Welcome Issue Catalyst
TREATMENT ADVOCACY CENTER
Special Edition – Welcome Issue

Origins of the Treatment Advocacy Center

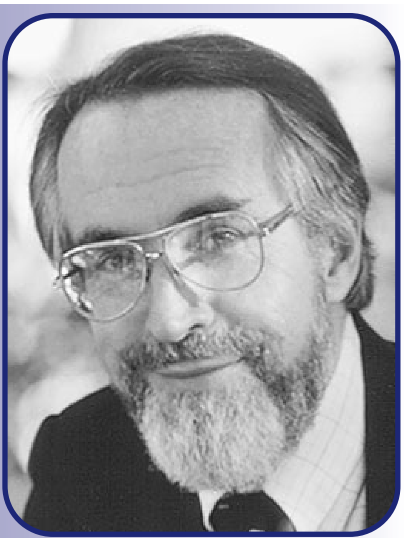
by E. Fuller Torrey, M.D., President

The Treatment Advocacy Center is a product of two circumstances. First, for 15 years, I ran a clinic for homeless individuals with severe psychiatric disorders. I was saddened by the quality of many of their lives (e.g., eating out of garbage cans, women being raped, etc.) and by how many of them had little or no awareness of their illness because of their brain dysfunction. Many of them would not accept medication or other treatment because they did not believe they were sick.

The other circumstance was writing *Out of the Shadows: Confronting America's Mental Illness Crisis,* during which I became aware of studies showing a continuing increase in the number of severely mentally ill individuals in jails and prisons. I had visited jails in 15 states and was aware that the quality of life for severely mentally ill prisoners is abysmal. I was also profoundly impressed by the increase in episodes of violence associated with non-treatment; these episodes of violence are the primary cause of stigma against mentally ill persons, and it seemed to me that it would be difficult, if not impossible, to decrease stigma until we first decreased violence.

Mr. and Ms. Stanley, who were generously supporting research on schizophrenia and bipolar disorder, shared my concern and offered to help. After extensive consultations with other mental illness professionals and lawyers, we decided that the initial focus of our efforts would be to address state treatment laws that prevent the treatment of severely mentally ill individuals who are deteriorating before they became homeless or incarcerated. A secondary objective would be to improve the treatment system, including the abolition of the IMD exclusion, so that psychiatric services could deliver what patients need, not merely what federal Medicaid would cover.

The Center formally came into existence in the summer of 1998, when we opened our office in Arlington. From the outset, we were aware that we would encounter substantial and well-organized opposition. This has included civil libertarians and a small but vocal group of ex-patients who believe that nobody, no matter how psychotic, should be involuntarily treated; anti-medication professionals who acknowledge receiving support from anti-treatment forces; and the Bazelon Center for Mental Health Law, which is largely responsible for the anti-treatment bias in state treatment laws. We also knew that our efforts would be opposed by many of the federally funded Protection and Advocacy (P and A) programs, many of which continue to advise patients on how to avoid treatment, and by the federal Center for Mental Health Services, which has funded "consumer-survivor" conferences at



E. Fuller Torrey, M.D., President
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OUR MISSION

THE TREATMENT ADVOCACY CENTER IS A NONPROFIT ORGANIZATION DEDICATED TO ELIMINATING LEGAL AND CLINICAL BARRIERS TO TIMELY AND HUMANE TREATMENT FOR AMERICANS WITH SEVERE BRAIN DISORDERS WHO ARE NOT RECEIVING APPROPRIATE MEDICAL CARE. FOCUSING ON SCHIZOPHRENIA AND MANIC-DEPRESSIVE ILLNESS (BIPOLAR DISORDER), THE CENTER WORKS TO PREVENT THE DEVASTATING CONSEQUENCES OF NON-TREATMENT: HOMELESSNESS, SUICIDE, VICTIMIZATION, WORSENING OF SYMPTOMS, VIOLENCE, AND INCARCERATION.

AN ESTIMATED 1.4 MILLION INDIVIDUALS WITH SCHIZOPHRENIA AND MANIC-DEPRESSIVE ILLNESS ARE NOT BEING TREATED FOR THEIR ILLNESS AT ANY GIVEN TIME. ASSISTED TREATMENT (SUCH AS OUTPATIENT COMMITMENT, SUBSTITUTED JUDGEMENT, OR GUARDIANSHIP) MUST BE PROVIDED BEFORE INDIVIDUALS BECOME A DANGER TO THEMSELVES OR OTHERS, PARTICULARLY FOR THOSE WHO LACK AWARENESS OF THEIR ILLNESS—A COMMON SIDE-EFFECT OF THESE DEVASTATING DISORDERS.

CURRENT FEDERAL AND STATE POLICIES HINDER TREATMENT FOR PSYCHIATRICALLY ILL INDIVIDUALS. THE CENTER IS WORKING ON THE NATIONAL, STATE, AND LOCAL LEVELS TO EDUCATE CIVIC, LEGAL, CRIMINAL JUSTICE, AND LEGISLATIVE COMMUNITIES ON THE BENEFITS OF ASSISTED TREATMENT.

Catalyst

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and letters to the editor

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which patients are instructed how to stop taking medication. Some of these groups have already threatened litigation to block the use of new laws that would make treatment more accessible to those who refuse it.

Despite this opposition and the formidable barriers to reversing the non-treatment trend of more than two decades, we launched the Center's efforts to be a voice for those who cannot speak for themselves because of their illness. In doing so, we were encouraged by the people with whom we consulted, including some who had previously been on the other side of the treatment issue. There was virtually unanimous agreement that "the pendulum had swung too far toward non-treatment." Therefore, the Center is pushing the pendulum back toward a more reasonable center.

Meet President E. Fuller Torrey, M.D.

E. Fuller Torrey, M.D. is the leading research psychiatrist specializing in schizophrenia. In addition to his role at the Center, he is executive director of the Stanley Foundation Research Programs, which support research on schizophrenia and manic-depressive illness. He is also a guest researcher with the Clinical Brain Disorder Branch of the National Institute of Mental Health (NIMH).

He was on the clinical staff of St. Elizabeth's Hospital for nine years, specializing in the treatment of severe psychiatric disorders. After that, Torrey directed a major study of identical twins with schizophrenia and manic-depressive illness. His research has explored viruses as a possible cause of these disorders, and he has carried out research in Ireland and Papua New Guinea.

Dr. Torrey earned his B.A. Magna Cum Laude at Princeton University. He received his M.D. at McGill University and an M.A. in Anthropology at Stanford University. He trained in psychiatry at Stanford University School of Medicine.

He practiced general medicine in Ethiopia as a Peace Corps physician, in the South Bronx in an O.E.O. Health Center, and in Alaska in the Indian Health Service. He was a special assistant to the Director of the National Institute of Mental Health for five years.

Dr. Torrey has also written 15 books and more than 200 lay and professional papers including: *Out of the Shadows: Confronting America's Mental Illness Crisis*; *Care of the Seriously Mentally Ill: A Rating of State Programs*; and *Surviving Schizophrenia: A Family Manual*. Some of his books have been translated into Japanese, Russian, Italian, and Polish.

In addition to books and papers, Dr. Torrey has written for many national newspapers. He also has regularly appeared on national television news programs and talk shows.

Dr. Torrey was one of ten recipients of a National Caring Award, and the U.S. Public Health Service twice awarded him Commendation Medals. NAMI awarded him the Special Families Award as well.

A Catalyst To Stop Forced Suffering From the Consequences of Nontreatment

by Mary T. Zdanowicz, J.D., Executive Director

The inaugural issue of the Treatment Advocacy Center's newsletter was dedicated in memory of Kenneth Scott Hardman. Scott was one of countless victims of an untreated mental illness, taking his own life after years of torment. Scott's plight brought his mother, Lorraine Gaulke to the Treatment Advocacy Center and inspired her to become the editor of *Catalyst.* Our collective hope is that this newsletter will serve as a catalyst for change to eliminate barriers to treatment for individuals suffering from serious mental illnesses, such as schizophrenia and manic-depressive illness.

How did we get to the point where so many individuals with serious mental illness are suffering needlessly? To answer that question, we must look back twenty or thirty years to legal and policy reforms that make it virtually impossible today to treat an individual who refuses treatment until they become dangerous.

