The Center launches new initiative

The Treatment Advocacy Center (the Center) is always looking for new and meaningful ways to achieve its goals. With this inaugural issue of *Catalyst*, the Center unveils its newest tool to communicate news and information to key individuals and organizations.

With in-depth reports, individual case studies, and stories of personal experience, *Catalyst* will inform readers about ongoing issues that contribute to the insufficient medical care of individuals with severe brain disorders.

Field experts will report on the progress made toward educating legal, criminal justice, policy and legislative communities on the benefits of assisted treatment, in an effort to decrease homelessness, jailings, suicide, violence and other devastating consequences caused by lack of treatment.

Updates will be given on the principle activities of the Center, including:

- ❖ Educating policymakers and judges about the true nature of severe brain disorders, advanced treatments available, and the necessity of community ordered treatment as a last resort.
- ❖ Working within states to promote assisted treatment to ensure that individuals with severe brain disorders who are most in need of treatment finally get it.
- Researching factors that affect the ability of persons with serious brain disorders to make informed decisions about their treatment.
- ❖ Promoting innovative approaches to diverting those who are psychiatrically ill away from the criminal justice system and into appropriate treatment.
 - ❖ Holding states responsible for providing adequate psychiatric services and following up with patients upon their release from the hospital.

The Center serves as a catalyst to achieve proper balance in judicial, legislative, and policy decisions that affect the lives of persons with serious brain disorders. *Catalyst* is just one more tool the Center will use to reach the people and organizations essential in helping to achieve that balance. 47a

NOTE: This first issue of *Catalyst*: is dedicated to the memory of Kenneth Scott Hardman. His mom wrote the following story.



Scott was my son, a 30-year-old young man, who committed suicide following a 17-year battle with the atrocious brain disease, schizophrenia. ... Lorraine Gaulke

In memory of Kenneth Scott Hardman

Scott didn't have to die! And he certainly didn't have to die in the way that he did!

Can you imagine not knowing the whereabouts of your desperately ill son for eleven months? Is he out in the bitter cold, standing around a trash-barrel fire with other homeless, nameless people? Is he wandering helplessly from state to state, thumbing rides at truck stops? Worst of all, is he dead? Whether he is three or thirty doesn't matter; he is your child, and he is lost.

After those eleven long months, can you imagine being told that not he, but his remains have been found by a hunter in the woods--and that his skull has been dragged away from the rest of his skeleton by wild animals? Think about hearing your child referred to as Unidentified Case Number such and such, and that the coroner cannot release his remains to you until his dental records have been matched up, and all investigations into the possibility of foul play have been completed.

I no longer have to imagine how all of that feels. I know.

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Catalyst

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TREATMENT ADVOCACY CENTER
3300 North Fairfax Drive,

Suite 220

Arlington, VA 22201 Phone: 703-294-6001

Fax: 703-294-6010 Web Site: www.psychlaws.org E-mail: info@psychlaws.org

BOARD OF DIRECTORS
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The Center is a nonprofit organization dedicated to eliminating legal and clinical barriers to timely and humane treatment for the millions of Americans with severe brain disorders who are not receiving appropriate medical care.

Current federal and state policies hinder treatment for psychiatrically ill individuals who are most at risk for homelessness, arrest, or suicide. As a result an estimated 1.5 million individuals with schizophrenia and manic-depressive illness (bipolar disorder) are not being treated for their illness at any given time.

The Center serves as a catalyst to achieve proper balance in judicial, legislative and policy decisions that affect the lives of persons with serious brain disorders.

Scott endured the torments of schizophrenia for seventeen years. During some of those years, his suffering was reduced, although he never stopped hearing voices. He lived more normally, achieving some of the goals of life that healthy people take for granted.

Thanks to an excellent program called Pathways, Inc., he was able to live in safe housing, keep house and cook for himself, form friendships, and enjoy recreational activities. With the help of a staff job coach, he was even able to get and keep a paying job. His greatest happiness was found in a loving relationship with a young woman named Beth, and having my wonderful grandson, Brandon, who just turned eight years old.

