



# Catalyst

TREATMENT ADVOCACY CENTER

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## Kendra's Law Passed in New York

In August 1999, the Governor of New York signed a bill that allows a court to order assisted outpatient treatment. Specifically, the bill made the following changes to the state's assisted treatment law:

- ❖ allows a court to order assisted outpatient treatment if an individual meets eight criteria, including a need for treatment to prevent deterioration which would likely result in harm based on a consideration of the patient's history and current behavior;

- ❖ requires that individuals who receive assisted outpatient treatment orders must be provided either case management or assertive community treatment team services as well as other services that the court may order;



**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.**

- ❖ provides that parents, spouses, adult siblings, adult children and adults living with an individual, among others, can petition the court for assisted outpatient treatment;

- ❖ provides that an individual who is non-compliant with an assisted treatment order may be hospitalized for a 72-hour evaluation if a physician determines that the individual may meet the inpatient criteria.

On November 9, 1999, New York's Governor announced a proposal to add \$125 million to the state's 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, bringing the total budget commitment for new services to \$420 million (including implementation of Kendra's Law).

The Governor also announced the suspension of the state's initiative to eliminate inpatient psychiatric hospital beds. <sup>47</sup>

## State Updates

### Laws Enacted

#### Wyoming

In March 1999, the Governor of Wyoming signed a bill that adds, "a probability that destabilization will occur as a result of not taking or refusing medication" as a criteria for assisted treatment, allows the court to order assisted outpatient treatment, and allows the court to issue a medication order in the initial commitment hearing.

Specifically, the bill made the following changes to the state's assisted treatment law:

- ❖ included as evidence that an individual is "dangerous to himself or others": if there is a substantial probability that serious mental debilitation or destabilization from lack of, or refusal to take, prescribed psychotropic medications for a diagnosed condition will occur;

- ❖ provided that during court proceedings for emergency detention and continued hospitalization, the court shall make findings as to the individual's competence to make informed decisions regarding the need for treatment and the individual's need for medication, and that the court can order medication during the period of emergency detention and continued hospitalization if the person is incompetent to make an informed decision;

- ❖ provided that the court can order

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## Catalyst

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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 diseases 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 diseases.

conditional outpatient treatment if the court finds that the proposed patient does not require continuous inpatient hospitalization (1999 WY H.B. 35).

### Nevada

In April and May 1999, the Governor of Nevada signed bills that allow for the consideration of past history in assisted treatment decisions and created a mechanism to return individuals on conditional release to the hospital.

Specifically, the bills made the following changes to the state's assisted treatment law:

- ❖ a court may consider an individual's past history in determining whether the individual meets the "clear and present danger of harm" criteria for inpatient treatment (1999 NV A.B. 140); and

- ❖ an individual who is on conditional release from a hospital can be ordered to return to the hospital by the administrative officer of the facility if the psychiatrist and member of the treatment team determines that conditional release is no longer appropriate because the individual presents a clear and present danger of harm (1999 NV A.B. 141).

### Laws Proposed

#### South Dakota

South Dakota's Division of Mental Health has proposed changes to the state's assisted treatment laws. The text of the proposed statute revisions can be found at [www.state.sd.us/dhs/dmh/index.htm](http://www.state.sd.us/dhs/dmh/index.htm) (or call 1-800-265-9684).

Among the proposed statute revisions are amendments to the criteria for assisted treatment to require:

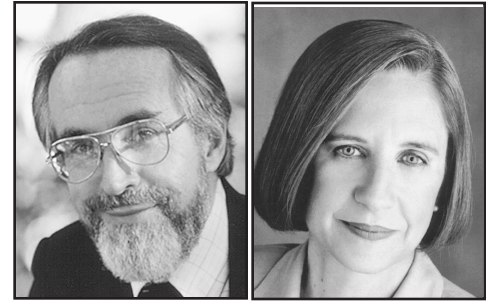
- ❖ consideration of an individual's treatment history;

- ❖ recent omissions as opposed to recent acts only;

- ❖ a reasonable expectation of harm in the near future, as opposed to the very near future; and

- ❖ acts or omissions which result in a

failure to obtain essential medical care as evidence of harm to oneself. <sup>§7</sup>



## 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 assisted outpatient 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."

