



Truth and courage

by Treatment Advocacy Center President E. Fuller Torrey, M.D.

TAC's first five years have been more successful than any of us envisioned when we began. TAC has established itself as the one organization willing to speak out for treatment for individuals with severe psychiatric disorders, especially those who have limited awareness of their illness. Amidst the cacophony of pseudo-civil rights and political correctness, TAC speaks with a clear voice of common sense.

But it is also apparent that we have just begun our task.

There are still nine states that have no statutory provision for assisted outpatient treatment: Maine, Massachusetts, Connecticut, New Jersey, Maryland, Florida, Tennessee, Nevada, and New Mexico. States that have such provisions or recently implemented them, such as New York and California, must be monitored and encouraged to use these laws.

We must educate the legal profession, media, and general public that the failure to treat individuals with severe psychiatric disorders is a major reason so many end up homeless, in jails,

and being victimized. And that failure to treat leads to episodes of violence that, in turn, are the greatest cause of stigma against individuals with psychiatric disorders.

Above all, we must continue to be a coordinating center to geographically link those affected, their families, state legislators, and local media to work together on these problems.

TAC's greatest asset is the passion of our supporters who believe in our mission and make our work possible. We are, it is true, a comparatively small David challenging a larger and better-funded Goliath. But we have wonderfully sharp stones as weapons, for they have on them points of logic.

A handwritten signature in black ink that reads "E. Fuller Torrey" with a stylized flourish and an arrow pointing to the right.

Coerced care vs. no care

by Treatment Advocacy Center Executive Director Mary T. Zdanowicz

Severe mental illnesses, by their nature, make coerced care necessary in some instances.

Nearly half of people with schizophrenia and manic depression suffer moderate to severe impairments of their awareness of illness.¹ Studies show that anosognosia and non-adherence to treatment are strongly associated.²

The moral or ethical question is "what is the impact of coerced care compared to the impact of no care at all?" The consequences of nontreatment are all too well documented: relapse of symptoms, rehospitalization, homelessness, arrests, victimization, suicide, and episodes of violence.

But what is the impact of coerced care?

We now have empirical evidence that in the majority of cases, coerced care is not detrimental. In fact, it is beneficial. Many studies have found that the majority of patients retrospectively agree that involuntary medication had been in their best interest.³

Those who are ideologically opposed to coerced care claim, without empirical evidence, that it drives people away from treatment.

But two recently published studies

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Kendra's Law: A Mother's Thanks

by Pat Webdale, from the *New York Post*, Feb. 25, 2004, reprinted with permission of the author

When my daughter was killed by a man who was not being treated for schizophrenia, all of the joy in this world became diminished for me. It has been a blessing to know that the law named in her memory - Kendra's Law, which can force mentally ill patients to comply with medical treatment - is helping so many people.

I thank *The Post* for hailing the recent Court of Appeals ruling upholding the law as a victory for the mentally ill. Kendra's Law can be a lifeline for those who are suffering from demons similar to those of my daughter's killer - those hearing voices caused by a severe untreated brain disease, unable to discern the difference between truth and fantasy, incapable of choosing to be treated because they don't believe they are ill. New York's Office of Mental Health said that assisted outpatient treatment "has increased accountability at all levels regarding delivery of services to individuals who have high needs and who are at high risk to themselves or others." This law not only commits people to the system, but it commits the system to help those who need it most.

Thank you for helping to educate the public on mental illness and available options for getting those you love into a treatment plan. Kendra's Law has been proven to reduce incidences of hospitalization, homelessness, arrest and incarceration. Like Kendra, it is about compassion.

- Pat Webdale, Fredonia

THE BENEFITS OF KENDRA'S LAW

For 1,407 people who completed their first Kendra's Law Program as of September 2003:

- 63% fewer experienced psychiatric hospitalizations;
- 75% fewer have been arrested;
- 69% fewer have been incarcerated; and
- 55% fewer experienced homelessness.

Participants also saw dramatic reductions in harmful behavior:

- Incidents of harm to self reduced 45%;
- Incidents of harm to others reduced 44%;
- Incidents of damaging or destroying property reduced 43%; and
- Incidents of creating a public disturbance reduced 32%.

Participants were more likely to regularly participate in services and take medication as prescribed by a physician:

- The number of individuals exhibiting poor adherence to medication decreased by 67%;
- The number of individuals exhibiting poor engagement to services decreased by 34%; and
- The number of individuals reported having severe difficulty accessing and using community services also decreased by 34%.

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About TAC

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

Since 1998, the Treatment Advocacy Center has served as a catalyst to achieve proper balance in judicial and legislative decisions that affect the lives of people with serious brain disorders. TAC works on the national, state, and local levels to decrease homelessness, incarceration, suicide, victimization, violence and other devastating consequences caused by lack of treatment.

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Winter 2003/Spring 2004

The Courts

Reaffirmed: Assisted treatment constitutional

In February, New York's highest court rejected a number of potentially crippling judicial attacks on the nation's best-known assisted outpatient treatment law and proclaimed Kendra's Law constitutional.

Stressing the importance of the program, the unanimous Court of Appeals described it as "an effort to 'restore patients' dignity ... (and) enable mentally ill persons to lead more productive and satisfying lives, while at the same time reducing the risk of violence posed by mentally ill patients who refuse to comply with necessary treatment."

The decision by Chief Justice Judith Kay clearly pronounced the core of Kendra's Law to be constitutional, noting that "The state's interest in immediately removing from the streets noncompliant patients previously found to be, as a result of their noncompliance, at risk of a relapse or deterioration likely to result in serious harm to themselves or others is quite strong."