Before returning to the past, it is important to recognize how much our understanding of and ability to treat these illnesses has advanced since that time. According to the National Advisory Mental Health Council, the treatment success rate for schizophrenia is comparable to the treatment success rate for heart disease, and the treatment success rate for manic-depressive illness is a remarkable 80 percent. Yet, on any given day, approximately 40 percent of individuals with schizophrenia and manic-depressive illness are not receiving treatment. We now know that a major contributing factor to treatment non-compliance is lack of insight, a symptom in which the illness affects that part of the brain that is used for self-monitoring and causes the individual to lack awareness of his or her illness. Studies have shown that approximately half of all patients with schizophrenia and mania have markedly impaired awareness of their illness as measured by tests of insight; thus, they are similar to some patients with cerebrovascular accidents (strokes) and Alzheimer's disease. Such individuals consistently refuse to take medication because they do not believe they are sick.

We also have ample evidence of the devastating consequences of non-treatment. Up to 13% of individuals with schizophrenia and 15% of individuals with manic-depressive illness commit suicide. Approximately 150,000 individuals with serious mental illness are homeless. As much as 16% of the population of our nation's jails and prisons, more than 280,000 individuals, suffer from these illnesses. Individuals with severe psychiatric disorders are 2.7 times more likely to be victims of violent crimes than the general population. Studies suggest that the adverse effects of delaying treatment include: increased treatment resistance, worsening severity of symptoms; increased hospitalizations, and delayed remission of symptoms. A leading cause of stigma is the nearly 1,000 homicides each year in the United States that are committed by individuals who are not being treated for these illnesses.

Individuals who suffer from lack of insight and refuse treatment often go untreated unless some form of assisted treatment is provided. Assisted treatment occurs when a person with a severe mental illness is treated over an expressed objection. Assisted treatment is necessary when a person is: gravely disabled; in danger of substantial deterioration; incapable of making an informed decision about treatment (e.g. lacks insight into his illness); and/or poses a danger to himself or others.

There are many forms of assisted treatment, such as involuntary civil commitment, assisted outpatient treatment, guardianship or conservatorship. Assisted outpatient treatment has been demonstrated in numerous studies to be an effective means of ensuring medication compliance and reducing hospitalizations for individuals who suffer from severe mental illnesses, such as schizophrenia and manic depressive illness, but refuse treatment. The study of the Bellevue Hospital Pilot Outpatient Commitment Program showed that, although not statistically significant, there was a significant difference in the need for hospitalization between individuals with an assisted outpatient treatment order and those who did not have an order. In fact, individuals with treatment orders spent 57% less time in the hospital than those without orders. A report prepared by the individuals responsible for implementing the Bellevue Program described some of the benefits of the orders to include the following:

For some patients, the order allows initial engagement with service providers, and is rarely an issue after that time. For other patients, the order serves as an ongoing reminder that compliance with outpatient treatment is necessary to prevent relapse and rehospitalization. And outpatient commitment orders appear to increase feelings of accountability among patients about managing serious symptoms of mental illness such as hallucinations, paranoia and fluctuations in mood.

Thirty years ago, a course of events transpired that made the provision of assisted treatment exceedingly difficult. During the civil rights revolution in this country, a group of lawyers set out to represent the rights of individuals with mental illness. The goal of these attorneys, who came to be known as the mental health bar, was not to focus on the treatment needs of such persons, but rather to free people regardless of the consequences. Bruce Ennis, the founder of the mental health bar stated, "My personal goal is either to abolish involuntary commitment or to set up so many procedural roadblocks and hurdles that it will be difficult, if not impossible, for the state to commit people against their will."

The mental health bar saw an opportunity to reduce commitments by confining the basis for commitment to dangerousness. This changed the whole focus and perception of civil commitment; it redirected the purpose of involuntary commitment from a therapeutic one to one based on protecting society by removing those individuals who are dangerous. It was, and still is portrayed by many as punitive, rather than therapeutic. One of the first important federal cases, Lessard v.

(continued on page 14)

Treatment Advocacy Center Honorary Advisory Committee

The Committee is composed of distinguished individuals who are devoted to improving the lives of individuals who suffer from severe mental illnesses. Each individual has made his or her own contributions to furthering that goal. We thank them for their work and for supporting our mission.

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Kendra's Law--The Culmination of a 10-Year Battle for Assisted Outpatient Treatment in New York

by E. Fuller Torrey, M.D., President, & Mary T. Zdanowicz, J.D., Executive Director

Before Governor Pataki signed the bill that became Kendra's Law on August 9, 1999, New York was one of only 10 states without an assisted outpatient treatment law. Following on the heels of a largely unsuccessful 10-year effort by advocates in New York to pass the law, the Treatment Advocacy Center played a decisive role in making court-ordered community treatment available throughout the state. The history of this effort may be helpful to others who would like to pursue similar reforms in their own states.

Assisted outpatient treatment was first proposed in New York in 1989 as a way to help individuals with brain disorders who suffer because their illness prevents them from accepting treatment. In 1994 the New York City chapter of NAMI convinced the New York legislature of the need for assisted outpatient treatment. The legislature established a watered-down, three-year pilot program, recognizing that "some mentally ill persons frequently reject the care and treatment offered them on a voluntary basis and decompensate to the point of requiring repeated psychiatric hospitalizations."

The statutory authorization for the Bellevue pilot program was scheduled to expire June 30, 1999. The New York Treatment Advocacy Coalition (NYTAC) was formed in late 1998 to mobilize support for both extending the pilot program and to make assisted outpatient treatment available statewide. DJ Jaffe, Treatment Advocacy Center Board member and long-time advocate for individuals with neurobiological disorders, is NYTAC's coordinator. Jonathan Stanley, Treatment Advocacy Center Assistant Director, serves as the NYTAC liaison. DJ, Jon, and NYTAC members were tireless in their efforts.

As the new year approached, it was not clear that New York legislators had the political will to extend assisted outpatient treatment. All of that changed on January 3, 1999, when Kendra Webdale, a beautiful, vivacious, 32-year-old woman was pushed to her death in front of a New York subway train by a man with untreated schizophrenia. Her family explained that, "Kendra was the kind of person who would have tried to help the kind of person who pushed her."

Governor George Pataki (R-NY) with Treatment Advocacy Center Board member, DJ Jaffe, after press conference announcing agreement to pass Kendra's Law on August 3, 1999

Immediately following the incident, New York's newly elected Attorney General, Eliot Spitzer, contacted the Treatment Advocacy Center. He was seeking a means of helping both individuals with brain disorders and the communities where they live. The Treatment Advocacy Center recommended that the Attorney General pursue passage of a comprehensive assisted outpatient treatment law for New York. On January 28, 1999, the Attorney General announced his proposal for statewide assisted outpatient treatment and acknowledged the assistance provided by the Treatment Advocacy Center in crafting the bill.

The Treatment Advocacy Center also partnered with Kendra Webdale's family, who, as a tribute to Kendra, were seeking a way to improve the quality of life for individuals who suffer from severe mental illnesses and their communities. They enthusiastically supported the bill and allowed it to be named "Kendra's Law."

As if Kendra's death was not enough to demonstrate the need for assisted treatment, more tragedies soon followed. On April 6, 1999, Charles Stevens, a 37-year-old man with untreated schizophrenia, wearing fatigues and wielding a sword, was shot eight times by police on a Long Island Railroad train. Remarkably, he lived.

On April 28, 1999, Edgar Rivera, a 36-year-old father of three young children, was pushed in front of a subway train by a man with untreated schizophrenia. Mr. Rivera lived, but lost part of his legs. Mr. Rivera, like the Webdales, showed compassion for his assailant. At the hospital he said, "I have no legs, but at least I have my mind. This guy doesn't have that. I think I'm ahead."

The Treatment Advocacy Center approached the Rivera and Stevens families and found that they, too, enthusiastically supported Kendra's Law. Kendra Webdale's family, Charles Stevens' family, and Edgar Rivera and his family joined forces with NYTAC and the Treatment Advocacy Center to advocate for Kendra's Law. The Center for the Community Interest also played a vital role in the campaign.

From then on, momentum for passage started building.

The families set out on meetings with newspaper editorial boards, reporters and legislators. While support from the conservative media was expected, support from New York's more liberal media was not. Major breakthroughs occurred when the *New York Times* and *Newsday*, two liberal publications, joined conservative publications like the *New York Post* and *Daily News* in support of Kendra's Law. In fact, New York's six largest newspapers all enthusiastically supported Kendra's Law. The numerous letters written by NYTAC members no doubt contributed to this success.

The Webdale family arranged meetings with Republican Governor George Pataki's counsel and invited the Treatment Advocacy Center to attend. Following the meetings, Governor Pataki joined the effort to pass Kendra's Law. Democratic Assembly Speaker Sheldon Silver announced his support of Kendra's Law with Attorney General Spitzer in a press conference on May 19, 1999, and invited the Stevens, the Webdales, and the Treatment Advocacy Center. The same day, Governor Pataki introduced a slightly different version of Kendra's Law.