In July 1995, the pilot program began operating at Bellevue Hospital Center in

New York City. The program's director, Dr. Howard Telson, was largely responsible for its success. Under the program, individuals who met the statutory criteria for assisted outpatient treatment appeared before a judge to determine if they were eligible for court-ordered outpatient commitment. As of January 1, 1999, 198 patients received court orders in the pilot program.

The legislature also directed that a study be performed to determine the program's effectiveness in preventing rehospitalization. Policy Research Associates, Inc. (PRA) was selected to perform the research study despite concerns expressed by advocates about a PRA's pre-existing prejudice against assisted outpatient treatment. The study began in January 1996 and required that individuals in the pilot program consent to be included in the study, which served to preclude individuals from the study who otherwise were good candidates for assisted outpatient treatment.

PRA initially indicated that 150 subjects would be required for the research to have statistical significance, but only 142 individuals participated in the study. The experimental group of 78 individuals received court-ordered enhanced community services while the control group of 64 individuals received enhanced community services, but no court order.

PRA issued its final report (PRA Report) on December 4, 1998. PRA itself acknowledged that the study was flawed, reporting that a "limit on [its] ability to draw wide-ranging conclusions is the modest size of [the] study group." There have been numerous studies of assisted outpatient treatment, all of which have concluded that assisted outpatient treatment is effective with the exception of two studies, one of which was the PRA study. However, in both studies there was no effective mechanism to enforce the orders. During the entire PRA research study period, there was no procedure in place to transport individuals who did not comply with treatment orders to the hospital for evaluation. An enforcement mechanism was not put in place until shortly before PRA published its report. In other words, non-adherence to a treatment order had no consequences.

Despite those limitations, PRA's research suggests that the court orders did

in fact help reduce the need for hospitalization. Patients in the court-ordered group spent a median of 43 days in the hospital during the study year, while patients in the control group spent a median of 101 days in the hospital. PRA reported that, although not statistically significant, there was a "big difference" between the experimental and control groups. The difference, in fact, just misses statistical significance at the level of  $p = 0.05$ .

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.

A public hearing on the pilot program was held on December 13, 1998. The Treatment Advocacy Center presented testimony in support of assisted outpatient treatment and critical of the PRA Report. NYTAC members, family, consumers and other advocates also testified in favor of the expansion of the pilot program. Opposition testimony, relying heavily on the flawed PRA Report, was presented by primarily civil libertarians, some community mental health providers, and consumer/survivor/ex-patients.

As the new year approached, it was not clear that New York legislators had the political will to extend assisted outpatient treatment statewide, particularly in light of the PRA Report. 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."

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 to ensure that New Yorkers most in need of treatment for severe mental illness finally got it. 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



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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](http://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*. ¶

## Half a Million Liberated from Institutions to Community Settings Without Provision for Long-Term Care

by Curtis Flory MBA and Rose Marie Friedrich RN, MA

Deinstitutionalization has progressed since the mid-1950s. Although it has been successful for many individuals, it has been a failure for others. Evidence of system failure is apparent in the increase in homelessness (1), suicide (2), and acts of violence among those with severe mental illness (3). Those for whom deinstitutionalization has failed are increasingly re-admitted to hospitals. It is common to find persons who have been hospitalized 20 times over a 10-year period. Tragically, there are more persons with mental illness in jails and prisons than there are in state hospitals (4).

Beginning also in the 1950's, new treatment philosophies were introduced that emphasized short-term and community-based treatments. Unfortunately, the wide range of community support necessary to maintain persons with severe mental illness in the community has not developed in many communities. In addition, the legal development of "least restrictive" environment has frequently been interpreted as independent living for all consumers, regardless of whether the setting is justifiable on clinical or humanitarian grounds.