The two main arguments of the plaintiffs in the case, *In the Matter of K.L.*, centered on allegations that Kendra's Law was unconstitutional because it violated due process protections of patients. One insisted that Kendra's Law contravened the dictates of a previous decision of the Court of Appeals, *Rivers v. Katz*, by not requiring the explicit finding of

"A recent decision by New York's top court declaring Kendra's Law constitutional was a triumph of common sense. The Court of Appeals cut a careful path through a thicket of due process arguments and concluded that the state's compelling interest in protecting the public can sometimes trump the right of the mentally ill to refuse treatment Used properly, Kendra's Law lets doctors and relatives intervene before a mentally ill person poses a danger to himself or others. That's good for everyone, including the mentally ill."

— Kendra's Law Is Good Both For Public And Mentally Ill, *Newsday* editorial, Feb. 20, 2004

"It's difficult not to appreciate how many tragedies might have been avoided if New York had enacted a Kendra's Law even earlier, as 40 other states had done The Court of Appeals' ruling is an important step in protecting society from the mentally ill - and those same poor souls from their own tragic demons."

— "A Win for the Mentally Ill," *New York Post* editorial, Feb. 22, 2004

incapacity necessary for medication over objection with inpatient committees. The other main assault on the law concerned the lack of hearing prior to the 72-hour hold for an emergency evaluation authorized by the law when someone under an assisted outpatient treatment order may meet the standard for inpatient hospitalization.

The Court of Appeals soundly denied each of the plaintiff's arguments.

Newspapers across the state, regardless of political bent, lauded the wisdom of the court's ruling. Both *Newsday*, a notoriously liberal outlet, and the *New York Post*, a staunchly conservative one, emphatically praised the decision.

The ruling was faithful to the law but it was also - as the *Newsday* editors noted - a triumph of common sense. Although minor changes to the program because of future judicial rulings could be necessary, this precedent essentially insulates Kendra's Law from attacks on constitutional grounds in New York courts.

As if a prohibition to that explicit effect was the Twenty-Eight Amendment to the Constitution, many opponents brand assisted outpatient treatment as "unconstitutional." In fact, no court has ever made such a finding.

With the ruling *In the Matter of K.L.*, a total of twelve judges in New York have examined the constitutionality of Kendra's Law; each of them has found the law constitutional, including the state's highest-ranking ones.

Can't wait for the next issue of *Catalyst*? Visit us online at www.psychlaws.org for fact sheets, news stories, and advocacy tips. Updated daily!

States can't afford not to use AOT

Don't buy the lie that AOT costs are prohibitive. Nontreatment breaks the bank.

Oftentimes in states without a program for assisted outpatient treatment, unfounded excuses are offered for not adopting such a program. One common excuse is: "Kendra's Law only worked in New York because the state budgeted \$150 million. Our state can't afford that."

But how much does New York state really budget for assisted outpatient treatment (AOT) under Kendra's Law?

Kendra's Law was passed in a time of budget surpluses, and its passage allowed New York to infuse its mental health system with more resources. However, only a small portion of that money is actually dedicated to assisted outpatient treatment.

The facts: The advocacy around Kendra's Law resulted in a commitment from New York's governor and legislature to increase resources for treatment of people with serious mental illnesses. State leaders promised \$125 million for the Enhanced Community Services Program, which significantly expanded case management, housing, family support and other mental health services. Each year, \$86.4 million is appropriated, which, when combined with other funding sources, provides \$125 million for community services. But it is important to realize that the appropriations and resulting services are not earmarked for Kendra's Law.

A separate commitment was made to appropriate \$32 million for the provisions in Kendra's Law, which encompassed more than assisted outpatient treatment. The Kendra's Law advocacy also resulted in a commitment to fund a presumptive Medicaid program in New York, meaning that those awaiting eligibility determinations are covered by the state in the interim. According to New York's Office of Mental Health, \$10.5 million is dedicated to assisted outpatient treatment, specifically intensive case management and supportive case management services covered by Medicaid. Assuming 74 percent Medicaid eligibility and a 50 percent Medicaid reimbursement rate for New York, only about \$6.6 million of state funds specifically support assisted outpatient treatment under Kendra's Law.

New York enhanced its community services, but many other states have had comparable infusions of money in community services programs. For example, New Jersey invested \$50 million annually in enhanced community services since closing its largest state psychiatric hospital in 1998. This is roughly an equivalent per capita investment to New York's investment in Enhanced Community Services and Kendra's Law combined.

It is also important to remember that Kendra's Law was passed in a time of budget surpluses - unlike the current atmosphere of fiscal restraint. It is not as likely now that legislatures will

make substantial investments in new services in any area.

But even states that have not made substantial investments in services cannot afford not to use assisted outpatient treatment.

For instance, many states have Assertive Community Treatment (ACT) teams that comprise the most progressive community service model for people with severe mental illnesses. ACT provides 24 hour, 7 day a week mobile treatment teams that travel to clients' homes to provide treatment. In states that do not utilize assisted outpatient treatment, ACT teams cannot require clients to take medication. This can severely limit positive outcomes. The problem of medication compliance is not insignificant, as noted by an ACT team psychiatrist in Sarasota, Florida:

Many clients regularly refuse to take their medications. Some used to take older medicines that had terrible side effects and they don't trust their new prescriptions. Others feel better after a few doses and quit, but most just don't believe they need drugs. "They have no insight and they don't believe they have a mental illness, so they don't believe there's any reason to take their medication," said Tim McGaughy, the team's psychiatrist. He estimates that about 85 percent of the team's clients won't take all or some of their prescribed medications. - "Team Makes Sure Patients Don't Fall Through Cracks," Herald Tribune, Nov. 9, 2001

Empirical evidence also suggests that court-ordered treatment can improve the effectiveness of intensive community services for individuals with severe mental illnesses who would otherwise refuse treatment. In November 2001, results of a study were published that indicated that intensive community services alone do not reduce the risk of violence among individuals with a diagnosis of psychosis and at least two inpatient admissions for psychotic illness. Although that study showed that intensive services alone did not reduce violence, the most comprehensive study of assisted outpatient treatment conducted at Duke University showed that intensive services (termed "regular services") combined with long term AOT cut the probability of violent behavior in half.