The slight differences in the bills provided an opportunity for opponents to try to divide and conquer. A further complication was that the legislature became engaged in a protracted battle over the state budget. However, the Treatment Advocacy Center, NYTAC members, the Webdale, Stevens and Rivera families kept the pressure on and continued to build its coalition. In June the New York State Association of Chiefs of Police passed a Memorandum in Support of Kendra's Law.

The efforts culminated on August 3, 1999, when Treatment Advocacy Center staff, the Webdales, and Mr. Rivera traveled to Albany to hold a press conference to beseech the Governor and the legislature to enact Kendra's Law. Shortly before our press conference was scheduled to begin, the Governor announced that a political agreement to pass Kendra's law had been reached. One hour later, Governor Pataki and leaders of the State Senate and Assembly held their own press conference announcing that they reached an agreement to pass Kendra's Law. The bill subsequently passed the legislature by an overwhelming majority (Senate 49-2/Assembly 142-4) and was signed into law on August 9, 1999.

The efforts to pass Kendra's Law shed light on the failures of the mental illness treatment system in New York. As a result, Kendra's legacy is even more than bringing assisted outpatient treatment to New York.

On November 9, 1999, Governor Pataki announced that he is halting the decades-old failed deinstitutionalization policy in New York. The Governor proposed infusing an additional $125 million in the budget for community-based services, of which $52 million is earmarked for assertive community treatment, and $20 million will create 2,000 new supervised housing units. This brings the Governor's total commitment for increased budget allocations this year to $420 million for community treatment, supervised housing, and implementation of Kendra's Law. The Governor is also suspending the push to eliminate 2,300 of New York's existing 6,000 inpatient psychiatric hospital beds (down from 96,664 beds in 1955).

It is sad that years of efforts by relentless mental health advocates like DJ Jaffe to secure the benefits of assisted outpatient treatment for citizens with severe mental illness had previously yielded such meager results. It is also discouraging that tragedies and concerns about public safety became the catalysts to make Kendra's Law a reality. However, it is a lesson about the importance of advocating outside the traditional mental health arena and involving those with an interest in public safety and the victims of untreated mental illness. The bill clearly would not have passed had it not been for Attorney General Eliot Spitzer, the Webdales, the other families, the Center for the Community Interest, and the Treatment Advocacy Center.

In the end, Kendra's Law will benefit individuals with severe mental illnesses because treatment will finally be accessible to those who need it most. Achieving that goal is the only hope of ending the senseless tragedies that make headlines; the ones that are responsible for creating stigma against individuals with brain disorders. It is the first real prospect of a better quality of life for individuals who are most ill with these devastating diseases of the brain.

[Note: Visit www.psychlaws.org (State Activity/NY) for a copy of Kendra's Law and the Treatment Advocacy Center's summary, A Guide to Kendra's Law.]

Kendra's Law At Work

As of June 1, 2001, 1119 assisted outpatient treatment orders—each of which by law must provide for either assertive community treatment teams or intensive case management—had been issued under Kendra's Law. Investigations not leading to orders had resulted in enhanced services for an additional 813 people in need of treatment.

Based on preliminary findings for the first 141 people in assisted outpatient treatment (as of January 2001), those in the Kendra's Law program have experienced a:

- **129% increase in medication compliance;**
- **194% increase in case management use;**
- **107% increase in housing services use;**
- **67% increase in medication management services use;**
- **50% increase in therapy use;**
- **26% decrease in harmful behavior; and**
- **100% decrease in homelessness.**

Sources:
New York State Office of Mental Health web site: www.omh.state.ny.us, Statewide AOT Report as of June 1, 2001 (viewed June 19, 2001). New York State Office of Mental Health, Progress Report on New York State's Mental Health System (Jan. 2001), pp. 16-18.

Refusing to Settle for Pigeon Research

Despite a promise "to continue phasing out questionable or irrelevant research," the National Institute of Mental Health (NIMH) continues to fund as many research grants for the study of pigeons as it funds to study the clinical or treatment aspects of manic-depressive illness. We must refuse to settle for pigeon research when so much rides on NIMH accomplishing its mission to "reduce the burden of mental illness through research."

On September 6, 2000, the Treatment Advocacy Center released ***Missions Impossible: The Ongoing Failure of NIMH To Support Sufficient Research on Severe Mental Disorders.***[1] This report documents that only 22.1 percent of NIMH's 1999 research grants were related to the most severe disorders. Even more glaringly, only 8.3 percent of the institute's funding went to the clinical or treatment aspects of these illnesses.

Missions Impossible compares the number of NIMH research grants for schizophrenia, manic-depressive illness, severe depression, and other severe mental disorders with the number of NIMH grants for the study of pigeons, songbirds, fish, and crickets. The report exposes how NIMH has also lost track of its primary mission through its allocation of substantial research resources to human and social problems that are the responsibility of other government agencies.

A review of 1,349 new research grants funded by NIMH revealed that:

♦ For schizophrenia, which affects 2.2 million adult Americans, NIMH approved 110 new research grants, including 35 related to clinical and treatment aspects. At the same time, NIMH funded more than 110 other grants on subjects that should have been assigned to other divisions of the National Institute of Health (NIH), such as the National Cancer Institute.

♦ For major depression, which affects 9.9 million adult Americans, NIMH approved 120 new research grants, including 57 related to clinical or treatment aspects. At the same time, NIMH funded more than 120 other grants that should have been assigned to other government agencies outside of NIH, such as the Department of Education.

♦ For manic-depressive illness, which affects 1.6 million adult Americans, NIMH approved 32 new research grants, including 7 related to clinical or treatment aspects. At the same time, NIMH also funded 7 new research grants to study pigeons.

Despite promises by its leaders to rededicate the Institute to its fundamental mission, ***Missions Impossible*** finds no increased distribution of NIMH resources to severe mental disorders last year as compared to 1997. It notes that, "Breast cancer, cognitive process of birds, alertness of railway engineers, reading problems, students' transition to middle school, adolescent romantic relationships, daytime sleepiness, how emotion is perceived in music—there are virtually no boundaries to what NIMH is currently funding." The report emphasizes that much of the behavioral and basic neuroscience research being funded by NIMH is worthwhile but should logically be done by the National Science Foundation and other government agencies. NIMH is only able to allocate significant resources to such research by neglecting severe mental disorders.

The report makes five recommendations for improving the NIMH research portfolio:

♦ Rapidly and markedly increase NIMH research spending on severe mental disorders.

♦ Hold Congressional hearings to clarify the primary mission and priorities of NIMH.

♦ Merge NIMH with the National Institute of Neurological Disorders and Stroke to create a National Brain Research Institute.

♦ Change the name of NIMH to the National Institute of Mental Illnesses, as an interim measure.

♦ Shift large amounts of basic behavioral research from NIMH to the National Science Foundation.

Missions Impossible is a call to action for those with a vested interest in research into the nature, treatment and prevention of severe mental illness. The AIDS movement would never acquiesce to a similar failure to do AIDS research. Nor would the breast cancer community concede research funds that are so desperately needed. We also must refuse to relent in our demands for vital research. We must keep hope alive. Contact your representatives in Congress. Tell them not to let NIMH go to the birds!

[To view the full report online, visit the Center's web site at: www.psychlaws.org or more specifically, www.psychlaws.org/nimhreport/index.htm. For copies of the report, contact the Treatment Advocacy Center at 703-294-6001, or by email to: info@psychlaws.org.

[1] The report is authored by E. Fuller Torrey, M.D., President, Treatment Advocacy Center; Irving I. Gottesman, Ph.D., Department of Psychology, University of Virginia; John M. Davis, M.D., Department of Psychiatry, University of Illinois; Michael B. Knable, D.O., Stanley Foundation Research Programs; and Mary T. Zdanowicz, J.D., Executive Director, Treatment Advocacy Center.]

The Duke Studies

The Duke Studies are the largest and most respected of the controlled examinations of assisted outpatient treatment (AOT). Among the released findings of this one year randomized trial:

AOT Reduces Hospitalizations: Assisted outpatient treatment for more than 6 months, combined with routine outpatient services (3 or more outpatient visits per month), reduced hospital admissions by 57% and length of hospital stays by 20 days.