A comment from one frustrated mother clearly describes the plight of some who do not find appropriate care in the community:

*My son, who has schizophrenia, has been ill for 20 years. During his illness he has been moved in the system 62 times, with 23 hospitalizations. He has been arrested numerous times and has lived in shelters and on the street a*

*minimum of 6 times. He has a substance abuse problem and has been diagnosed with hepatitis and acute infections. We don't have much hope for the future. (MA)*

## A Special High Risk Population

There is general agreement that about 2.8 percent of the U.S. adult population suffers from severe mental illness during any given year (5). Among this population, there is a subgroup of individuals who do not respond to traditional community treatment. It is estimated that this high-risk population includes an estimated 1 million individuals, or one-fifth of those with serious mental illness (6).

Unfortunately, discussion and research of this most vulnerable group has been neglected, falling victim to the ideological war between pro-community integration and pro-hospital camps. The most severely disabled have been forgotten not only by society, but by most mental health advocates, policy experts, and care providers.

As co-directors of the National Alliance for the Mentally Ill (NAMI) Long-Term Care Network, we conducted a study of this special population to determine their demographics, treatment histories and quality of life. We developed a questionnaire that addressed several areas of concern including housing, a variety of health issues, social and family relationships, employment, finances, and safety.

Questionnaires were mailed to former members of the NAMI Hospital and Long-Term Care Network and members of NAMI affiliates in Iowa and Massachusetts. Responses were received from 500 families in 23 states. Most respondents were parents.

Issues related to housing and health are presented in this article. Commonly occurring themes are presented along with family comments in these areas.

The majority of the following responses are from families who had an ill member diagnosed with schizophrenia. In fact, 78 percent of the respondents reported that their ill family member had the diagnosis of schizophrenia.

## Frequent Transitions

❖ Clients resided in a wide range of settings and showed high frequency of movement, which is symptomatic of fragmented care. The average client changed places of residence at least 14 times.

❖ Lack of adequate housing in the community was described by many. This lack of housing option impeded returning to the community and opportunities for rehabilitation:

*My son has been ready for about a year to come out of the hospital—but there is a lack of 24-hour supervised housing—so he is still waiting for a placement. (MD)*

*He was in the state hospital for 6 1/2 years for his safety because he was a wanderer and was unsafe. They kept saying there was no place for him in the community. (AZ)*

❖ Lack of services resulted in total disability for clients and impacted every aspect of their lives. On the average they had been ill for 21 years.

A parent from Alaska summed it up well, "It has caused (my son) to be totally disabled. The combining of so many failures in treatment has left him with so many residual problems that his potential for success . . . is minimal."

## Medical Illness Was Pervasive

Medical illnesses frequently go undiagnosed and untreated among persons with severe mental illness (7,8). The degree to which medical problems interfere with treatment and rehabilitation efforts, and the danger that the presence of mental illness creates in the management of medical disorders, have also been ignored in service planning. Furthermore, clients are often unable to communicate their symptoms and give a coherent account because of the internal chaos associated with their psychiatric illness and, therefore, the illness may become severe before it is recognized and treated.

Medical problems may also result as a consequence of the poor health habits of

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this population and/or the side effects of medications. For example, many persons with severe mental illness are overweight, secondary to side effects of their medications, sedentary lifestyle, and poor eating habits. This combined with heavy smoking leads to additional cardiac risks. With proper monitoring and support services, these risks can be reduced.

- ❖ 48 percent of clients had medical problems.

- ❖ The most commonly cited medical diagnoses were arthritis, hypertension, and diabetes.

- ❖ Medical problems were frequently exacerbated by lack of a protective setting.

- ❖ Bad health habits and side effects of medications were commonly cited as contributing to poor physical health.