So what happened? Why did Scott's life deteriorate again before finally ending so sadly? All of his successes were achieved while taking his medications regularly under close staff supervision and careful in-house monitoring. It took many years of trial-and-error to find this particular combination of medications, precise dosages, and level of care in order for Scott to experience some relief from psychotic symptoms.

Unfortunately, under our current, dangerous mental health laws, Scott was deemed "too well" to remain any longer at Pathways. The psychiatrist at the health department determined that he was functioning at too high a level to qualify for further residential care. He was allowed to move out from their system of care and into his own trailer. Scott, of course, thought this was wonderful, and began to think he was "normal" now. I was not surprised when Scott had these delusions, and quit taking his meds, but I was devastated by this unfair decision made by "the system."

I tried to insist that Scott be allowed to remain safely at Pathways. I knew that he was still very sick, and should not be out on his own. He just seemed well when he was properly medicated and cared for. Because he was no longer a minor, I, his mother, had no right to interfere with or influence his decision. Instead I was promised that staff members would continue to visit him and monitor his medications.

Less than a year later, he was living in his darkened trailer, the windows curtained, dirty dishes piled on the counter, pet bird chirping, and music playing loudly to block out the voices that had become intolerable. Psychotic. Paranoid. Hopeless. He had exercised his "right" to refuse to take his meds. This right allowed him to return to a state of misery and despair, believing he had no hope for a happy future. He walked into the woods on a bitter January night, laid down on his back under a tree, and exercised his right to die.

There are thousands of mentally ill adults who, like my son, do not receive adequate treatment for devastating brain diseases. How many are there like Scott, who demonstrate that they can do well under proper treatment, but then are denied the right to remain in the system of care? If Scott had been three instead of thirty, I would have been charged with criminally neglecting his medical needs. But, Scott was permitted to make decisions, with the rights of an adult--not the judgement of one. I was left only with the right to cry for him.

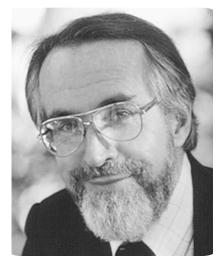
I believe that three things might have saved Scott's life:

- ❖ Laws that would allow parents to continue their parental rights after the age of majority and participate in assisted treatment decisions if a child is found to be persistently and consistently mentally impaired--unable to make appropriate medical decisions for himself.
- * Laws that would allow access to the same search mechanisms for missing mentally impaired and at risk adults that exist for missing minors. I learned that the National Missing Children Network's resources are not available for children who are thirty years old, no matter how severely impaired they are. No trained dogs were sent searching for him. No milk carton labels were printed. No major sheriff or police force was called into action. Instead, the local department did a cursory search of the major roads. With the help of Scott's friends and other family members, I put ads in the newspapers and on local radio and TV stations. We made posters and did our own heart-wrenching searches by car, by foot, and by phone.
- ❖ Sufficient funding and appropriately designed services to provide adequate levels of staff, care, and safe housing for mentally ill adults.

Scott really did not have to die. apa

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



E. Fuller Torrey, M.D., President of the Board of Directors of the Treatment Advocacy Center.

guest researcher with the Clinical Brain Disorder Branch of the National Institute of Mental Health (NAMI).

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. \$\pi^{\text{p}}\$

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.

Up to 13% individuals with schizophrenia and 15% of individuals with manicdepressive illness commit suicide.

From the outset, we Twere aware that we would encounter substantial and wellorganized opposition. . . . civil libertarians . . . a small group of expatients who believe that nobody, no matter how psychotic, should be involuntarily treated . . . anti-medication professionals . . . antitreatment forces . . . the Bazelon Center for Mental Health Law . . . even federally-funded P and A programs.

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.

Tr. E. Fuller Torrey

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 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 Executive Director Mary T. Zdanowicz, Esq.

