



Dedicating this issue of *Catalyst* to a True Advocate — Dr. Morton Birnbaum

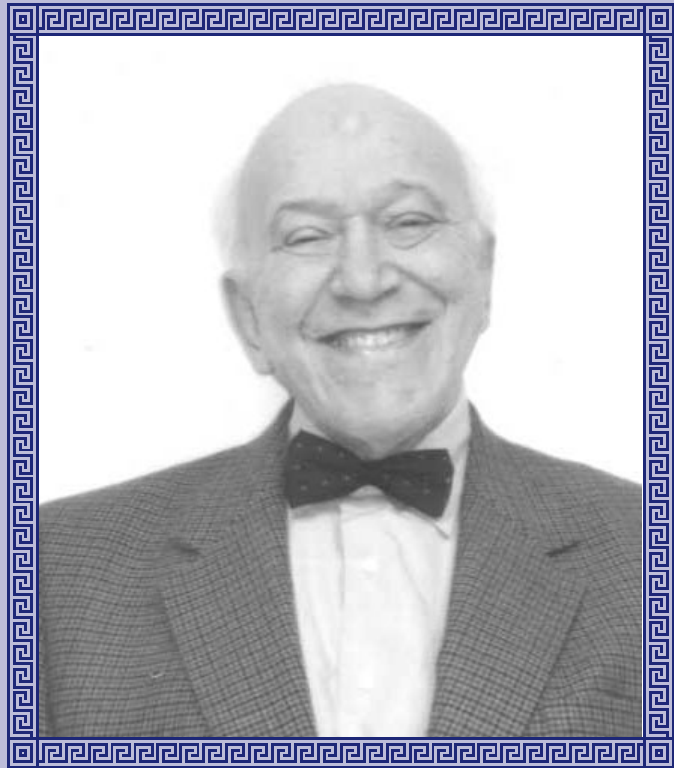
By Mary Zdanowicz

Congratulations to Dr. Morton Birnbaum, first recipient of the new **Torrey Advocacy Commendation Award** for outstanding advocacy for treatment of the most severe mental illnesses. This issue of *Catalyst* is dedicated to Dr. Birnbaum.

About the award

The Treatment Advocacy Center (TAC) has taken on a monumental task — ensuring the right to treatment for individuals who are so disabled by severe mental illnesses that they do not recognize that they need treatment. TAC works to reduce the consequences of non-treatment including: homelessness, suicide, incarceration, victimization and episodes of violence. This means advocating, when necessary, that treatment be provided against a person's expressed wishes based on their need for treatment rather than waiting until they become dangerous. It also means requiring a person to stay on medication and in treatment long enough that they are able to recognize the difference between being psychotic and being without symptoms so that they may develop sufficient insight into their illnesses to stay in treatment without a court-ordered mandate.

These are not always popular positions. But, we are continually reassured when we find that we are not the



Dr. Morton Birnbaum is the recipient of the Treatment Advocacy Center's inaugural Torrey Advocacy Commendation Award

lone voice advocating a position around which there is no consensus in the mental health community. We are inspired by our advocates in the field — those selfless individuals who are not deterred by criticism and opposition — whose primary concern is securing humane and timely treatment for individuals who are suffering from the most severe mental illnesses.

The Board of Directors of TAC decided to formally recognize the vital role of these selfless advocates by instituting the **Torrey Advocacy Commendation Award**. Board member Fred Frese suggested the title which most fittingly honors the man who inspired the Treatment Advocacy Center — the most fearless and dedicated advocate for the most severely ill — **Dr. E. Fuller Torrey**. Included in this issue of *Catalyst* is an article Dr. Torrey wrote more than 20 years

ago on the very issue that is the foundation of TAC's work today. The sad fact that his message still rings true today amplifies how much our dedicated TAC advocates are needed.

The TAC Board of Directors overwhelmingly agreed to award the inaugural **Torrey Advocacy Commendation Award** to Dr. Morton Birnbaum. Dr. Birnbaum was nominated by Rael Jean Isaac, who co-authored *Madness in the Streets — How Psychiatry and the Law Abandoned the Mentally Ill*. Ms. Isaac wrote a wonderful tribute to Dr. Birnbaum for this issue of the *Catalyst* [see page 2] that clearly illustrates why Dr. Birnbaum's dedicated advocacy overwhelmingly exemplifies the ideals of the **Torrey Advocacy Commendation Award**. We are proud to dedicate this issue of the *Catalyst* to Dr. Morton Birnbaum.