### **Substance Abuse**

Approximately 50 percent of people with a diagnosis of severe mental illness also have a diagnosis of substance abuse disorder (2). Clients may self medicate because symptoms of the illness are not under control or as a way to deal with their social isolation. Consequences include noncompliance with medications, frequent rehospitalization, and homelessness.

- ❖ 21 percent of clients had a substance abuse problem.

- ❖ Families related the occurrence of substance abuse to a variety of factors, including lack of case management and social isolation.

### **Noncompliance was Common**

Seventy-four percent of neuroleptic-responsive outpatients become noncompliant within two years. The consequences of noncompliance account for at least 40 percent of all episodes of schizophrenia relapse and for at least one-third of all inpatient costs (9). The reasons clients do not take their medication are varied and may include lack of insight, side-effects of medications, and inadequate structure and support within the environment.

- ❖ 43 percent of clients had histories of noncompliance with medications, which led to relapses in illness.

- ❖ Lack of insight into the illness was often associated with noncompliance. According to one family member.

*This is such a small space to  
describe 44 years of sheer hell.  
Most of my childhood she refused  
medications. . . . The adult children  
had to commit her four times. . . .  
She was delusional in New York  
City, Minneapolis, Tucson and she  
dug through garbage. It's always up  
to the family to save her. (IA)*

- ❖ Discharging the client prematurely from the hospital or removing the ill person from a highly structured setting resulted in noncompliance.

- ❖ Inadequate staff and lack of follow-up also increased noncompliance.

- ❖ Noncompliance resulted in a progressively lower level of functioning.

*Every time he has gone off  
medications he has never reached  
the level of capabilities he had  
previously. (SD)*

### **The Revolving Door Syndrome**

The duration of stays in hospitals has become shorter under managed care standards. Often clients are admitted and treated in hospitals before clients' records can be transferred. Clients are often diverted from a familiar hospital to an available bed in another hospital where staff are unfamiliar to the client. Stability and consistency is a requirement of quality care for the severely mentally ill population.

- ❖ 75 percent of clients had been in the state psychiatric hospitals 1 to 50 times.

- ❖ 65 percent had been hospitalized in the acute care setting.

- ❖ The average number of acute care hospitalizations was seven.



❖ The impact of the revolving door syndrome was devastating.

*Our son has cycled in and out of apartments and hospitals for 6 years getting progressively worse. Lack of support services left him with his illness escalating beyond control. (NC)*

### **High Incidence of Suicide**

Recent studies of persons with schizophrenia point out that about one-third will attempt suicide, and about 1 in 10 will complete suicide. The suicide rate for those with mood disorders is 15 percent. This is in contrast to the suicide rate for the general population, which is 1 percent (2).

❖ 42 percent of clients had attempted suicide.

❖ Of those who attempted suicide, most had made two or more attempts.

❖ Families lived in constant fear of suicide.

*We have constant fear that she will kill/hurt herself, sadness that she is so unhappy, and have feelings of helplessness and guilt. (Has made 3 suicide attempts in the past). (MA)*

❖ Many of those in this subgroup are at high risk. They are primarily male, single, unemployed, and often live alone. They also have chronic, relapsing illness, which requires frequent hospitalization; have poor response to their medications, and feel hopeless about their future.

❖ Suicide and attempts were attributed to lack of adequate services and medication noncompliance.

### **Alarmingly High Death Rate**

A fact that is seldom discussed but alarmingly true is that the death rate is significantly higher for those who are severely mentally ill than it is for the general population. It is clearly established that individuals with schizophrenia die at a younger age than do individuals who don't have schizophrenia.

The largest single contributor to this statistic is suicide, which is 10 to 15 percent as compared with 1 percent in the general population. Also contributing to early death are poor health habits including heavy smoking, obesity, and alcohol abuse. The presence of undiagnosed and untreated diseases, such as heart disease and diabetes, account for a significant number of those who die young. Homelessness also increases the mortality rate because of increased susceptibility to accidents and diseases (10).