Mary Zdanowicz has a sister and brother with schizophrenia and, as a result, understands well the many inadequacies in today's mental health system.



Mary T. Zdanowicz, Founding Executive Director of the Treatment Advocacy Center.

Prior to joining the Center in June 1998, to serve as founding executive director, Ms. Zdanowicz was an attorney in private practice in New Jersey. In addition to her litigation responsibilities with a leading law firm there, she devoted much of her time to advocating improved care and services for persons suffering from severe brain disorders.

In fact, seeking appropriate care and treatment for those with severe psychiatric illnesses has long been a priority for Ms. Zdanowicz. For example, in 1995 she challenged the government's right to close a statutorily mandated institution and brought suit against the state of New Jersey when the Governor and the Commissioner of Human Services announced the closure of the state's largest psychiatric hospital where her sister was then a patient.

Ms. Zdanowicz also held numerous volunteer positions with diverse organizations. Those include vice



president of the Mental Health Association of Monmouth County, New Jersey, a member of the Board of Trustees of NAMI New Jersey (formerly New Jersey Alliance of the Mentally III), and chairperson of the Marlboro Psychiatric Hospital Family Advisory Association. At Marlboro she established a partnership program in which family members regularly toured and monitored conditions at the hospital.

In addition, she was appointed to serve on a New Jersey Senator's Accountability Monitoring Board for Quality Mental Health Treatment. There she advised policymakers on issues impacting people with serious brain disorders. She also organized forums featuring mental illness experts and prominent media professionals.

Ms. Zdanowicz continues to regularly tour a state psychiatric hospital in New Jersey to monitor patient care. She volunteers at a clubhouse program for individuals with severe brain disorders in Virginia. She believes that it is essential that, in her position, she have contact with individuals who are debilitated by the severest forms of mental illness such as schizophrenia and manic-depressive illness. To

A CATALYST TO STOP FORCED SUFFERING FROM THE CONSEQUEN-CES OF NON-TREATMENT

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

The inaugural issue of the Treatment Advocacy Center's newsletter is 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 manicdepressive illness are not receiving treatment.1 We now know that a major contributing factor to treatment noncompliance 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 their illness. Studies have shown that approximately half of all patients with schizophrenia² and mania³ 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 nontreatment. Up to 13% of individuals with schizophrenia⁴ and 15% of individuals with manic-depressive illness⁵ commit suicide. Approximately 150,000 individuals with serious mental illness are homeless.6 As much as 16% of the population of our nation's jails and prisons, more than 280,000 individuals, suffer from these illnesses.7 Individuals with severe psychiatric disorders are 2.7 times more likely to be victims of violent crimes than the general population.8 Studies suggest that the adverse effects of delaying treatment include: increased treatment resistance,9 worsening severity of symptoms;10 increased hospitalizations, 11 and delayed remission of symptoms. 12 A leading cause of stigma is the nearly 1,000 homicides each year in

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 their mental illnesses.

We now that a major contributing factor to treatment noncompliance is lack of insight, a symptom in which the illness affects that part of the brain that is used for selfmonitoring and causes the individual to lack awareness of their illness.

the United States that are committed by individuals who are not being treated for these illnesses.¹³

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.14 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.15 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.¹⁶

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."17

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. 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 focussed 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."18 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.¹⁹

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 nondangerous individual who is capable of surviving safely in freedom by himself with the help of willing and responsible family members or friends."20 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."21 [emphasis added] 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.²² 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.23

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.²⁴ 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

Ctudies 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.

On any given day, approximately 40 percent of individuals with schizophrenia and manicdepressive illness are not receiving treatment.

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.²⁵ §§a

Endnotes for Catalyst to Stop Forced Suffering by Mary Zdanowicz, page 5.

¹Regier, D.A., Narrow, W.E., Rae, D.S., Manderscheid, R.W., Locke, B.Z., Goodwin, F.K. The de facto US Mental and Addictive Disorders Service System: Epidemiologic Catchment Area prospective 1-year prevalence rates of disorders and services. Archives of General Psychiatry, 50:85-94 (1993).