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Catalyst

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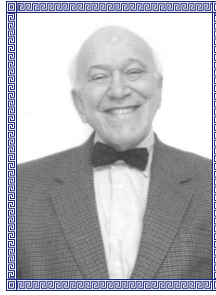
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The Center is a nonprofit organization dedicated to eliminating legal and clinical barriers to timely and humane treatment for the millions of Americans with severe brain diseases who are not receiving appropriate medical care.

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 1.8 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 mental illnesses.



A Tribute to Dr. Morton Birnbaum

By Rael Jean Isaac

When we think of the giants of mental health reform in the United States, the names of Dorothea Dix (the woman who through her single-minded devotion persuaded state legislatures to create the system of asylums for the mentally ill), Clifford Beers (father of the National Association for Mental Health and the child guidance clinic), and Albert Deutsch (whose *Shame of the States* exposed the extent to which asylums had been allowed to deteriorate, with patients left untended and untreated) come to mind. But there is another individual, his contribution today generally overlooked, who belongs in the class with these pioneering figures: Morton Birnbaum, father of the concept of a "right to treatment."

Today this is such a familiar principle that it is hard to believe that in 1960 it was considered an outlandish notion. The first two sentences in Birnbaum's seminal article of that year, *The Right to Treatment*, sum up its thesis: "The purpose of this article is to advocate the recognition and enforcement of the legal right of a mentally ill inmate of a public mental institution to adequate medical treatment for his mental illness. For convenience, this right will be referred to as the right to treatment." Birnbaum argued that, "incarceration by the state in a mental hospital without proper treatment is a deprivation of liberty without due process [i.e., unconstitutional]."

The article accumulated rejection slips. Birnbaum remembers his disappointment. "I sent the article off. It seemed to me absurdly simple. I couldn't understand that no one would accept it. I could show you maybe fifty rejections. I sent it off to the *New England Journal of Medicine* — it came back. I sent it to the

Journal of the American Medical Association. It came back. *American Journal of Psychiatry*; it came back. I sent it to *Harvard Law Review*, *Yale Law Review*. They didn't even send it out for peer review lots of times. One journal sent it back with a note saying, 'This is preposterous.' I sent it out for a couple of years."

Finally, in 1960, the *American Bar Association Journal* not only published the article, but accompanied it with an editorial endorsing the idea. And, in its Sunday edition, the *New York Times* published an article about this novel idea of a "right to treatment."

Birnbaum's background made him a surprising advocate for mental patients. He received his law degree from Columbia in 1951 and subsequently went to medical school, in 1957 receiving his M.D. in general medicine, not psychiatry. His interest was in catastrophic illness, the kind of illness which the average person or family could not cope with financially. He came to focus on severe mental illness as the chief catastrophic illness where improvement in care was most needed, developing the ideas for his groundbreaking article as a post-doctoral fellow at the Harvard University Training Program for Social Scientists in Medicine in 1958-59.

But even the favorable editorials did not have the effect Birnbaum expected. Says Birnbaum: "I thought once it got published, the doors would break down and everyone would say, 'What a wonderful idea, you discovered a new penicillin.' But nobody broke down the doors. What amazed me was that the only real comments I got on it were from two patients in state hospitals. One was Donaldson in Florida and the other was a guy, Stevens, in New York." Birnbaum took on both cases at his own cost. Fifteen years later, *O'Connor v. Donaldson* became a landmark Supreme Court ruling. (Birnbaum pursued the "right to treatment" Stevens case with equal tenacity, but Stevens was finally freed by an administrative decision, not through victory in the courts.)

Well before his triumph in freeing Donaldson, who had been held in Florida State Hospital for fourteen years, the "right to treatment" had a major impact on mental health law. (Ironically, much to

Birnbaum's disappointment, the Supreme Court used other grounds, not the "right to treatment," to release Donaldson.) Birnbaum's testimony in 1961 before a Senate subcommittee looking into mental health law led to the drafting of a model bill with a provision recognizing and enforcing the right to treatment. But the language did not survive. Enacted in 1964, the final model bill had only a phrase referring to the right.

While Birnbaum was, of course, deeply disappointed, only two years later the U.S. Court of Appeals for the District of Columbia recognized the right to treatment on the basis of that hesitant reference in the 1964 bill.