Researchers and health professionals have long observed that psychiatric patients have reduced life expectancy. In a study of 43,274 adults served by the Massachusetts Department of Mental Health, Dembling et al. (11) found that this population lost 8.8 more years of potential life than persons in the general population, a mean of 14.1 years for men and 5.7 for women.

### **Structure is the Key Ingredient in Ideal Community-Based Residences**

There is a need for both a structured and long-term care environment for this high-risk population. According to H. Richard Lamb, structure is considered a "bad word" in the treatment and rehabilitation of persons with severe mental illness compared to the "good words" of independence and freedom. He states that although structure is often considered a bad word, it represents a good and useful concept. Research indicates that many persons with schizophrenia lack the ability to create their own internal structure. If placed in the community in a living arrangement without sufficient structure they may quickly decompensate and return to the hospital or to the streets (12).

In order to identify the important characteristics of structure, we surveyed NAMI family members. Our questionnaire was published in many NAMI newsletters in Spring 1997. Responses from 300 family members indicated that long-term care residences were unavailable in a majority of communities.

Even if long-term care was unavailable, family members described the staff and services that should be

included in long-term care settings. Specifically, families identified that onsite professional staff were very important. Approximately two-thirds of the respondents considered it important that nurses and social workers be on site. About one-fifth wanted physicians on site. Although onsite professional staff was identified as very important, many felt it was not necessary for them to be in the setting full time.

Medication supervision was identified as the most important onsite service. Most (92 percent) said it was very important. Onsite recreational/social activities and meals were also cited as very important by over three-fourths of the respondents. Learning job and community living skills, while very important, may best be accommodated outside the living situation according to family members (13).

### **The IMD Exclusion is a Major Barrier to the Availability of Long-Term Care**

Size of the ideal setting is a critical factor, since onsite services tend to make smaller group settings less economical. The typical cost per day for facilities in Massachusetts and Iowa was \$114 (9.7 beds mean) vs. \$56 (31.7 beds mean) respectively. The smaller facilities in Massachusetts did not have onsite professional services and programs which were characteristic of the larger Iowa facilities (14).

The federal Medicaid exclusion of institutions of mental diseases (IMD exclusion) is a major barrier to the development of long-term care facilities with adequate structure and support services for individuals suffering from severe mental illnesses.

The IMD exclusion prohibits Medicaid reimbursement for institutions with more than 16 beds, that are primarily engaged in providing diagnosis, treatment, or care of persons with mental diseases (15). This law has become a major barrier to the availability of economical long-term settings, which can provide structure and professional supervision, and should be eliminated.

## Endnotes for "Half a Million Liberated from Institutions" article beginning on page 5.

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## Your Voice -- Will Make a Difference

*When I read the story of your son, Scott, it broke my heart. I cried my eyes out because my worst fears for my brother who is also schizophrenic, became a reality [for you]. I am so sorry that this avoidable tragedy happened. I feel sorrow and anger at an uncaring system that destroys instead of helps.*

*I have a 47-year-old brother who is diagnosed with paranoid schizophrenia. He has been ill for 28 years. There have been numerous attempts to dump him by the state system. The line we get is that John is "too well for the hospital and too sick for a group home." He functions at a very low level and is unable to care for himself. He is currently in a New York*

*state hospital, and not controlled well with medication. He isn't resistant to treatment, but we still are having great difficulty getting it for him. There is a very real possibility that he can end up like Scott, or in jail. . . . No mentally ill person or his family should have to be subjected to this. This is a disgrace.*

*I would like to see a march on Washington to protest the barbaric treatment the mentally ill receive. Thank you for finding the courage to write about your son's plight. I know I can no longer sit by and watch. I feel a need to do something so I don't feel so hopeless.*