²Amador, X.F., Strauss, D.H., Yale, S.A., and Gorman, J.M. Awareness of illness in schizophrenia. Schizophrenia Bulletin, 17:113-132, 1991.

³Ghaemi SN. Insight and psychiatric disorders: a review of the literature, with a focus on its clinical relevance for bipolar disorder. Psychiatric Annals 27:782-790, 1997.

⁴Caldwell, C. and Gottesman, I. Schizophrenics kill themselves too: a review of risk factors for suicide. Schizophrenia Bulletin, 16:571-589, 1990. ⁵Goodwin, F.K. and Jamison, K.R. Manic-Depressive Illness, at 230 (Oxford University Press, 1990).

Tessler, R.C. and Dennis, D.L. A Synthesis of NIMH-Funded Research Concerning Persons Who Are Homeless and Mentally III. Rockville, MD: National Institute of Mental Health (1989); Priority Home!: The Federal Plan to Break the Cycle of Homelessness, Interagency Council on the Homeless (March 1994).

Ditton, P.M. Mental Health and Treatment of Inmates and Probationers, Bureau of Justice Statistics Special Report, U.S. Department of Justice (July 1999). Harlow, C.W. Profile of Jail Inmates 1996. Bureau of Justice Statistics Special Report, U.S. Department of Justice (April 1998); Jemelka, R., Trupin, E., & Chiles, J.A. The mentally ill in prisons: A review. Hospital and Community Psychiatry, 40: 481-485 (1989); Correctional Populations in the United States, 1995. Bureau of Justice Statistics, U.S. Department of Justice (May 1997).

*Hiday VA, Swartz MS, Swanson JW, Borum R, Wagner HR. Criminal victimization of persons with severe mental illness. Psychiatric Services 50:62-68, 1999

⁹Edwards, J., Maude, D., McGorry, P.D., Harrigan, S.M., and Cocks, J.T. Prolonged recovery in first-episode psychosis. British Journal of Psychiatry (Supplement), 172:107-116 (1998).

¹⁰Lieberman, J.A., Koreen, A.R., Chakos, M., Sheitman, B., Woerner, M., Alvir, J.M.J., and Bilder, R. Factors influencing treatment response and outcome of first episode schizophrenia: implications for understanding the pathophysiology of schizophrenia. Journal of Clinical Psychiatry, 57: 5-9 (1996).

¹¹Power, P., Elkins, K., Adlard, S., Curry, C., McGorry, P., and Harrigan, S. Analysis of the initial treatment phase in first-episode psychosis. British Journal of Psychiatry, 172: 71-76 (1998). 12Wiersma, D., Nienhuis, F.J., Slooff, C.J., and Giel, R. Natural course of schizophrenic disorders: a 15year follow-up of a Dutch incidence cohort. Schizophrenia Bulletin, 24: 75-85 (1998). ¹³Torrey, E.F. Out of the Shadows: Confronting America's Mental Illness Crisis, at 49 (John Wiley & Sons, 1997). Dawson, J.M. and Langan, P.A. Murder in Families. Bureau of Justices Statistics Special Report, U.S. Department of Justice (July 1994). ¹⁴Bursten B. Posthospital mandatory outpatient treatment. American Journal of Psychiatry 143:1255-1258 (1986); Fernandez, G.A. and Nygard, S. Impact of involuntary outpatient commitment on the revolving-door syndrome in North Carolina. Hospital and Community Psychiatry 41:1001-1004 (1990); Hiday, V.A. and Scheid-Cook, T.L. The North Carolina experience with outpatient commitment: a critical appraisal. International Journal of Law and Psychiatry, 10:215-232 (1987); Munetz, M.R., Grande, T., Kleist, J., and Peterson, G.A. The effectiveness of outpatient civil commitment. Psychiatric Services, 47:1251-1253 (1996). Rohland, B.M. The role of outpatient commitment in the management of persons with schizophrenia. Iowa Consortium for Mental Health, Services, Training, and Research (May 1998);