Birnbaum has been a consistent advocate both for mental hospitals and for treatment. He harbored no hidden agendas, as would so many in the emerging mental health bar, who invoked the "right to treatment" in order to achieve the opposite: massive deinstitutionalization coupled with the right to refuse treatment. In his 1960 article, Birnbaum wrote that he did not expect any major decrease in the number of hospitalized patients since the new neuroleptic drugs had produced only a slow, irregular drop in the patient population, patients continued to relapse despite the drugs, and no radically new methods of treatment were on the horizon.

Birnbaum harbored a simple, humanitarian conception that would, alas, turn out to be naive. He conceived of the right to treatment as a pragmatic solution to the hitherto intractable problem of maintaining decent conditions in state hospitals. Periodically there would be exposes of dreadful conditions and public wrath would force improvements, but then the situation would revert to its previous condition. Birnbaum saw the right to treatment as an enforcement device. As he explained in a 1971 article in *The Alabama Law Review*, he proposed giving the patient the right to obtain his discharge from a hospital, regardless of the severity of his illness, if the hospital was unable to prove that it lived up to objective, institution-wide standards (like a set ratio of patients and physicians) for providing adequate treatment.

Birnbaum was convinced that if the public discovered courts were discharging severely ill patients because hospitals

were not providing treatment, it would (as he wrote in *The Right to Treatment*) "force the legislatures to increase appropriations sufficient to make it possible to provide adequate care and treatment so that the mentally ill will be treated in mental hospitals." Birnbaum even wanted to limit the right of hospitals to discharge sick patients into the community. In his 1971 article he wrote: "If no family is available, and if no publicly supported halfway house, or similar facility is available, the patient may not be discharged."

Birnbaum's first clear victory in achieving court recognition (and enforcement) of the right to treatment was in *Wyatt v. Stickney*, the famous Alabama case in which Birnbaum served as co-counsel. (The lead attorney was Alabama lawyer George Dean.) It was a Pyrrhic victory because he had inadvertently teamed up with lawyers who were intent on subverting his concept. Bruce Ennis, and the other lawyers who cut their teeth on *Wyatt v. Stickney* (and would form the Mental Health Law Project) had no interest in promoting treatment. Ennis said frankly that he initially refused to touch right to treatment cases and only decided to become involved in *Wyatt v. Stickney* because there was advance information that the judge would not only endorse the existence of a "right to treatment" but would set standards so high Alabama could not meet them, and would be forced to embark on radical deinstitutionalization.

When it turned out that Alabama indeed could not meet the standards imposed by Judge Frank Johnson, Birnbaum looked to the federal government. He decided to challenge the constitutionality of the 1965 Medicaid legislation that excluded state mental hospital patients under age sixty-five from Medicaid benefits. Because of Medicaid's matching provisions, he calculated that if Medicaid included state mental hospital patients, Alabama would be able to quadruple its expenditures on these patients without increasing state appropriations. It was at this point Birnbaum ran aground on the insistence of Dean, Ennis and the other like-minded lawyers involved in the case, that state mental hospitals should be done away with in favor of alternative community facilities. Says Birnbaum: "My arguments

that a sufficient number of alternative facilities were not available were of no avail." Disillusioned, Birnbaum dropped out of *Wyatt v. Stickney* and turned to his opponents in the case. "I said maybe you're interested. They're going to give a judgment against you, you'll need the money. For \$100 of Alabama funds, you'd get \$300 of federal funds. Without it you're going to get nothing."

In fact, Birnbaum had much more in common with his ostensible chief opponent in the case, Alabama Health Commissioner Stonewall Beauregard Stickney, than he did with the members of his own legal team: both of them genuinely wanted to improve treatment of the mentally ill. At the outset, Stickney had conceded Birnbaum's case: patients had a right to treatment. Stickney approached then Governor George Wallace, who agreed to bring the state of Alabama into a suit challenging the Medicaid exclusion.

Perhaps nothing in his career proved his single-minded dedication to the welfare of the mentally ill so much as Birnbaum's willingness to forge an alliance with George Wallace, then a presidential candidate and a symbol of the populist far right, whom Birnbaum, as a political liberal, regarded with horror. The incipient alliance ended abruptly when Governor Wallace was shot and paralyzed.

Birnbaum brought his suit, *Legion v. Richardson*, in 1972, asking that the Medicaid exclusion be declared unconstitutional. In the end, he would lose the suit. But on crucial issues, Birnbaum never gives up. During the Clinton administration, he brought suit again in federal court (*Doe v. Shalala*) to end the Medicaid exclusion. The importance of this issue, long neglected by advocates for the mentally ill, has now been recognized by the Treatment Advocacy Center.