The significance is that intensive services alone do not ensure medication compliance, while AOT orders can mandate medication. The Duke study found that those who did not adhere to prescribed medication regimens were 63 percent more likely to be violent than those who complied. Therefore, even if assisted outpatient treatment legislation is enacted without new funding for services, it is needed to make existing services more effective.

NIMH fails to research severe mental illnesses Treatment Advocacy Center report card keeps pressure on

The National Institute of Mental Health (NIMH) is grossly failing in its primary task of researching the causes and treatment of serious mental illnesses: schizophrenia, bipolar disorder, autism, severe forms of depression, obsessive-compulsive disorder, and panic disorder (as defined by NIMH's advisory council). NIMH shows little interest in research on serious mental disorders, instead concentrating on general research on human behavior and basic neuroscience. Much of this research is the responsibility of, and is already being done by, other federal agencies.

The Treatment Advocacy Center's latest study on NIMH's research priorities, coauthored with Public Citizen, is *A Federal Failure in Psychiatric Research: Continuing NIMH Negligence in Funding Sufficient Research on Serious Mental Illnesses* (Nov. 2003). Visit www.psychlaws.org to read the full report.

The report found that only 28.5 percent of all 2002 NIMH research awards (1,187/4,157) had any relationship to serious mental illnesses. Furthermore, only 5.8 percent (242/4,157) of the awards were clinically relevant to serious mental illnesses, i.e., likely to improve the treatment or quality of life for individuals currently affected. In other words, only 1 out of every 17 research grants currently funded by NIMH is likely to help individuals who now have these diseases.

Equally disturbing is that during the 1997–2002 period in which the NIMH budget doubled from \$661 million to \$1.3 billion, the proportion of awards for research on serious mental illnesses decreased. During that period, NIMH rejected many applications for the study of these illnesses but funded many others unconnected to any mental disorder.

- ❑ NIMH rejected funding for research on the causes of postpartum depression but funded research on the hearing mechanism of crickets.
- ❑ NIMH rejected funding for research on why individuals with schizophrenia are unaware of their own illness, and they refuse to take medication, but funded research on communication among electric fish.

- ❑ NIMH rejected funding for research on the side effects of antipsychotic and antidepressant medication in adolescents but funded research on how pigeons think.
- ❑ NIMH rejected funding for a treatment trial to establish the most effective medication for individuals with a severe form of schizophrenia but funded research on how people in Papua New Guinea think.

The important question is not how people in Papua New Guinea think but how officials at NIMH think. It is known that serious mental illnesses account for 58 percent of the direct care costs of all mental illnesses, yet NIMH allocates just over 28 percent of its research resources to these diseases. It is known that 5.6 million Americans suffer from serious mental illnesses, and that on any given day approximately 250,000 of them are living on the streets or in jail because of their mental illnesses. It is known that serious mental illnesses cost the federal government alone approximately \$45 billion per year and that these costs have been rising at a rate of \$2.6 billion per year. From both a humanitarian and an economic point of view, NIMH's failure to do research on these diseases is irresponsible.

Imagine what the public would say if fewer than one-third of all research awards from the National Cancer Institute were going for research on cancer. And that fewer than 6 percent of the awards—1 out of 17—were likely to help anyone who today has cancer. That is the equivalent situation at NIMH today.

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NIMH's failure to research serious mental illnesses is not news within NIMH. Last year, they undertook their own study to document the problem. Some preliminary data that NIMH made public suggest that NIMH's failure to do research on serious mental illnesses is at least as bad as this report indicates. NIMH recently implemented a few projects to improve its research portfolio. However meritorious, these efforts are the equivalent of a face-lift for an agency in need of a heart transplant.

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Recommendations for NIMH

Continued from page 5

- ❑ A congressional committee should hold hearings to clarify NIMH priorities and specifically address two issues:

What percentage of NIMH research resources should be allocated to research on serious mental illnesses in general?

What percentage should be allocated to clinically relevant research on serious mental illnesses, i.e., research that is reasonably likely to improve the treatment and quality of life of individuals currently affected with these disorders?

- ❑ NIMH should be required to report to Congress annually the percentage of its funding supporting research on each serious mental illness and the subset of that number that is supporting research on clinically relevant aspects of that illness.

- ❑ Dr. Elias Zerhouni, Director of NIH, and Tommy Thompson, Secretary of Health and Human Services, are ultimately responsible for NIMH. Both should review discrepancies between resource allocation and public need.

- ❑ The General Accounting Office (GAO) should be asked by Congress to evaluate the current research portfolio of NIMH in relationship to public needs. This is consistent with GAO's mandate to "improve the economy, efficiency, and effectiveness of the federal government through financial audits, program reviews and evaluations, ... and the government's accountability to the American people."

- ❑ Basic neuroscience research is important, but its support should be coordinated. NIMH officials should meet regularly with officials from the National Institute of Neurological Disorders and Stroke (NINDS), other NIH institutes supporting basic neuroscience research, and the National Science Foundation (NSF) to coordinate research and establish targeted amounts that each organization will spend on such research.

