our success hinges on support from generous donors like you. Every donation, large or small, makes a difference. Thank you for helping us keep the pressure on and get the message out.

#### I want to help the Treatment Advocacy Center with a gift of \$ \_\_\_\_\_

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Charge my credit card (check one): VISA	Mastercard AMEX
Account number:	Expiration date:
Signature (as on card):	
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City: State: ZIP:	200 North Glebe Road, Suite 730
Phone:	Arlington, VA 22203
Email:	The Treatment Advocacy Center is a nonprofit 501(c)(3) organization. Gifts are tax-deductible to the extent allowed by law.
☐ Gift is in memory of: ☐ Gift is in honor of:	TAC does not accept funding from pharmaceutical companies.
	Spring 2006