Swartz, M., Swanson, J., Hiday, V., Borum, R., Burns, .B and Wagner, R. Can Involuntary Outpatient Commitment Reduce Hospital Readmissions Among Severely Mentally III Individuals? Presented at the International Congress on Law & Mental Health. Paris, France (July 1998); Van Putten, R.A., Santiago, J.M., Berren, M.R. Involuntary outpatient commitment in Arizona: a retrospective study. Hospital and Community Psychiatry 39:953-958 (1988); Zanni, G. and deVeau, L. Inpatient stays before and after outpatient commitment. Hospital and Community Psychiatry 37:941-942 (1986).

¹⁵Research Study of the New York City Involuntary Outpatient Commitment Pilot Program, Policy Research Associates, Inc. (December 1998). (See table 5 - total median length of hospital stay: 101 days for patients without orders / 43 days for patients with orders).

¹⁶Telson, H., Glickstein, R. and Trujillo, M. Report of the Bellevue Hospital Center Outpatient Commitment Pilot Program, Bellevue Hospital Center Department of Psychiatry (March 1999). ¹⁷Isaac, R.J. and Armat, V.C. Madness in the Streets, at 111 (The Free Press, 1990).

¹⁸Lessard v. Schmidt, 349 F. Supp. 1078, 1094 (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).

¹⁹Treffert, D.A. The MacArthur coercion studies: A Wisconsin perspective. Marquette Law Review, 82:760, 766 (1999)

²⁰O'Connor v. Donaldson, 422 U.S.563, 576 (1974). ²¹Id. at 573-574.

²²E.g., Arizona, Hawaii, Michigan, Minnesota, Mississippi, Missouri, Montana, North Dakota, Ohio, Oklahoma, South Dakota, Washington, Wisconsin, Wyoming.

²³Treffert, supra 19, at 781.

²⁴Vermont lawsuit invokes ADA to oppose forced medication. Mental Health Weekly, 19:1, 4-5 (1999). ²⁵Hardin, H. Uncivil Liberties. Vancouver Sun, July 22, 1993.

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Treatment Advocacy Center Live on the Internet

As part of its commitment to reduce rates of violence, homelessness, incarceration and suicide among Americans with untreated severe mental illnesses, the Treatment Advocacy Center established an Internet web site located at http://www.psychlaws.org on March 17th.

Designed to benefit legal, legislative, medical, criminal justice and media

professionals, as well as individuals looking for guidance in helping a family member, the Center's site contains a wealth of statistical information on the complexities of schizophrenia and manic-depressive illness, consequences of non-treatment, and treatment laws.

The Center's Executive Director, Mary Zdanowicz, pointed to antiquated state treatment laws as the primary reason for today's mental illness crisis. She said that unless we have appropriate treatment laws, the unfortunate trend of homeless, incar-cerated, violent and victimized severely mentally ill will continue, since current policies allow 40 percent of the 3.5 million in this vulnerable population to remain untreated.

"People with severe mental illnesses must receive appropriate medical care if they are to escape the demons caused by their brain disease," said Ms. Zdanowicz. "Without treatment, they will not get better. Neither these individuals nor society should have to wait until they are a danger to themselves or others before interceding with appropriate treatment. It is madness to bury our heads in the sand, while individuals with untreated mental illness commit suicide, slowly die on a park bench from malnutrition or freezing temperatures, shoot someone or push a passerby into the path of an oncoming subway train. The legal standard should be need for treatment, not dangerousness. Society has an obligation to save people from degradation, not just death."

"We hope our web site enlightens society to the enormity of this disgraceful social and human crisis," said Ms. Zdanowicz. "More important, we hope that it serves as a resource for those dedicated to improving the lives of people with severe mental illness."