- ❑ Consideration should be given to ultimately merging NIMH with NINDS to form a National Brain Disease Research Institute to coordinate research on all brain diseases, including serious mental illnesses. If Congress deems that more non-disease-related behavioral research is needed other than what is already supported by NSF and the National Institute of Child Health and Human Development, a National Institute for Behavioral Research could be created.

It is nothing less than a national tragedy to misallocate public research dollars that should be used to offer hope of better treatments and possibly a cure for severe mental illnesses like schizophrenia and bipolar disorder. NIMH's refusal to do research on serious mental illnesses is not only a waste of taxpayer funds, it is a federal disgrace and a personal tragedy for individuals affected with these diseases.

Many people turned to NIMH for research on postpartum depression after the tragic story of Andrea Yates. Between 1972 and 2002, how many research grants had NIMH given to research postpartum depression?

One.

How many grants did it give out to study how pigeons think?

Ninety-two.

UNBELIEVABLE - BUT TRUE ...

In 2002, only **28.5 percent** of NIMH awards went to research on serious mental illnesses. These illnesses account for **58 percent** of the total costs of all mental illnesses.

Only **5.8 percent** of all NIMH awards went to clinically relevant research on serious mental illnesses. "Clinically relevant" means reasonably likely to improve the treatment and quality of life for individuals presently affected.

Between 1997 and 2002, the proportion of NIMH research awards for all aspects of serious mental illnesses **decreased by 11 percent** (from 32.1 to 28.5 percent). For clinically relevant aspects of serious mental illnesses, it **decreased by 22 percent** (from 7.4 to 5.8 percent).

Only **1 out of every 17** NIMH 2002 research awards is reasonably likely to improve the treatment and quality of life for individuals presently affected by a serious mental illness.

NIMH's failure to fund sufficient research on serious mental illnesses is the main reason why research on these illnesses is so grossly underfunded compared to other diseases. For example, per person affected, for every \$1 NIMH spent in 1999 for research on bipolar disorder, NIH spent over \$12 for research on cervical cancer. For every \$1 NIMH spent for research on depression, NIH spent almost \$15 for research on multiple sclerosis. For every \$1 NIMH spent for research on schizophrenia, NIH spent \$30 on research for HIV/AIDS.

Research on serious mental disorders is not an important part of the NIMH research portfolio.

During the five-year period of doubling of the NIMH budget, a period that could have been used by NIMH to correct its traditional neglect of research on serious mental illnesses, the proportion of NIMH research awards allocated to serious mental illnesses actually **decreased**, rather than staying the same or increasing.

In memory of a noble man: Howard Telson, M.D., expert, advocate, friend

With a deadened heart, we tell you that Dr. Howard Telson passed away April 5, 2004, from complications of a very aggressive cancer. He was only 49.

A clinical associate professor of psychiatry at NYU School of Medicine, a former board member of NAMI New York City metro, and a superlative psychiatrist, Dr. Telson is best known to readers of *Catalyst* for heading the pilot outpatient commitment program at Bellevue Hospital in New York that was subsequently expanded statewide by Kendra's Law. In many ways, Howard Telson was and is the father of Kendra's Law. During the battle for Kendra's Law, both sides vehemently argued whether or not the Bellevue Pilot demonstrated that outpatient commitment worked. No one could agree on anything except that Howard had helped everyone in the program. Family members of those under his care portrayed Dr. Telson as virtually divine. Opponents insisted that the success of the program was not because of assisted outpatient treatment, but an amazing doctor.



Howard's was one of the kindest hearts that we have or will ever run across. As was noted in his *New York Times* obituary, "All those who knew him were touched by his warmth and the profound humanity of his relationship with others."

Our condolences go out to Dr. Anand Pandya, Howard's longtime partner.

Opposition to coercion can mean opposition to care

Continued from page 1

found that there is no relationship between perceived coercion during hospitalization and future adherence with treatment.⁴

The McArthur Coercion Studies revealed another very significant, yet counterintuitive, finding. Legal status (voluntary versus involuntary treatment) does not necessarily correlate with perceived coercion.⁵ For example, 47 percent of involuntarily hospitalized patients believed there was no reasonable alternative to hospitalization. Conversely, while one would expect that all voluntary patients agreed to hospitalization because there were no reasonable alternatives, 25 percent of voluntary patients thought there were reasonable alternatives to hospitalization. Furthermore, 35 percent of involuntary patients did not perceive being coerced and 22 percent thought it was their idea. Surprisingly, 49 percent of voluntary patients indicated that someone else had initiated their coming to the hospital and 10 percent perceived that they had been coerced.

Because legal status doesn't predict perceived coercion, those advocates who are most concerned about patient welfare are better off advocating for quality care rather than against legal mechanisms for involuntary treatment. There are many ways to reduce coercion even within a framework of involuntary care.

Perceived coercion can be reduced if:

- others, including friends and family, are involved in the decision making as a form of caring;
- the patient believes others acted out of genuine concern;
- the patient believes he or she is treated respectfully and in good faith; and
- the patient has a chance to tell his or her side of the story.⁶

Coerced care occurs on a progressive continuum, from persuasion, to inducement, to threats, and finally force. There are many forms of coerced care, otherwise known as assisted treatment. Some of these include advanced directives, representative payee, assertive community treatment and outpatient commitment (also called assisted outpatient treatment, or AOT).⁷

Assisted outpatient treatment is the most controversial merely because of its court-ordered legal status. But, as already noted, legal status alone does not predict perceived coercion. And AOT statutes often require that patients be given an opportunity to participate in formulating their treatment plan.