Carol Whitley, R.N.  
Dingmans Ferry, PA

[From the editor: I would like to express my appreciation for the many letters and phone calls of caring and concern for my family. Your financial and active support—calls to legislators, contacts with mental health professionals, passing along a *Catalyst* to someone who needs to hear our message, and continuing to make your frustrations in getting appropriate treatment for yourself or a loved one known to the Center staff—will make a difference for someone in the future. Lorraine]

*I received your Catalyst newspaper 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

*Your description of Scott so fits my brother. I've resigned myself to never being able to have anything more than a phone relationship with Buddy. I just don't think his sitting day after day in an apartment staring at the walls is quality life. Especially since he can't work. I think he would have been better off if they had left him in the group housing where he related to others daily rather than pushing him out of the system.*

Dorothy Groh  
Spring Hill, Florida

*Congratulations on a great inaugural issue of Catalyst! This endeavor will be a primary "catalyst" for people to learn of the true mission of [the Center]. . . Many of our people cannot afford or do not have access to a computer. They must rely on a printed newsletter. You have now filled that void for the Center.*

*Here in the Tampa Bay Area of Florida, we are making some real headway in the areas of: Crisis Intervention Training for Law Enforcement Officers, stigma and discrimination issues, and public awareness. . . Our "End the Mystery Celebration and Candlelight Vigil" attracts hundreds and is the kick-off for Mental Illness Awareness Week.*

*In future issues of Catalyst, I hope you will encourage submissions from the field.*

Donald G. Turnbaugh  
President  
NAMI Pinellas County, Florida, Inc.

[From the editor: Hope this issue and future ones include what you had in mind. The Center intends to publish articles from a broad range of sources on latest research and legal issues involving treatment of the most seriously mentally ill. Submissions will be reviewed and considered for publication. Thanks for the encouraging words.]

*Can I get 300 copies of the Catalyst to send to legislators and other political leaders? How much does it cost to subscribe to the Catalyst?*

*Can I copy articles from Catalyst as long as I give credit in our newsletter?*



*Thanks to Dr. Torrey, President, for founding the Center; the Board; Mary Zdanowicz, Executive Director; and Lorraine Gaulke and Diane McCormack, co-editors. The Stanley's have been so generous in so many ways and I want them to know how much gratitude I have in my heart . . . there are simply not words to express the depth of gratitude I feel.*

Mary Ann Renz  
Executive Director  
NAMI Mississippi

[From the editor: Thank you for your interest. Please do feel free to copy articles from the *Catalyst*. Another 300 copies are on the way to you. There is no cost to subscribe, but donations to support our mission are welcome.]

*Thank you for sending the Catalyst. The information in it is dear to my heart as I suffer from manic depression. In its ongoing battle, any legislation to improve my chances of necessary care is welcomed.*

*Your efforts in this regard are applauded. I am enclosing an essay I*

*wrote. If it can be of any use please feel free to use it.*

Darry Burton  
Nebraska

[Essay follows: A Case for Involuntary Commitment]

## **A Case for Involuntary Commitment**

**by Darry Burton, Nebraska**

It was an Easter holiday weekend in 1965. I had a three-day weekend from work at a General Motors plant in Southgate California. Six months prior to that time, while at work, I had been taken from the plant with a total blackout of events in the past and present. After being seen at two hospitals it was determined that I was mentally ill and, since I had insurance, I was put in Alhambra Neuropsychiatric Hospital for treatment of my mental illness.

At this hospital I received the best treatment available. With the aid of

psychiatric, recreational, and occupational therapy, as well as a good diet, I was fit at the end of a 30-day stay.

Not realizing that once a psychiatric break happens it takes a lifetime effort of care and medicine to maintain recovery, I resumed my life without the many available aids to combat this terrible disease. As a result, my three-day holiday was to have a monumental impact on my life.

The holiday began routinely enough, but I became disoriented while driving and had an accident. The investigating officer of the accident was alert enough too see I needed medical help so he took me to Orange County General Hospital.