AOT Reduces Arrests: For a subgroup with a history of multiple hospitalizations as well as prior arrests and/or violent behavior, the re-arrest rate of those in AOT for more than 6 months was one-quarter (12 % versus 47%) that of those who were not under treatment orders.

AOT Reduces Violence: Assisted outpatient treatment of more than 6 months combined with routine outpatient services reduced the incidence of violence in half (24% versus 48%).

Sources:

Swartz, M.S., Swanson, J.W., Wagner, R.H., et al: ***Can involuntary outpatient commitment reduce hospital recidivism? American Journal of Psychiatry,*** 156:1968-1975 (1999).

Swanson, J.W., Borum, R., Swartz, M.S., et al: ***Can involuntary outpatient commitment reduce arrests among persons with severe mental illness? Criminal Justice and Behavior***, Vol. 28, No.2: 156-189 (2001).

Swanson, J.W., Swartz, M.S., Borum, R., et al: ***Involuntary outpatient commitment and reduction of violent behaviour in persons with severe mental illness. British Journal of Psychiatry***,176: 224-231 (2000).

Model Law for Assisted Treatment

by Jonathan Stanley, J.D., Assistant Director

Released in 2000, the Treatment Advocacy Center's ***Model Law for Assisted Treatment*** is a cautiously considered proposal to promote the provision of care for those who need it because of the effects of severe mental illness. At the same time, the Model Law includes numerous overlapping protections to safeguard those under court-ordered treatment and to ensure that only those for whom it is appropriate are placed or remain in assisted treatment.

The Model Law is more remarkable for what it is not than for what it is. It incorporates a host of substantive and procedural mechanisms common to current laws for securing treatment for those overcome by mental illness.

A cursory examination may give the impression that the Model Law maintains the status quo when it is actually a compilation of the most effective provisions of existing state laws. Variations of virtually all of this proposal's sections are the current law somewhere in the United States. In essence, we have combined each of the best available components into a statutory model better than any currently in effect.

Only in one area have we dared to be creative: the protection of the rights and well being of those placed in assisted treatment. There we put forth procedures more extensive and vigilant than those now in place anywhere in the nation.

Following is a description of some of the key aspects of the Model Law.

STANDARDS

In developing a system to place individuals in psychiatric care, the most crucial question is, "When is such an intervention appropriate?" In addition to the common treatment eligibility criteria based on being a danger to self or others, the Model Law sets out two additional standards that can justify assisted treatment.

1. **Chronically disabled:** Only a few states have criteria designed to help people stuck in the "revolving door" of repeated hospitalizations, symptomatic behavior, and, for many, incarcerations. "Chronically disabled" allows consideration of possible harm to a person with symptomatic mental illness in light of past psychiatric history (which would include previous non-compliance with treatment), current likelihood of treatment compliance, and the risk of deterioration without treatment.

2. **Gravely disabled:** A number of states have included "gravely disabled" as grounds for treatment placement. Most of these laws define this condition as when a person becomes so incapacitated by mental illness as to lose the ability to provide for his or her basic needs, with these normally delineated as food, clothing, shelter and, sometimes, medical care. The Model Law mimics the more progressive of the jurisdictions with gravely disabled criteria by explicitly including someone who is likely to suffer significant harm without treatment.

Incapable of making an informed medical decision: While not an independent ground for treatment placement, the "gravely disabled" and "chronically disabled" criteria each also requires that the person is either unaware that he or she is ill or is otherwise incapable of making rational decisions concerning proposed treatment. Non-dangerous individuals who are capable of making informed medical decisions should not be placed in assisted treatment.

PROVISIONS PROMOTING CLINICAL AND JUDICIAL EFFICIENCY

Many provisions of existing assisted treatment laws make little sense. They delay needed treatment, are inefficient from either a judicial or clinical perspective, or are concepts from other areas of law ill tailored to assisted treatment proceedings. The Model Law adopts procedures from various states that promote both clinical and judicial efficiency.

Combined Commitment and Treatment Proceedings: Although a common practice, the disadvantages of having separate hearings on whether a person should be committed and on his or her capacity to refuse treatment are patent. Having an interval between rulings on commitment and treatment produces the inherently cruel circumstance of medical professionals having to confine a psychotic or delusional patient without being able to provide treatment. Under the Model Law, the judicial determinations about treatment placement and the ability to refuse treatment are made in the same hearing. There is no reason either logically or constitutionally, that both decisions should not be made concurrently.

Psychiatric Treatment Board: Most times, the decisions of whether or not to place a person in treatment and, if so, what type of care is most appropriate are left to a judge with little experience with or understanding of mental illness. The Model Law's decision-maker is a judicially empowered panel made up of a lawyer, a physician and a person who has demonstrated experience, either personally or through a close relative, with mental illness.

Treatment plans: Extensive services may be included in an assisted treatment order providing for treatment on an outpatient basis. A treatment plan is mandatory for a person being discharged from assisted treatment.

PROVISIONS PROTECTING CONSUMER AND FAMILY RIGHTS

Where the Model Law does substantially depart from existing state laws is in enhancing the rights guaranteed to people with mental illness placed in assisted treatment and the rights of their families.

Family rights: Under the Model Law, relatives may, under certain circumstances, become actual parties to the assisted treatment proceeding, with the right to have counsel, present evidence, cross-examine witnesses, and appeal. When bringing a petition, family members are also eligible for the assistance of designated counsel.

Consumer rights: The Model Law has an extensive number of protections for those placed in assisted treatment. Subjects of assisted treatment petitions have the rights delineated in most state laws, i.e., designated counsel, presentation of witnesses, to appeal, not having placement in treatment not otherwise affect one's legal status, etc. Additionally, the Model Law introduces two novel procedures. Included is a formal grievance procedure whereby patients can bring complaints to the facility's medical director and, if necessary, to the Psychiatric Treatment Board. Perhaps even more significantly, the Model Law calls for the examination of a person placed on inpatient assisted treatment for medication side effects every thirty days by a psychiatrist or physician other than the one treating him or her.

American Psychiatric Association
Resource Document on Mandatory Outpatient Treatment
Summary of Conclusions and Recommendations

1. Mandatory outpatient treatment, properly implemented, can be useful as part of a program of intensive outpatient services to improve compliance, reduce rehospitalization rates and decrease violent behavior among a subset of the severely and chronically mentally ill.

2. Mandatory outpatient treatment should be available to help prevent relapse or deterioration for patients who currently may not be dangerous to themselves or others but whose relapse would predictably lead to sever deterioration and/or dangerousness.

3. Predictions about the likelihood of relapse, deterioration, and/or future dangerousness to self or others should be based on the occurrence of such episodes in the recent past.

4. Mandatory outpatient treatment should be available to patients who as a result of their mental illness are unlikely to seek or comply with needed treatment, but not just those who lack insight.

5. Studies show mandatory outpatient treatment is most effective when it includes intensive services, such as the assertive community treatment or intensive case management models. States adopting mandatory outpatient treatment statutes must assure that adequate resources are available.

6. Studies show that long-term mandatory outpatient treatment (i.e. at least 180 days) is most successful. Mandatory outpatient treatment statutes should authorize initial commitment periods of 180 days and should permit extensions based on specified criteria demonstrated at regularly scheduled hearings.

7. Thorough medical examination should be a required component of mandatory outpatient treatment since many patients also suffer from medical illness and substance abuse disorders.

8. Clinicians must be involved in the decision-making process to assure that the proposed treatment plan is feasible and appropriate. The judge should ensure that the recommended treatment is available through the proposed provider before issuing an order.

9. Patients should be consulted about their treatment preferences and should be provided with a copy of the mandated outpatient treatment plan.

10. Mandatory outpatient treatment statutes should contain specific procedures for patient noncompliance (i.e. empowering law enforcement officers to bring non-compliant patients to a treatment facility for evaluation and specific provisions for a court hearing if patient's noncompliance is substantial and informal efforts will not likely motivate compliance).

11. Psychotropic medication is an essential part of treatment for virtually every mandatory outpatient treatment patient and the expectation that a patient take such medication should be clearly stated in the treatment plan. The APA resource document makes no recommendation about whether mandatory outpatient treatment statutes should either permit or preclude forced medication. If forced medication is permitted, it should be allowed only if a court specifically finds that the patient lacks the capacity to make an informed decision regarding his or her need for the medication.

Mandate Treatment for Mentally Ill

By CINDY SOTO

(reprinted from Los Angeles Times, January 27, 2001 with permission of the author)

Last May, Steven Allen Abrams intentionally ran his 4,000-pound Cadillac into a Costa Mesa preschool, killing two children and injuring five others. Three-year-old Brandon Wiener was trapped underneath the vehicle. His mother, Pam, screamed as he was freed and rushed to the hospital. About an hour later, he died in his mother's arms.