AOT has been shown to reduce homelessness, hospitalization, arrests, and victimization.⁸ If the choice is between coerced care and no care at all, the decision is obvious for those who care more about the individual than ideology.

1 Treatment Advocacy Center, "Impaired awareness of illness: A major problem for individuals with schizophrenia and bipolar disorder."

2 Treatment Advocacy Center, "Why individuals with schizophrenia and bipolar disorder often do not take their medication."

3 Treatment Advocacy Center, "The effects of involuntary medication on individuals with schizophrenia and manic-depressive illness."

4 S.D. Rain, et al., "Perceived coercion at hospital admission and adherence to mental health treatment after discharge," *Psychiatric Services* 54: 103-105 (2003); S.D. Rain, et al., "Perceived coercion and treatment adherence in an outpatient commitment program," *Psychiatric Services* 54: 399-401 (2003).

5 Darold Treffert, "The MacArthur coercion studies: A Wisconsin perspective," *Marq. L. Rev.* 82: 759-785 (1999).

6 *Id.* at 729.

7 Treatment Advocacy Center, "Options for assisted treatment."

8 Treatment Advocacy Center, "Assisted outpatient treatment reduces hospital stays, violence and arrests and improves chances of recovery for people with severe mental illnesses."

Forty years of neglect: The federal role in caring for the severely mentally ill

On October 31, 1963, President John F. Kennedy signed the Community Mental Health Centers Act, through which psychiatric patients would be treated in small community clinics rather than in large and expensive state hospitals. Though the act promised to improve conditions and save millions of dollars, it mostly added to the growing wave of deinstitutionalization that began a few years earlier. Some of the released patients were able to manage well on anti-psychotic medications with attendant social services, but many others landed on the streets and in jails. Today, at least a third of the homeless and up to one quarter of those incarcerated have severe mental disorders such as schizophrenia and manic-depressive illness. On the fortieth anniversary of this legislation's enactment, a panel of mental health and policy experts gathered at the invitation of Dr. Sally Satel at the American Enterprise Institute to discuss the federal government's neglect of the severely mentally ill. This article is derived from an indepth summary by AEI research assistant Nell Manning.

Legislation's failure is no surprise

Dr. E. Fuller Torrey, TAC president

The 1963 Community Mental Health Centers Act was the last major piece of legislation signed by President Kennedy prior to his assassination. It has become a symbol for how a well-meaning action can become a total and complete disaster.

The Act's failure can be attributed to four flaws in its design and implementation. First, it was based on a number of failed assumptions about what was wrong with the severely mentally ill. Those responsible for the legislation did not fully understand brain diseases; assumed that if released from state institutions, the mentally ill could live happily ever after; and neglected to investigate a condition known as anosognosia. Anosognosia is an integral part of severe mental illness. As many as 50 percent of those with schizophrenia and 40 percent of those with bipolar are impaired to such an extent that they cannot recognize what is wrong with them. (See the fact sheet on anosognosia on page 11 of this issue.) So a significant portion of the severely mentally ill cannot live "happily ever after" without direct treatment and supervision.

Secondly, the Act suffered from flawed planning. It bypassed the states entirely and placed the burden of funding community mental health centers on the federal government. The National Institute of Mental Health failed to provide essential oversight of the centers. The community mental health centers were failed by a total unwillingness to take responsibility for center management at both the state and federal levels.

Thirdly, before the movement toward deinstitutionalization, the states covered 95 percent of the financing for care of the severely mentally ill. In the hopes of moving patients out of the state hospitals and into the community, the federal government made patients in state hospitals ineligible for aid while hospitalized, but eligible when discharged from the hospitals, thus providing the states with enormous incentive to empty out

“Reliance on the cold mercy of custodial isolation will be supplanted by the open warmth of community concern and capability.”

– President John F. Kennedy, address to the nation, Feb. 5, 1963

the hospitals. Deinstitutionalization quickly became the priority for state mental health agencies and there was no incentive to ask what happened to patients once they left the hospital.

The civil rights era exacerbated an already deteriorating situation. Some activists decided that the severely mentally ill needed to be 'liberated' from hospitals, arguing that "no one should be deprived of freedom for the sake of mental health," and "the goal should be nothing less than the abolition of involuntary hospitalization." These theories represented distorted views of "freedom" and "liberty." Some psychiatrists countered: "Freedom to be sick, helpless and isolated is not freedom," and, "Is it really liberty if someone walks the streets in terror because of paranoid delusions or threatening hallucinations?"

So the question now becomes, after those substantial failures, where are we left now? After the passage of the Act and the resultant deinstitutionalization, about half the patients are better off, but half are considerably worse off. Many of them were not deinstitutionalized, but rather trans-institutionalized: moved into nursing homes, large group homes, or other facilities, which are often worse than the large hospitals. There has also been what can be termed a 'ghettoization' of the mentally ill: one-third of the homeless are severely mentally ill. Currently 7 percent of inmates in jails and prisons are psychotic, and the Department of Justice and Human Rights Watch suggest that those numbers are even higher -- 16 percent and 20 percent respectively. The three largest mental institutions in the United States are all correctional facilities; the L.A. County Jail, the Cook County Jail and Riker's Island in New York.

Despite this desperate situation, we continue to incur enormous cost in programs that are obviously failing. In direct costs alone, \$71 billion a year is spent on care for the mentally ill; when coupled with indirect costs, that number more than doubles. Since 1961, there has been more than a ninefold increase in cost, and the federal government is carrying two-thirds of that cost. Federal costs are increasing at a rate of \$2.6 billion. There is a lack of intelligence about how the money is being spent, not a lack of funding. President Kennedy's 1963 Act has been a failure, and its legacy persists today: a clear example of the danger when ideology wins out over rational policymaking and political correctness wins out over scientific correctness.