While there for an indeterminate amount of days, I received the usual acute care and treatment. My condition remained poor. In spite of this, and against the advice of a nurse, I checked myself out of the hospital.

My car had been returned to the hospital after the accident. Getting in the car and intending to travel to Van Nuys, I

**THE FOLLOWING MEMORIALS AND TRIBUTES WERE RECEIVED BY THE TREATMENT ADVOCACY CENTER IN SEPTEMBER/OCTOBER 1999. PLEASE ACCEPT OUR DEEP APPRECIATION FOR CHOOSING TO SUPPORT OUR MISSION IN MEMORY OR IN HONOR OF SOMEONE VERY SPECIAL TO YOU. . . .GOVERNING BOARD AND STAFF.**

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SCOTT HARDMAN MEMORIAL FUND -60 RELATIVES/FRIENDS  
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SCOTT HARDMAN (STEPBROTHER)  
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SCOTT HARDMAN  
BARBARA MARCUS BLUMENTHAL  
  
JEANINE ERSKINE  
  
CARL AND ROSE UMANZIO (PARENTS)  
SCOTT HARDMAN  
SCOTT HARDMAN (BROTHER)  
SCOTT HARDMAN  
SCOTT HARDMAN  
JEAN GROJEAN

### **IN HONOR OF**

GEORGIANA HARBEN  
JOSHUA BREEZLEY  
E. FULLER TORREY  
  
DANIEL MOSCHELLI  
LARRY ERSKINE  
DAVID HUNT  
ALL OF YOU  
REID NEUWIRTH  
TED AND VADA STANLEY  
SARAH PETER  
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E. FULLER TORREY  
  
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left and entered the flow of traffic. Another break occurred, and I was off on a terror-ridden, high-speed drive from California to a violent crash in Tulsa.

This break was so severe that it took three hospital stays amounting to four consecutive years of treatment before resuming my quest for independent living.

In any illness it is best to treat it in its early stages for optimum results. Mental illness is the same as other illnesses in this regard. If it is discovered and treated before a complete break is allowed to take place, the prognosis and results of care improve the chances for recovery.

In my experience, if the enforcement of the Involuntary Commitment Law had been utilized it would have saved untold grief for me, my loved ones, and the ones paying the bills.

Later on in the course of my illness I switched care from a psychiatrist to a regular physician. Due to side effects from medicine he decided I was taking too much medicine. He gradually reduced my medicine. This resulted in frightening symptoms but by the time I noticed them it was too late. I had another break. I ended up in protective custody.

While safely in custody, an officer noticed I needed help. The proper channels were notified and my father-in-law and the judge helped commit me. I was only hospitalized for three months. During my stay at the hospital, I gained work experience, educational experience, alcohol [abuse] treatment, and much more. This would have all been impossible had I not been committed.

Since the time of my discharge in 1973, I have returned to hospitals for care periodically. The longest hospital stay has been for two weeks for medication adjustments. Had I not had the benefit of our medical and judicial systems judgement and decision of commitment, I would never have had the opportunity of experiencing the recuperative powers of commitment. However, I could have more unnecessary trauma and heartache without it.

With the help of compassionate mental health professionals, staff members, self-help groups, a concerned member of the community, employers, and God, my health has functionally returned. I am married, employed, and working towards better health. On the basis of my

experience, I strongly assert that the Involuntary Commitment Law should be utilized. ¶

## **The Story Behind Kendra's Law**

A 30-year-old man wrestles with schizophrenia for over a decade. He suffers visual and auditory hallucinations. He is in and out of mental health facilities. He is involved in six unrelated treatment programs in as many years. Repeatedly, he is released after a few weeks of hospitalizations with nothing more than instructions to take his anti-psychotic medicine.

Perhaps he tires of the side effects, feels he is well enough to do without the medications, or doesn't recognize he is ill at all. Whatever the reasons, he stops taking the drugs that control the voices, irrational behavior, and delusions.