Her small body broken and her skull crushed, four-year-old Sierra Beth had no need of a hospital. She was killed instantly.

Sierra was my daughter. As I drove onto the scene, disbelief surrounded me even before I was told my daughter was dead. After, I went into shock. My life was over. My beautiful, sweet, loving child was gone, forever.

Abrams was mentally ill. Although he exacerbated his illness by years of drug abuse, he was nonetheless sick and in need of treatment.

As the insanity phase of his trial unfolded, I was shocked and appalled to hear of the countless times Abrams had been in and out of treatment and in and out of a doctor's care, only to be released back into the community unmonitored. His refusal to comply with voluntary treatment and to take medication, except when he was made to, shows that he was not capable of making rational treatment decisions. He also had a history of violence and instability, which suggested that he was capable of future violence.

Abrams was a time bomb waiting to explode. He did.

In California, individuals are not eligible for involuntary treatment unless they present an imminent danger to themselves or others. Such treatment, when it occurs, is usually short-term and in an inpatient setting. This leaves a gaping hole in California's treatment of the mentally ill. There are voluntary community programs and much-needed steps being taken to strengthen those programs.

Cindy Soto

But, these voluntary programs fail to address individuals such as Abrams, who had access to care, but could not or would not comply with treatment. In order to help someone like Abrams, California needs a form of involuntary treatment that includes evaluating the history of an individual and, where appropriate, legally mandating that the noncompliant person stay in treatment once out of the hospital.

This care would allow the individual to continue to recover as well as to safely live and work in the community.

There are those, like the ACLU, who believe that mandated treatment infringes on the civil rights of the individual. While I understand their concern, I pose to them this question: "Should the rights of an individual who refuses to comply with treatment, who has a severely deteriorating condition, and who has a history of becoming violent when in such a condition, supersede the rights of my four-year-old daughter to live safely in her community?" I'd answer, "No."

Many times mentally ill individuals harm themselves when their illness renders them incapable of making sound decisions with regard to their own care. It is not in their best interest to end up repeatedly hospitalized or jailed. Civil rights become a hollow exercise under these conditions. If people overwhelmed by severe mental illness, like Abrams, were instead placed in mandated community treatment, they could get well enough to knowingly exercise and enjoy their civil rights. Meanwhile, our right to live in a safe and secure society would be protected.

Abrams was unable or unwilling to comply with treatment. For that, my daughter, Sierra, and Brandon paid the price. Mandatory treatment legislation is important because the right to life is the most important right of all.

[Cindy Soto Is the Founder of Sierra's Light Foundation, a Group Dedicated to Making Preschools Safer for Children.] ⚖

What Do Consumers Really Think About Assisted Outpatient Treatment?

by J. Nelson Kull, III

I would like to discuss two issues: political correctness and paternalism. These issues are on my mind as a result of the debate in Florida about outpatient commitment or as it is now called, assisted outpatient treatment.

I began responding to questions about this issue at least a year ago, maybe two. I spoke against it vehemently at a focus group of advocates and government officials, including state legislative staffers. I talked about all the usual reasons for opposing it. It was stated at that meeting that it would criminalize the mentally ill. It would interfere with trust between consumers and providers. It would clog up our system by giving priority to court-ordered patients so that they would displace people coming into the system from the traditional civil system. I went on to talk about constitutional rights. I may have even quoted one of the founding fathers:

> "Those who would trade freedom for security deserve neither freedom nor security."
>
> —Benjamin Franklin

People present at some of those discussions accused me of using high rhetoric. Looking back at it, I may have.

I have now read in excess of 300 pages on the topic. Here are some of my observations: Many, if not most, states have some type of outpatient commitment law. Yet the problems predicted above do not seem to be apparent. Most people in most states never have cause to get involved in outpatient commitment. They probably do not even know what their state law says. I find it hard to understand how, if the above problems were true, why do we hear so little about them?

Another observation: When I began talking about this issue with my fellow Pathways' members and other consumers, it became apparent that they either believed that the law already existed, in some seldom-used form, or that it should.

I was so surprised that I took some informal polls. Pathways serves 50 to 60 consumers a day. On one day when 22 people were present, I explained the topic to the best of my ability and asked them to vote. Twelve people supported outpatient commitment, seven opposed, with the remainder abstaining. One of the abstainers said he wanted to change to pro, but he is not included in that category.

The next day I polled 10 consumers at People, Inc., a peer support group. All 10 voted for the pro position.

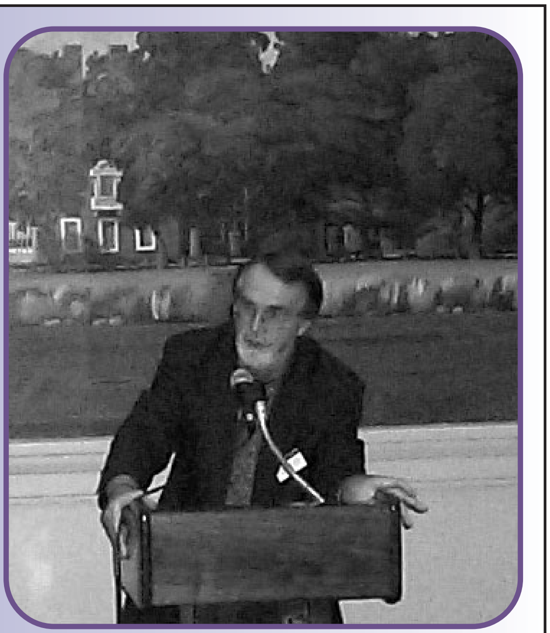
A couple of days later, I polled 43 consumers at Lakeside Alternatives, our local community provider. Twelve polled in favor, one opposed, and the rest chose not to vote.

Some more observations. This is an issue that people are having much difficulty sorting out. A lot of anger is already being expressed. It is sad when people start questioning one another's motives and integrity. This often comes in the form of attacking how the other side got their results and their motives.

I will note that both sides have been guilty of this. However, the traditional consumer advocates spend more of their time arguing against the other side's methodology and less giving examples of actual current events that result from the proposed policies. On the other hand, the supporters of outpatient commitment stress events in the news instead of scientific studies.

What I find really interesting is something that at first seems counterintuitive (science talk for "not what one expects," or different from what common sense would have one expect). What I am talking about is the difference between what people I call the "consumer elites or the consumer leadership" and the people whom they are supposed to serve and represent. It has often surprised me that people like this who are always talking about tolerance, diversity, and individualism, are often the most heavily invested in political correctness.

Some of these people have actually said to me that they will not allow the use of language that is not "person first." They seem to believe that they have the right to control speech as a method of controlling thought, and I assume reality. To me the best definition of an ideologue is a person who is determined to see reality in light of his/her ideology, instead of his/her ideology in light of reality.



Dr. E. Fuller Torrey presenting a lecture for the Manhattan Institute at the Harvard Club in New York City.

What is offensive is censorship in American society, especially by people who wax eloquently about human rights and freedom of expression. These people claim to be protectors of diversity and the right to be different. They would no doubt describe themselves differently, but like all who support censorship as serving a special purpose. The first principle of censorship is that the ends justify the means. Most wrongs begin with this predicate.

Political correctness in its true and extreme form is a type of paternalism. That is, one American telling another what they can do or say for their, and hopefully others, good. Those who have the right to censor are often self-appointed, or appointed by like-minded who trade legitimacy for support.

I have attended national conferences in which I was disappointed by the lack of real diversity. There were people of different races, religions, national origin, and first languages present. However, too many people talked like tape recorders. They all seemed to be saying the same mantra. The professionals, families, government, and drug companies were all wrong and the consumers are always right, provided they conform to political correctness. There were no dissident views. There was very little debate about really serious issues where people would have legitimate and serious disagreements such as outpatient commitment.

I personally like a good disagreement. Many of my best friends introduced themselves by screaming at me. Hopefully, some of you will do the same. I find it suspicious when everyone sounds like the same tape recorder. It is not healthy. It reminds me of those old films about communist party meetings where everyone always voted unanimously.

Obviously, I am using an extreme example, but you get the idea. The forces of political correctness can never understand what the founding fathers intended. The founding fathers never intended to protect the truth. They were far too clever for that. What they intended was to create a free market of ideas where conflicting ideas could compete with free access to the media and the public. The ultimate predicate of democracy is that the average citizen is not a fool, and that if allowed to hear both or all sides of an argument will be able to discern the truth or the most truthful.