One of the most striking aspects of Birnbaum's writings is his ability to recognize key problems long before they come to general attention. Birnbaum touched on many of the issues that TAC president E. Fuller Torrey, through his books and articles, has brought to public awareness. In 1970 Birnbaum was writing about the dwindling number of psychiatrists addressing the needs of the seriously mentally ill; the failure of the new community mental centers to treat

them (Birnbaum pointed out that in 1969, for all the publicity about their role as an alternative to state hospitals, the centers accounted for only 4% of inpatient care episodes for those under 65 and only 2% of those over that age); the failure to provide "support and rehabilitative services needed by the severely ill"; the growing number of homeless people roaming the streets in various states of undress.

Dr. Birnbaum, who maintains a modest geriatric practice in the run-down Bedford Stuyvesant section of Brooklyn, has said wryly: "I make my living as a doctor and throw it away as a lawyer." Evening and weekends over the last decades he has persevered on the lawsuits he has brought to improve conditions for mental patients — e.g., against the two-tier system of care in psychiatric units of general hospitals and in state hospitals (1982), against the egregious overcrowding in Kingsboro Psychiatric Center (1986). His litigation and other activities, as Birnbaum has written, "are essentially both a one-man activity and personally financed, as I receive no fee or subsidy."

Dr. Birnbaum has always followed his own star and this is probably the reason his enormous contribution has been overlooked. If he had been willing to swim with the tide, and join forces with the Mental Health Law Project in its battle to "free" involuntary mental patients from both institutions and treatment, he would doubtless have been celebrated as a "father" of what passes today as legal reform.

To Birnbaum it would have been unthinkable to betray his vision for the sake of fame and recognition. He has never become an organizational leader, although he tirelessly mobilized support of organizations as *amicus curiae* in the early lawsuits he brought. Now in his mid-seventies, Dr. Birnbaum perseveres in his driven, selfless quest to improve the lot of the mentally ill. We humbly salute him. ^{OT}

Refusing to take your medicine

[Editor's note: The following brilliant article by Dr. Torrey was originally published in 1980 in *Psychology Today*. It is amazingly, and sadly, still relevant today.]

"Can medication be forced on patients in mental hospitals? An advance look at the Supreme Court's 1985 decision shows..."

by E. Fuller Torrey

In the 1970s the big issue in psychiatric-legal circles was the right to treatment. Kenneth Donaldson won release from the Florida State Hospital under a U.S.

Supreme Court ruling that said a patient may not be confined for psychiatric reasons unless he receives treatment for his illness. In the 1980s, the big issue is the right to refuse treatment. Particularly, does a person in a mental hospital have the right to refuse the medications prescribed for a variety of psychiatric symptoms?

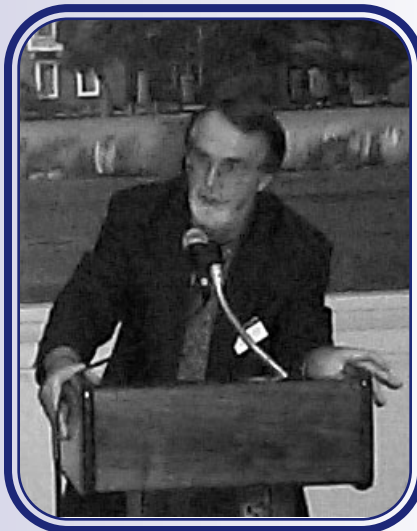
This question moved to center stage on the national scene last October, when Federal Judge Joseph L. Tauro in Boston ruled that patients in Boston State Hospital have the right to refuse injections of psychotropic drugs except in emergency situations ("when there is a substantial likelihood of extreme violence, personal injury, or attempted suicide"). Judge Tauro argued that forcing a person to take medication was an invasion of privacy, an affront to human dignity, and a violation of the First Amendment right to think and make decisions relating to his or her own welfare. He characterized it as "involuntary mind control." Consent of the court or a court-appointed guardian would be required, Judge Tauro ruled, before incompetent patients could be medicated against their will.

Alan Stone, then president of the American Psychiatric Association, called Judge Tauro's decision "the most impossible, inappropriate, ill-considered judicial decision ever made in the field of mental health law." The issue had been joined.