In direct costs alone, \$71 billion a year is spent on care for the mentally ill; when coupled with indirect costs, that number more than doubles.

Dismantle inefficient, ineffective system

Dr. Jeffrey Geller, University of Massachusetts

Title II of the 1990 Americans with Disabilities Act is devoted to public services. Section 12132 reads, "No qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."

A number of court cases have been tried over that particular section, the most famous of which is the Olmstead case in the U.S. Supreme Court. Brought on behalf of two women with mental illness and mental retardation, the court found, in a six to three majority that:

...for any person with mental disability, community based treatment rather than institutionalized placement is required of the states when 1) the state's treatment professionals have determined that community treatment is appropriate; 2) the transfer from institutional care to a less restrictive setting is not opposed by the affected individual; 3) community placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with mental disabilities.

Throughout federal cases to date, fundamental questions remain unanswered. None of these cases addresses the fact that our current system is tilted toward moving people from institutions that cannot receive federal funds to institutions and non-institutional settings that can benefit from federal support.

There are six ways to begin to dismantle a paradigm that is preventing efficiency and effectiveness. First, the unfounded concept that restrictiveness and/or isolation is inextricably linked to the locus of room and board should be abandoned. Second, the present institution for mental diseases (IMD) exclusion must end. Third, a system of Medicaid-reimbursed treatment for eligible persons should exist in all settings,

including jails and prisons. And it must be a requirement that in all settings these treatments meet the same CMS standards. Fourth, a conscious effort must be made to introduce and sustain the concept that restrictiveness and integration is individually, not categorically, determined. In other words, what is

restrictive or not is dependant upon the individual's perception and appreciation. Fifth, addressing the issue from a fiscal point of view, each state should require that the percentage of a person's Social Security Income or Social Security Disability Income

checks that is applied to room and board be the same, independent of the location at which room and board is supplied. And sixth, if we are going to truly respect safe autonomy, self-determination and free choice, do we not have to respect unpopular as well as popular decisions in both directions? Informed decisions made by patients must be respected, however unpopular or unwise they are seen to be.

The existent fundamental assumption that life outside of institutions is always better is unquestionably flawed. The truth is, for persons with severe mental illness, each individual is different, and the option to remain in an "institution" must be available after exposure to safe alternatives have been provided.

Federal government does more harm than good for severely mentally ill

Mary Zdanowicz, Esq., TAC Executive Director

The question of involuntary treatment was brought to the nation's capitol five years ago by Russell Weston, when he stormed its steps trying to find the "ruby-satellite system" he thought he needed to control the space-time continuum. Weston's case is one of the most extreme examples of the federal government's role in coercive strategies, and it demonstrates why such strategies are needed sooner rather than later.

Shortly after Weston was released from a state hospital, he reported to a community mental health facility for what he thought was court-ordered treatment. When he learned that a judge had not ordered him to keep the appointment, he left and never came back. A federal court ordered him to take medication, but only after two people died - now the goal is to restore him to competency for a trial.

Why are coercive strategies necessary? About half of people with schizophrenia and manic depression have impaired awareness of their illness. Many state laws require, or are interpreted to require, that a person be dangerous before anything can be done to override their objections to treatment. The clear implications of these laws: without coercive strategies, the most severely mentally ill will not receive the treatment they need.

Continued on page 10

Federal government fails the sickest

Continued from page 9

The federal government must first support change at the state level. The Center for Mental Health Services should focus on supporting state efforts to serve the vulnerable population that is incapable of accessing voluntary services. Secondly, the federal government should leverage treatment compliance. America's Law Enforcement and Mental Health Project authorized funding for mental health courts. And the Mentally Ill Offender Treatment and Crime Reduction Act (S-1194) would provide resources for states to keep the most severely mentally ill out of the criminal justice system, thereby stopping the cycle at its conception.

Thirdly, the federal government must try harder to do no harm. Protection and Advocacy systems are federally funded state-based legal advocacy programs for people with disabilities. These programs are often used to bring lawsuits against states attempting to reform laws governing treatment, and lobby and protest against laws that facilitate treatment for those who otherwise refuse it. Federal funds should not be used to support activity that challenges state laws governing the involuntary treatment of persons with mental illness.

Finally, Congress should resist advocacy efforts to forbid using funds for services that are not "voluntary." States can best determine the proper uses of their funds; at the state level we will most effectively deal with those unable to access voluntary treatment. Assisted outpatient treatment is an important option for judges, who must otherwise confine someone in a hospital for treatment, and has been shown to reduce the risk of re-hospitalization, violence, homelessness and arrest.

Comparing the advancements made at the state level to failings occurring at the federal level - for instance, the absence of discussion about anosognosia, involuntary treatment or even mental health courts in the President's New Freedom Commission report released in July 2003 - it appears that the proper role of the federal government in this issue is no role at all.

Legislation, litigation, and scandal

Dr. Wayne Fenton, George Washington University

Three factors have consistently influenced the government's perception of its role in caring for the mentally ill: legislation, litigation and scandal. Legislation and litigation guided the federal role, but scandal emerged as the force that brought the

mental health crisis to the forefront of the American conscience in 1946. The nation was shocked into motion by an exposé that appeared in *Life Magazine*, "Bedlam: 1946." This piece's strong language, along with its compellingly gruesome photos, brought the true horror of mental institutions to the nation's doorsteps, a theme repeated in popular movies such as "The Snake Pit."