If you believe in freedom, you must first believe in free thought and that means no censorship. If you can be trusted with the truth, then so can everyone else. The market place of ideas works better when left open and unregulated by the politically correct or government. Finally, if you believe in your cause, then censorship works against you. You do not need its protection and it gets in the way of projecting your own message with independent credibility.

[Mr. Kull is President, Pathways Drop-In Center, Inc., and a nationally-recognized consumer advocate. He encourages people to respond and comment on his article by e-mail at skull3@Earthlink.net.]

Your Voice— Will Make a Difference

[The following letters have been received as letters to the editor and published in Catalyst from September 1998 - June 2001.]

I received your *Catalyst* and finally felt confirmed in my beliefs about treatment for persons with severe mental illness. I have felt like the lone consumer advocate in my entire state. I testified on 12 bills this legislative session, was interviewed by newspaper and local news about a $60 million shortfall in our mental health state agency—Texas Department of Mental Health and Mental Retardation—and its effects on consumers. I have schizo-affective disease and am on 5 different meds and wouldn't have it any other way now that I can function more independently.

I just got a job at our state NAMI affiliate and I am so excited, for it is my first "real" job in 20 years. I also give speeches (graduate classes at University of Texas, training mental health staff at the state hospital, disability organizations, conferences). I just gave a speech two weeks ago at our state NAMI Convention and received a standing ovation. Words cannot even describe how proud I felt about myself for the first time in my entire life.

I find it more than coincidental that the very day I read your newsletter, I received an e-mail bashing your organization and claiming that PACT does not work and is forced treatment. If I weren't committed and/or forced to go into the hospital, I would be dead. No doubt in my mind.

I am glad to know you are out there working for the good of all involved with mental illness.

Diana Kern, Austin, Texas

Keep up the wonderful work. I appreciate the *Catalyst.* As president of a local NAMI affiliate, with my phone number circulating around the area, I receive calls every week from people seeking information and support concerning an ill family member. By far the most frequent issue is trying to get a psychotic person to accept treatment BEFORE harm is done. I now give them information about TAC and urge them to support the organization, even though it can't help them with their immediate problem. Locally, we have some big challenges to getting treatment for people against their will.

Also, could you send me 20 copies of the *Catalyst*? Either issue is fine, but the first has so much basic information in it, that would be great for a starter. I want to give copies out at our next Board meeting of our local affiliate and do a presentation. Then, I want to have copies available for people who call me.

Thank you, thank you, for your wonderful work!

Alice Fitzcharles, Media, PA

Just a short note to convey my appreciation for the work you do. As you know, I have been trying to piece together a working understanding of the issues surrounding mental illness. During this ongoing process, I have come to rely on the *Catalyst* as one of the greatest sources of innovative ideas and compassionate commentary on the subject.

Please convey to all associated with the publication the respects of an interested third party, who, like so many, is trying to understand why we can't do more for those who are mentally ill and living on the streets.

Robert L.E. Egger, Director
DC Central Kitchen, Washington, DC

Has the second edition of the *Catalyst* been released yet? My sick son read the whole thing and asked me when the new one would be out. This is the first time in 25 years of illness that he has been interested enough to read about his illness.

A lack of commitment resulted in his losing control and almost killing me two years ago. I believe that he has learned that his medicines can prevent something like this happening again. It was too bad for all concerned.

I am trying to get out the word to as many people as I can.

Thanks for all the help you [Mary] and those working with you are doing. *Catalyst* is exceptionally well written.

Edna Cramer, Riverside, California

[I cannot tell you how much it means to hear that your son enjoyed reading Catalyst. We will make sure that you and your son get a copy of the second, and all future, issues.—Mary Zdanowicz, J.D.]

I just read the *L.A. Times* Commentary by E. Fuller Torrey and Mary T. Zdanowicz.

I'm a police officer on LAPD. Southern California is home to a high number of mentally ill who are homeless and to those who are adult children still living with and frightening their parents.

Every day officers in my division respond to a call involving such a subject. It is discouraging to be able to do nothing more than stand there with my hands in my pockets because current legislation doesn't allow much more.

I cannot put handcuffs on a person and take away his liberty without probable cause to arrest or without clear guidance from California's Welfare and Institution Code. If I do, I lose MY liberty, my house, etc..

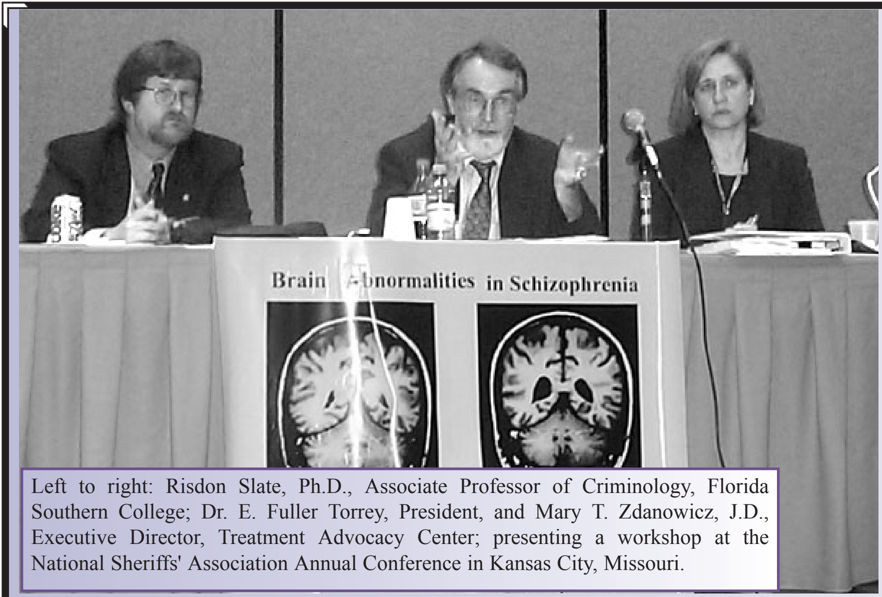
When a parent insists I take his son away because he refuses to take his medication and is acting out I can only suggest they consult their doctor—that the family is responsible.

Cuts in state funding the last few years have forced many cases away from mental health professionals into the laps of police officers. Most of these officers are young, and have only a high school education and cursory classroom instruction in how to handle the mentally ill.

I continue to hope that, with our "booming economy" some funding can be found to give more help where it's needed. Thank you for your hard work!

Richard Andert, West Hills, CA

In your July/August 2000 *Catalyst* your first article on the Model Law says hospital admissions fell after the adoption of need for treatment laws in Texas. I asked my psychiatrist about this because I always worry about returning to homelessness like over 15 years ago in Michigan. My psychiatrist said that Texas judges were more than reluctant to use current law to commit and force treatment on patients. No wonder



Left to right: Risdon Slate, Ph.D., Associate Professor of Criminology, Florida Southern College; Dr. E. Fuller Torrey, President, and Mary T. Zdanowicz, J.D., Executive Director, Treatment Advocacy Center; presenting a workshop at the National Sheriffs' Association Annual Conference in Kansas City, Missouri.

hospital admissions have fallen. I felt safer back in Michigan because I knew if I deteriorated that I would be re-hospitalized whether or not I was dangerous to myself or others. My psychiatrist said Texas judges were even reluctant to commit under the standards of dangerousness. So what do we do about judges who won't use the law? I have more job possibilities here in Texas and the climate is more conducive to my health that I hesitate to move back to Michigan. Fortunately, I have not been hospitalized or severely symptomatic in over 8 years. Assisted treatment does work, it just requires more than a quick investment. Once homeless, I now work full time as a research technician at the Baylor College of Dentistry. I see the psychiatrist only every three months. We need a federal approach to mental health rather than this state-by-state piecemeal approach to treatment.

Petra Moessner, Dallas, Texas

I cannot tell you how delighted I am to receive a copy of the *Model Law for Assisted Treatment.* If in place years ago it would have saved my daughter from two years as a homeless mentally ill person in Dallas and five years homeless in Norman, Oklahoma, etc. She is now 54 years old; lives in an apartment in Norman with her cat; is unable to care for herself without help, no meds, cannot work; fully delusional, refuses treatment; does not believe she is ill.

The direction TAC is going is appropriate to me. I did volunteer in Oklahoma for NAMI-OAMI legislation for eight years, so I really appreciate what you are doing. As I am now 83, I cannot do much, but I can pass the information along.