On his mother's birthday, January 3, 1999, and three weeks after he is released from a 22-day psychiatric hospital stay, he is standing next to a tall blond woman on a subway platform. She firmly tells him to "back off". He approaches another woman and asks her the time, and she replies.

A few moments later he grabs the woman around the shoulders and waist and throws her into the path of an oncoming train. She doesn't have time to yell for help before she is killed and dragged by the train.

Kendra Webdale is the victim in this incident. The 32-year-old record company receptionist was also an aspiring screenwriter, recording artist, and freelance photographer. She was 5'6" tall, 130 pounds, blond, vivacious, and in the wrong place at the wrong time.

Andrew Goldstein is the young man charged with second-degree murder in the case. He was found fit to stand trial and pled not guilty. If convicted, he faces 25 years to life in prison. If found not guilty by reason of insanity, he will be sent to a mental facility and kept until he is considered fit for release.

His trial began October 7, 1999, in Manhattan. In closing arguments, his attorney called Goldstein the victim of a devastating disease and broken mental health system. A 3,500-page psychiatric history was offered in support of that claim. The attorney also argued Goldstein's psychosis made him incapable

of understanding right from wrong.


The prosecuting attorney, however, argued Goldstein was using his mental illness as an "excuse" to avoid responsibility for hurting people. Goldstein admitted to killing Webdale and also claimed to have shoved or kicked other women during his time as an outpatient. He claimed to have pulled a knife on one woman at a supermarket.

One confirmed incident resulted in a gash on a woman's head. In the outburst at a Queens Barnes & Noble, Goldstein knocked a mother to the ground when her young child apparently got on his nerves. The woman declined to press charges.

On November 2, 1999, its 6th day of deliberations, the Manhattan jury was unable to reach a decision, forcing a mistrial. The jury of eight men and four women deadlocked 10 to 2 in favor of conviction.

Since Kendra's death, her family fought for better treatment of the mentally ill. Kendra's Law, signed August 9, 1999, brings assisted outpatient treatment to New York. Similar laws are already in

place in 40 other states. The New York law, dubbed "Kendra's Law" after Kendra Webdale, passed in August.

Kendra's story is a highly sensational case. However, it and other highly publicized cases helped raise awareness of the need for better treatment for the mentally ill. In one similar incident just months after Kendra's, Edgar Rivera lost both his legs after being pushed onto subway tracks. Police shot Charles Stevens eight times because he swung a sword at passengers on the Long Island Railroad. Stevens lost the use of his arm as a result of the shooting. His parents, Henry and Nadine Stevens, joined the Webdales and Riveras in supporting the passage of Kendra's Law. 

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### **New Additions to [www.psychlaws.org](http://www.psychlaws.org)**

■ **A Guide to Kendra's Law** - a comprehensive summary of Kendra's Law, New York's assisted outpatient

treatment law, prepared by the Treatment Advocacy Center.

■ **Summary of Statutory Assisted Treatment Standards - 50 States and DC** - state-by-state summary of statutory assisted treatment standards.

### **■ NEW SECTION - HOSPITAL CLOSURES AND THE MEDICAID IMD EXCLUSION**

Briefing Paper: Repeal of the Institution for Mental Diseases (IMD) Exclusion.

The Outdated Institution for Mental Diseases Exclusion: A Call to Re-Examine and Repeal the Medicaid IMD Exclusion.

■ **Report of the Bellevue Hospital Center Outpatient Commitment Pilot Program**, Howard Telson, M.D., et al. - report by the team that ran the Pilot Program, including a critique of the study performed by Policy Research Associates, Inc.

■ **Can Psychiatry Learn From Tuberculosis Treatment?** E. Fuller Torrey, M.D., and Judy Miller, B.A., Psychiatric Services, November 1999.

**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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**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.**

### **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.
- ♦ 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 his illness.



**Kendra's Law is passed! Signed into law by New York's Governor George Pataki—See story inside.**