There are at least five times as many persons with serious mental illness in jails and prisons than in all mental hospital beds in the country. The current situation is alarming, and the mental health community is divided on how to fix it. The most compelling scientific research shows that for those

maintained on neuroleptic anti-psychotic medication, there is a 70-80 percent chance that person will not relapse, but for those without medication or those assigned to placebo in a blind clinical trial, the results are completely reversed. It is clear that something must be done to get this at-risk population into care.

A new paradigm

Dr. Robert Keisling, Unity Healthcare

All the studies show that treatment works if you get it out to the people who need the treatment. The problem is that most of the people who need the treatment are not getting the treatment because they don't know they need any, or because bureaucratic policies and procedures prevent people from getting the help they need. We need a totally new way of doing business.

Balance and success

Stuart Butler, Heritage Foundation

When one thinks of the policy catastrophes we have seen in this country in the last fifty years, our dealings with mental health and with severe mental health must rank in the top four or five. The challenge now is to find a way of achieving Kennedy's vision.

The system does not function well today because there is, among policymakers, a profound misunderstanding and lack of knowledge about this issue, making it almost impossible to effectively solve the problem from both a logistical and financial point of view. We are unwilling to take a financial and political risk on an issue that we do not understand. There is also an imbalance of political forces on the issue of mental health and severe mental illness. Very few policymakers focus on the severely mentally ill. Far more take the concerns of the worried well - their more 'valuable constituents' - to heart.

[Protection and Advocacy programs] are often used to bring lawsuits against states attempting to reform laws governing treatment, and lobby and protest against laws that facilitate treatment for those who otherwise refuse it. Federal funds should not be used to aid or support activity that challenges state laws governing the involuntary treatment of persons with mental illness.

Impaired awareness of illness: Anosognosia

Impaired awareness of illness (anosognosia) is a major problem because it is the single largest reason why individuals with schizophrenia and bipolar disorder do not take their medications. It is caused by damage to specific parts of the brain, especially the right hemisphere. It affects approximately 50 percent of individuals with schizophrenia and 40 percent of individuals with bipolar disorder. When taking medications, awareness of illness improves in some patients.

Impaired awareness of illness is a strange thing. It is difficult to understand how a person who is sick would not know it.

Impaired awareness of illness is very difficult for other people to comprehend. To other people, a person's psychiatric symptoms seem so obvious that it's hard to believe the person is not aware he/she is ill. Oliver Sacks, in his book *The Man Who Mistook His Wife for a Hat*, noted this problem:

It is not only difficult, it is impossible for patients with certain right-hemisphere syndromes to know their own problems ...And it is singularly difficult, for even the most sensitive observer, to picture the inner state, the 'situation' of such patients, for this is almost unimaginably remote from anything he himself has ever known.

What is impaired awareness of illness?

Impaired awareness of illness means that the person does not recognize that he/she is sick. The person believes that their delusions are real (e.g. the woman across the street really is being paid by the CIA to spy on him/her) and that their hallucinations are real (e.g. the voices really are instructions being sent by the President). Impaired awareness of illness is the same thing as lack of insight. The term used by neurologists for impaired awareness of illness is anosognosia, which comes from the Greek word for disease (nosos) and knowledge (gnosis). It literally means "to not know a disease."

How big a problem is it?

Many studies of individuals with schizophrenia report that approximately half of them have moderate or severe impairment in their awareness of illness. Studies of bipolar disorder suggest that approximately 40 percent of individuals with this disease also have impaired awareness of illness. This is especially true if the person with bipolar disorder also has delusions and/or hallucinations.

Is this a new problem? I've never heard of it before.

Impaired awareness of illness in individuals with psychiatric disorders has been known for hundreds of years. In 1604 in his play "The Honest Whore," playwright Thomas Dekker has a character say: "That proves you mad because you know it not." Among neurologists unawareness of illness is well known since it also occurs in some individuals with strokes, brain tumors, Alzheimer's disease, and Huntington's disease. The term anosognosia was first used by a French neurologist in 1914. However in psychiatry impaired awareness of illness has only become widely discussed since the late 1980s.

Is impaired awareness of illness the same thing as denial of illness?

No. Denial is a psychological mechanism which we all use, more or less. Impaired awareness of illness, on the other hand, has a biological basis and is caused by damage to the brain, especially the right brain hemisphere. The specific brain areas which appear to be most involved are the frontal lobe and part of the parietal lobe.

Can a person be partially aware of their illness?

Yes. Impaired awareness of illness is a relative, not an absolute problem. Some individuals may also fluctuate over time in their awareness, being more aware when they are in remission but losing the awareness when they relapse.

Are there ways to improve a person's awareness of their illness?

Studies suggest that approximately one-third of individuals with schizophrenia improve in awareness of their illness when they take antipsychotic medication. Studies also suggest that a larger percentage of individuals with bipolar disorder improve on medication.

Why is impaired awareness of illness important in schizophrenia and bipolar disorder?

Impaired awareness of illness is the single biggest reason why individuals with schizophrenia and bipolar disorder do not take medication. They do not believe they are sick, so why should they? Without medication, the person's symptoms become worse. This often makes them more vulnerable to being victimized and committing suicide. It also often leads to rehospitalization, homelessness, being incarcerated in jail or prison, and violent acts against others because of the untreated symptoms.

Charles “Chuck” Sosebee

Courageous advocate wins 2004 Torrey Advocacy Commendation award

Charles “Chuck” Sosebee has been selected by the board of directors of the Treatment Advocacy Center as the second recipient of the Torrey Advocacy Commendation Award for outstanding advocacy for treatment of the most severe mental illnesses. Chuck was nominated by Katherine Minsk, who included in her nomination a tribute by Randall Hagar. Together, their description of Chuck’s courage makes it clear why he is the winner of this award.