Mary Main, Dallas, TX

Thank you for sending me the booklet, *“Model Law for Assisted Treatment.”*

My 23 year old daughter has been diagnosed with schizoaffective disorder and lacks any insight into her illness. Over the last year and a half she has been hospitalized 12 times. If your model for assisted treatment existed, it would have made a tremendous difference in the type of care my daughter received over this period of time.

I am a member of the Board of Directors of NAMI Bucks County in Pennsylvania, the secretary of a NAMI Family Advocacy Group whose primary goal is to establish PACT programs in our county, and a family member on the advisory board of a new Community Treatment Team in Penndel, Pennsylvania. I would like to distribute *"Model Law"* to as many people as possible. Please send me one or two dozen copies.

I am also enclosing a check that is a donation to your organization.

Thank you for all of the dedication and hard work of TAC. I look forward to receiving all of your emails and updates.

Jeanette M. Pulley, Newtown, PA

I just came across your [web] site in my ongoing self-education about mental health issues, and I wanted to make the following comments:

I've been involved in civic/governmental activism for over 20 years, working primarily to help people understand the importance of getting involved and influencing the decision-making process of the governmental process. One of the many social phenomena I've observed is the extent to which people are resistant to be "public" about their opinions and activities. I have been successful in overcoming that in many of the issues I've promoted, getting the public to attend meetings in numbers sufficient to influence the outcomes.

Recently, I've become involved in mental health issues, particularly those surrounding [people with manic-depression]. The problems associated with sufferers acknowledging they have a problem, them seeking treatment, and their continued "compliance" are topics I hear and discuss frequently.

It isn't clear to me whether your organization has members with actual personal experience with these issues, or whether your organization is simply a legislation advocacy group. Assuming it is the latter, I would like to suggest that the legislation you propose will do more harm than good.

Most people, because of the social stigmas surrounding mental illness, are fearful of seeking treatment, fearful of acknowledging that they have a problem, and fearful of the repercussions a diagnosis of mental illness will have on their jobs and family. Now you propose to add the fear of involuntary treatment. Of involuntary "guardianship." And you openly state that this "involuntary treatment" should be imposed "...BEFORE individuals become a danger to themselves or others."

With what you propose, WHY would ANYONE who even suspects they have a mental health problem even SEEK treatment, thus making themselves vulnerable to "involuntary treatment?"

Clear-thinking people with minor problems will be scared away from seeking appropriate treatment, but imagine how your approach would be viewed by the fearful, the deluded, the paranoid? Would the fear of your proposal actually INCREASE violence, as untreated, extremely ill people are approached by either innocent passers-by or civil servants, who are viewed as enforcers of your policies?

Fearful and confused people need reassurance that they will be listened to, that their particular problems will be heard and acted on in a compassionate manner. Any successful hostage negotiator will confirm this. Forcing people into positions that are fixed and undesirable to them creates a "no-win" situation, and they often react with a "nothing-to-lose" approach.

I believe your intentions are well meaning, but appear to be a bit reactive to recent media stories. I have worked with the media on stories for approximately 15 years (some of which aired globally), have written press releases, and organized a number of "media events." I am fully aware the extent to which the public and decision-makers can be swayed by dramatic reconstructions of current events. From my research into this issue, it appears your proposal relies heavily on the emotional and reactionary elements of the public's fear and misunderstanding of those suffering with mental illness.

It will be a relatively simple effort to interview a number of people whose lives were ruined by their MISDIAGNOSIS, people who lost everything, even the families of people who have died as a result of such "treatment." Dramatic presentations of "Reality" work both ways!

The mentally ill need to be ENCOURAGED to seek treatment, not driven from it by the fear your proposal generates.

Few would argue against forcing those that have demonstrated their violent behaviors [into treatment], but existing laws are ALREADY in place to address that problem.

Given my history of activism, and interest in this issue, I stand ready to prepare a public presentation to be distributed to both the media and appropriate lawmakers. I would be very interested in your thoughts.

Thanking you in advance, Tyler

*[**Note:** The following response is from Jon Stanley, Assistant Director, TAC]*

Dear Tyler: It was kind of you to develop and share your thoughts.

Your concern about some people becoming reluctant to utilize voluntary services if treatment laws are reformed is legitimate. Our views, however, differ as to the extent of that effect (if any) relative to the value of rational treatment laws.

Allow me to explain my assessment.

One of the two main reforms we promote is the need for treatment standard. The people who would qualify for treatment under such criteria are already refusing care. There is no fear of alienating them from treatment. They already have been by the symptoms of their illnesses. Many thousands who do not get help now pursuant to the dangerousness standard end up homeless, in jail, or taking their own lives. I see great value in helping them.

We also promote the adoption and use of assisted outpatient treatment, which reduces hospital days, promotes treatment compliance, decreases subsequent admissions, and reduces violence. It would allow some people treatment in the community rather than an inpatient facility. I see value in doing all those.

Your claim that legal reform will deter treatment participation makes logical sense, but there is a dearth of research in this area. Some outpatient commitment studies, however, show that people under treatment orders are more likely to maintain treatment after the order expires. I also know that the Policy Research Associates study of the pilot outpatient commitment program at Bellevue found no significant difference in the level of coercion perceived by those who were in court-ordered treatment and those who were not.

The changes we seek are already in many states. Forty-one have assisted outpatient treatment. About half have some type of need for treatment standard. We are in touch with hundreds of people all over the country. We have not heard of people shunning treatment because of these progressive laws. Plus, many of these have been around for decades. It is surprising that research has not emerged demonstrating the connection between treatment law reform and treatment avoidance.

I also know that my own experience is not unique. I refused treatment for almost three years after being diagnosed with bipolar disorder, all the while sinking into an increasingly dramatic symptomatic spiral. I was eventually placed in treatment against my "will." And because I was—I got better. I am now religiously faithful to my treatment. An intervention has made me more likely to seek treatment.

All this information is not sufficient for a definite conclusion, but it is enough to be certain that I do not know the effect of treatment laws on voluntary selection of treatment. Combine that with the vital benefits of treatment law reform, and you have why I share your concern but not your conclusion. I wish you luck in your advocacy efforts.

States continue to gain interest in outpatient commitment

by Rosanna Esposito, Attorney, Treatment Advocacy Center

The National Conference of State Legislatures and Health Policy Tracking Service recently released their 2001 Health Priorities Survey. The book compiles polling information from state legislators, legislative staff, governors' offices, executive agencies and other state health sources in order "to identify their legislative priorities."

The results show a dramatic increase in the number of states interested in outpatient commitment. Last year just nine states identified the issue as a legislative priority (*Catalyst,* Vol. 2 No. 1, January/ February 2000). In the 2001 survey, the following 30 states responded that outpatient commitment is a legislative priority:

Alaska, Arizona, California, Connecticut, Florida, Hawaii, Illinois, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, New Hampshire, New Jersey, New Mexico, New York, North Carolina, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, Tennessee, Texas, Virginia, West Virginia, Washington and Wisconsin.

(continued from page 3)

Schmidt, 349 F. Supp. 1078 (1972), vacated, 414 U.S. 473 (1974), on remand, 379 F. Supp. 1376 (E.D.Wis. 1974), vacated, 421 U.S. 957 on remand, 413 F. Supp. 1318 (E.D.Wis. 1976), challenged Wisconsin's civil commitment statute and focused primarily on the process of civil commitment. The real import of the Lessard decision was that it introduced the concept of imminent danger in treatment decisions. But, as often happens, this concept was not interpreted as the court originally intended. In Lessard, the court held that there must be a finding of imminent danger to oneself or others "unless the state can prove that the person is unable to make a decision about hospitalization because of the nature of his illness." Unfortunately, the qualifying statement referring to lack of insight was ignored.

The practical effect of the Lessard dangerousness standard has been devastating and can be directly related to the phenomenon of criminalizing individuals with mental illness. In the two years following the Lessard decision, the number of criminal observation cases in three Wisconsin state institutions affected by the decision nearly doubled, from 200 cases before the decision to 367 cases after the court articulated the dangerousness standard.

The Supreme Court's 1975 decision in O'Connor v. Donaldson, 422 U.S.563 (1974) is commonly cited as establishing a standard of dangerousness for civil commitment. The Donaldson case involved a non-dangerous mentally ill person who was confined to a psychiatric hospital without receiving treatment. The Supreme Court held in that case that "a State cannot confine without more, a non-dangerous individual who is capable of surviving safely in freedom by himself with the help of willing and responsible family members or friends." It is the phrase "without more" that is so important. The common interpretation is that it should be read "without more than dangerousness." However, read in context, it is clear the Court meant "without more than custodial care."