The web site is separated into eight categories, including: *Preventable Tragedies, General Resources, Legal Resources, Medical Resources, Press Room, State Activity, New! and Join Us.*

❖ Preventable Tragedies is the first-of-its-kind, state-by-state searchable database of more than 600 episodes of violence resulting from lack of treatment which is the leading cause of stigma against individuals with mental illness.

WHAT'S NEW!

TREATMENT ADVOCACY CENTER!

LIVE ON
THE
INTERNET!

AT

HTTP://WWW. PSYCHLAWS.ORG A pproximately
150,000
individuals
with serious
mental
illness are
homeless.

A s much as 16% of the population of our nation's jails and prisons, more than 280,000 individuals, suffer from these illnesses.

- ❖ General Resources is packed with briefing papers, fact sheets, pertinent news articles, and extraordinary personal accounts from people living with severe mental illness.
- ❖ Legal Resources contains legal articles, historic case summaries, state-bystate treatment statutes, and analyses of current state laws.
- ❖ Medical Resources provides medical studies on issues of insight, consequences of delayed treatment, and victimization of individuals with severe mental illness
- ❖ Geared to the news media, the **Press Room** contains press releases and statements, fact sheets, staff biographies, testimony and speeches.
- ❖ State Activity presents local activities and events that impact treatment laws
- ❖ Join Us is a section for interested parties to learn about the Center, join our effort, receive regular newsletters and alerts, and learn how to network with important audiences.
- ♦ New! provides late-breaking news items and events that viewers might have missed on their last visit.

The time for talk has passed

Well-meaning but misguided organizations such as the ACLU and the Bazelon Center spent the last 30 years changing state laws to make it nearly impossible to treat those who refuse treatment until they are a danger to themselves or others.

Assisted treatment--involuntary commitment, outpatient commitment, substituted judgment, guardianship-- must be provided before individuals become a danger to themselves or others, particularly for individuals who lack awareness of their illness. Community treatment orders must be available to

prevent the "revolving door syndrome," in which individuals repeatedly return to hospitals or jails because they fail to take the medication they need to remain well. The Center is the only organization that is willing to take on this fight. We believe that the time for hand-wringing and talk has passed. We will reverse this trend that has led to so many unnecessary tragedies.

Our staff of seven, including four lawyers, is already developing model statutes that encourage treatment while maintaining safeguards to protect individual liberties. Individuals, organizations and government officials in six states who want to change their laws have already turned to us for help.

We are teaching a course called "Law and Mental Illness" and will be offering seminars in mental illness treatment issues nationally to judges and state attorneys.

We are also trying to improve the treatment system in other ways, by:

- supporting mandatory recertification of psychiatrists to ensure that they are competent.
- * working to prevent the closure of state hospitals before adequate community services are in place.
- * eliminating federal funding restrictions that create incentives to reduce inpatient psychiatric beds to unsafe levels.

The time has come to do something about these tragic situations. We have been very encouraged by the initial response to our efforts, even from some individuals who originally led the fight we are now trying to reverse.

As one of them recently told us, "We made some mistakes. We didn't understand the nature of these illnesses."

It is time to correct these mistakes. However, we cannot do it without your support. If we don't do it, who will? ap



STANDARDS SHOULD BE BASED ON THE NEED FOR TREATMENT

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.
 - **A** Likely to benefit from treatment.
 - **\Delta** 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 his illness.

PLEASE HELP THE TREATMENT ADVOCACY CENTER TO ACHIEVE ITS MISSION 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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□ \$25	□ \$50	□ \$100	□ \$500	□ \$1,000	□ \$		
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TREATMENT ADVOCACY CENTER

CATALYST

3300 North Fairfax Drive, Suite 220 Arlington, Virginia 22201

Phone: 703-294-6001 Fax: 703-294-6010

Web Site: www.psychlaws.org E-mail: info@psychlaws.org

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The Treatment Advocacy Center (the Center) is a 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.

This inaugural issue of *Catalyst* is produced in memory of

Kenneth Scott Hardman 1966-1997