Katherine Minsk: In the five years I have known Chuck, he has worked unselfishly and tirelessly for access to services for severely and chronically mentally ill persons. He served on the San Diego (CA) County Mental Health Advisory Board, resigning to become coordinator of San Diego NAMI’s “Living with Schizophrenia” program. He taught “Family to Family” classes.

He was one of the first clients to endorse LPS reform, founding California Clients for LPS Reform, which grew to over 300 members. He became a coordinator of the California Treatment Advocacy Coalition, where he put his talents to work to advocate for the passage first of AB1800 and then AB 1421.

Randall Hagar, another coordinator of CTAC, describes Chuck’s contribution in getting LPS reform (finally) passed. There is not much I can add to this except that he is my hero too, and deserving of recognition for his continued advocacy for mentally ill persons.

Randall Hagar: I know there is no more courageous nor more deserving person; he has made a most painful sacrifice... and more importantly, he has been more effective in his inimitable way than I and I’m not ashamed to admit it.

Chuck was not only unafraid to bare his life and share his personal story and the effects his untreated illness has on himself and many others, but did it articulately, and perhaps with an unmatched humor and humanity that made him very appealing to these decision and policy makers. He did more to advance the cause of consumers generally because of his easiness and acceptance of his illness, and visibly displayed the obvious fruits of his recovery (if I can use the term) better than anyone I know before the most important audience I know.

He was not someone you would ever forget if you were a legislative staffer and he had a moral standing that exceed-

ed that of any family member, though I often thought family members were pretty high.

He could illustrate the dry, statistical and evidence-based argument that is necessary to make for the sake of public policy credibility with pithy personal anecdotes that finessed our arguments. He absolutely skewered the opposing consumers and their arguments. I think that he personally caused many staffers to re-evaluate their own opinion of and their own stereotypes about mental illness. That effect is incalculable and goes beyond 1421.

Chuck has been a hero, and he’s my hero. It’s not hard to accept your own illness when people like him are such good models.

Tell us about your hero

The TAC (Torrey Advocacy Commendation) Award rewards the courage and tenacity of those who selflessly advocate -despite criticism and opposition - for the right to treatment for those who are so severely disabled by severe mental illnesses that they do not recognize that they need treatment.

REQUIREMENTS: Nominees should have a continued and long-term focus on advocacy. They are strong advocates, paid or unpaid, in the field of mental illness; their advocacy supports securing humane and timely treatment for individuals suffering from the most severe mental illnesses and assisted treatment for those who do not recognize that they are ill. Nominees have made a substantial difference for a community, local or national, in terms of advocacy, awareness, research, or legislation in this field.

SUBMITTING A NOMINATION: Submit a 500-word essay on why the nominee should win this award. Nominations are accepted from anyone, but people cannot nominate themselves. Nominations cannot be anonymous. Please include full name and contact information of the nominator, as well as any affiliations with the nominee. The nominee does not have to consent to being nominated or be informed of the nomination. There is no entry fee.

Nominations must be postmarked by August 1, 2004, and sent via regular mail only (no emails or faxes) to The Treatment Advocacy Center, TAC Award Nominee, 3300 North Fairfax Drive, Suite 220, Arlington, VA, 22201.

The TAC award is presented at the sole discretion of the board of the Treatment Advocacy Center.

Memorials and Tributes

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

– *The board and staff of the Treatment Advocacy Center*

Nelson and Theresa Goguen, Ashby, MA	In memory of Louise Benoit
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Pam Jackson, Titusville, FL	In honor of my brother, Steve
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Ted Schultz, Chelan, WA	In honor of all you're doing to help
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Roman and Rose Mary Kerschen, Kingman, KS	In memory of Marie J. Freund
Lynn Smith, Kingman, KS	In memory of Marie J. Freund
August and Vada Freund, Great Bend, KS	In memory of Marie J. Freund

“I am so proud to be part of TAC; the work you do is invaluable.”

- from a letter sent in with a donation

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Merry Kelley, Hiawatha, IA	In memory of my daughter, Bonnie Picard
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Anne Lange, Norfolk, NE	In honor of the Norfolk Regional Center (a state mental hospital)
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Diane Derow, Philadelphia, PA	In memory of Leslie Derow (suicide 1-14-73)
Beatrice Rose, Anchorage, AK	In memory of Nathaniel Rose (1959-1993)
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Lisa Buchanan, San Francisco, CA	In honor of E. Fuller Torrey's immeasurable contributions
Gwen Luce, Palo Alto, CA	In honor of Stephen R. Luce, Jr., my son
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“Your efforts to improve the treatment of people who have mental illnesses are greatly appreciated, as are your efforts to educate the public.”
- from a letter sent in with a donation

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Jesse Stinson, Birmingham, AL	In honor of the work done by Dr. E. Fuller Torrey and staff
LaVerne Kemp, Tehachapi, CA	In honor of Dr. E. Fuller Torrey and in memory of my son, Thomas Kemp
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William and Marianne Kernan, Pinehurst, NC	In honor of all those suffering from mental illness
Rose May Thibeaux, Lafayette, LA	In memory of John Thibeaux - my husband, a dedicated mental health advocate

“Thank you for all of the work the Treatment Advocacy Center has been involved in over the years in helping to change the treatment laws in many states around the country.”

- from a letter sent in with a donation

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“Amidst the cacophony of pseudo-civil rights and political correctness, TAC speaks with a clear voice of common sense.”

- E. Fuller Torrey, M.D.

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