In fact, early in the decision, the Court specifically states that its opinion does not address "whether the State may compulsorily confine a non-dangerous, mentally ill individual for the purpose of treatment. "We need not decide whether, when, or by what procedures, a mentally ill person may be confined by the State on any of the grounds which, under contemporary statutes, are generally advanced to justify involuntary confinement of such a person—to prevent injury to the public, to ensure his own survival or safety, or to alleviate or cure his illness." This is an incredibly important distinction because the Court did not foreclose the use of commitment standards based on the need for treatment.

Despite the absence of a prohibition against the use of need for treatment standards in the law, most state treatment laws are based on dangerousness alone. Several states have abandoned dangerousness as the sole standard upon which inpatient treatment decisions are based. The states that have done so, have incorporated the following factors into their standards in different combinations:

- Probability of deteriorating symptoms that will result in dangerousness.
- Incapacity to make an informed treatment decision.
- Likely to benefit from treatment.
- History of a need for treatment.
- Exhibiting symptoms that previously resulted in the need for treatment.
- Needs treatment to prevent deterioration of symptoms.

Standards based on the need for treatment allow for a medical intervention before an individual spirals to the depths of their illness. Critics charge that reforming the standard for treatment will serve as a dragnet, dramatically increasing the number of individuals who are hospitalized and shifting resources away from community treatment. Experience proves that there is no basis for such alarmist claims. In December 1996, Wisconsin adopted a standard based on the need for treatment and none of those dire consequences occurred. There were only 35 requests for commitment under the new standard in the 22 months following its adoption.

Despite all that we now know about the benefits of treatment and devastating consequences of non-treatment, the mental health bar is still actively engaged in an assault on rational treatment laws. The Vermont Protection and Advocacy Inc. filed a lawsuit this year, which delayed the implementation of a new law that would have made outpatient commitment more effective in Vermont. In its Position Statement on Involuntary Commitment, the Bazelon Center for Mental Health "opposes all involuntary outpatient commitment as an infringement of an individual's constitutional rights."

Despite their efforts, the climate is finally ripe for reform. Several notable cases (Theodore Kaczynski, Michael Laudor, Russell Weston, and Andrew Goldstein) have caused the media to explore the nature of mental illness, the consequences of non-treatment and a means of preventing these tragedies. City leaders are looking for a solution to the decades old problem of the homeless mentally ill. Jailers are beginning to ask why the care of the mentally ill has been shifted to their budgets. The families of those suffering from mental illness are demanding that legislators untie their hands and enable them to get care for their loved ones before it is too late.

The Treatment Advocacy Center and the *Catalyst* will be resources for those seeking to effectuate reform. Regretfully, it is too late for Scott, and too many others like him, forced to suffer the consequences of non-treatment. The Center will continue to ask, as did Herschel Hardin, a former member of the board of directors of the British Columbia Civil Liberties Association and father of a child with schizophrenia:

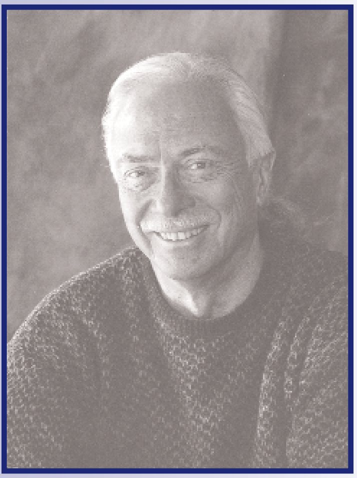
> "How can so much degradation and death—so much inhumanity—be justified in the name of civil liberties? It cannot. The opposition to involuntary committal and treatment betrays a profound misunderstanding of the principal of civil liberties. Medication can free victims from their illness—free them from the Bastille of their psychoses—and restore their dignity, their free will and the meaningful exercise of their liberties."

Idealism Gone Awry

EXPLORING ORIGINS OF DYSFUNCTION IN MENTAL HEALTH CARE

by John W. Milton, former State Senator, Co-chair, NAMI-MN Legislative Committee

Moved by Ken Kesey's book, *One Flew Over the Cuckoo's Nest,* a group of idealistic, energetic and naïve Minnesota state senators set out in the mid-1970s to reform the system of caring for the mentally ill. Visits to the old state hospitals confirmed our worst fears: Kesey's book, and the movie based on it, could just as easily have taken place here in Minnesota, presumed to be one of the nation's incubators of progress and reform.



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As one of the prime movers in that group, I believed that we were creating a better alternative to those large, brick-and-stone warehouses where people with brain disorders were managed by psycho-surgery, electro-shock and numbing meds like thorazine. Where patients—out of sight, out of mind—would live out their lives, and present no danger to the families and communities which had sent them away.

After all, it was the mid-1970s. Surely, if we could stop the Vietnam War, desegregate the schools, win voting rights for African Americans, fight for equal rights for women, improve safety for workers, and protect the environment, we could reform the mental health system. And surely, if it could be done anywhere, why not here in Minnesota?

The plan was deceptively simple. Close down the big warehouses. Take the money saved from that to establish programs in local communities, where families and friends would be close at hand to support the mentally ill. Replace the more invasive treatments with family-based therapy and improved medication. In time, we would not only save lives, we'd be saving the taxpayers' money. It seemed too good to be true.

It was. To begin with, the bureaucracy dragged its feet on shifting money and personnel to local programs. The stigma of mental illness produced a backlash in many communities, where the good citizens of Minnesota fought against having "those people" living down the street. Payment for services fell more and more under the control of three giant managed care plans, and these, rather than care providers, decided how much care was "medically necessary." Local governments were inclined to export their problems to the state, thus keeping a lid on local property taxes. And, state legislators of the 1980s and 1990s were mesmerized by the tangible benefits of cutting expenditures and returning money to the taxpayers. Whatever benefits might result from reform were too intangible and long-term, not relevant to incumbent legislators who ran on the short-term benefits they'd delivered to their constituents.

To make matters worse, when people with brain disorders were liberated from the old state hospital system, they were assumed to be competent to make choices about whether to continue treatment. The fact that nearly half of them suffered from anosognosia, a condition which rendered them incapable of recognizing their illness, was not as well understood as it is today, and the extreme civil libertarians were (and still are) unwilling to accept this as a factor in patients' choice of receiving or rejecting treatment. So in a caring place like Minnesota, where it is unthinkable to let a friend or relative with diabetes choose not to take insulin, where we prevent older people with Alzheimer's from wandering across freeways in the dead of winter, we continue to insist on letting people with serious brain disorders choose whether or not to be treated . . . until they deteriorate to the point where they become "imminently dangerous" to themselves or others. And then, in most cases, only if they are on the verge of, or in the act of, committing some heinous crime.

So, despite the fact that brain disorders strike roughly one in four Minnesota families, efforts to reform the commitment process are opposed by the Mental Health Association of Minnesota, (inexplicably) the state hospital association, and (predictably) the Scientologists, who don't seem to believe that mental illness even exists. To date, this coalition has succeeded in killing every legislative initiative for reform.

As a result, many of those who were formerly committed to the old state hospital system are now incarcerated in the state's maximum-security prisons. They have qualified to receive care by decompensating and committing violence to family, friends, or neighbors. Their stories are captured by the media, living in our consciousness for a day or two, then fading into the dark corners from which erupted the violence. Perhaps we've simply created a different kind of "cuckoo's nest."

There are rays of hope in this dark scene. NAMI-MN is backing a bill authored by Representative Mindy Greiling and Senator Don Betzold, which would permit earlier intervention, so that people with brain disorders could avoid decompensation without becoming "imminently dangerous." Another bill, authored by Senator Linda Berglin and Representative Fran Bradley, is aimed at funding community-based programs at a higher level, and making services more available throughout the state. If both of these pass during the 2001 legislative session, and if the managed care companies are required to pay mental health benefits on the same basis as those related to physiological health, Minnesota will take a significant step forward, and toward the vision which inspired those of us intending to reform the system a quarter century ago. Taking this step will require courage by legislators, and a better appreciation for the long-term return on this investment in our people.

It is not too much to hope for, but given political realities, it is perhaps too much to count on. Even in good old, progressive Minnesota.

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Catalyst is the newsletter of the Treatment Advocacy Center. Our mission is to eliminate the legal and practical barriers to treatment for millions of Americans who suffer from, but are not being treated appropriately for, severe brain disorders, such as schizophrenia and manic-depressive illness, and to prevent the devastating consequences of non-treatment: homelessness, suicide, victimization, worsening of symptoms, homicide, and incarceration.

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