Judge Tauro's decision was appealed, and the U.S. Supreme Court eventually heard the case in late 1985. We were fortunate to obtain a transcript of those proceedings, a portion of which is herein faithfully reproduced. Representing the plaintiffs was attorney, Patience Pro, a well-known American Civil Liberties Union lawyer and civil rights activist. Arguing the appeal for the state of Massachusetts was attorney, Constance Kahn, who had risen to prominence defending the right of the government to require motorcyclists to wear helmets. The proceedings were of wide interest within the legal community because of the unprecedented debate that took place on medical issues in the case and because of the unusual outcome.

Pro: We are asking this Court to up-hold Judge Tauro's decision that forcing medication on a psychiatric patient is a violation of that person's civil rights and constitutional freedoms. Not only is it an invasion of privacy, but it violates the right to freedom of thought and freedom of speech. It is not possible to have freedom of thought if a person is being involuntarily drugged with medications that, the defense agrees, change his thoughts and often sedate him excessively. These drugs can make people into walking zombies: surely the Constitution protects us from such gross intrusions.

Kahn: We are asking the Court to overturn Judge Tauro's decision. Freedom of thought and freedom of speech are meaningless if a person's brain is so impaired that he or she cannot think or speak rationally. A person also has a right to be free of disease, and in this case, freedom from disease is a prerequisite for freedom of thought and speech. The medications are necessary to treat the mental disease. As stated by one observer, psychiatric patients "will suffer if a liberty they cannot enjoy is made superior to a health that must sometimes be forced on them."



Pro: These drugs make it more difficult for the patients to defend themselves in court when trying to gain release from a hospital. They often appear drugged, thereby influencing the judge and making them appear to be sick when they really are not.

Kahn: By alleviating the symptoms of their illnesses, these medications make patients better able to think clearly and to defend themselves in court. People who do not know very much about psychiatry often look at psychiatric patients and confuse the symptoms caused by the disease with symptoms they erroneously believe are being caused by the drugs.

Pro: But these drugs have many side effects. They produce spasms of the neck and face muscles and cause a severely debilitating and irreversible disease called tardive dyskinesia in at least half the cases. They are harmful drugs, and to force anyone to take them would be a denial of that person's liberty without due process of law.

Kahn: The short-term side effects of most drugs used for psychiatric patients are not severe and are reversible. Often they can be avoided altogether by giving patients other drugs, such as Cogentin or Kemedrin, to cover them. Side effects like dry mouth, blurring of vision, or constipation are common in the first few days on these medications, but they are not serious and they usually go away by themselves. Tardive dyskinesia occurs mostly in people who take some form of antipsychotic medication for many years. It occurs in less than 10 percent of such patients and can often be successfully reversed by stopping the drug. Its danger has been overblown. These drugs are not dangerous drugs and in fact are generally considered to be safer than the drugs used for diseases such as arthritis, heart disease, or diabetes.

Pro: Patients with such diseases can refuse treatment if they wish. A heart patient has the right to refuse digitalis and a diabetic can refuse insulin. Members of some religious sects refuse blood transfusions. Why, then, shouldn't a psychiatric patient also have the right to refuse medications? After all, Judge Tauro specifically ruled that most such patients "are able to appreciate the benefits, risks, and discomforts that may

reasonably be expected from receiving psychotropic medications."

Kahn: Judge Tauro was wrong. The difference between a diabetic and a psychiatric patient is that the diabetic has a disease of the pancreas. The diabetic's brain, which he or she is using to decide whether or not to take the insulin, is assumed to be normal and capable of thinking clearly.

Psychiatric patients by definition have brains that are impaired. Many people now think that psychiatric patients with diseases such as schizophrenia and manic-depressive psychosis, who constitute the vast majority of hospitalized psychiatric patients, have true diseases of the brain just as surely as a diabetic has a disease of the pancreas. Of course, the person's whole brain is not diseased, just a portion of it. But we have no way of knowing which portion, or whether the person's refusal of treatment is being made with the part of the brain that is diseased or the part that is normal.

Pro: Forcing medications on psychiatric patients is usually done just to sedate them for the convenience of the hospital staff. We need to protect the patients against this forced drugging. The only way to do it is to give the patients the right to refuse treatment.

Kahn: You are forgetting that society has some rights, too. Psychiatric patients who are properly medicated are less dangerous both to themselves and to other people. They can be released from the hospital sooner, thereby saving funds and allowing psychiatric resources to be used more efficiently. Each day a hospitalized patient refuses medicine can prolong the hospitalization that much longer. In private hospitals, that means additional costs of over \$200 a day. We also require patients with some other diseases, such as smallpox and tuberculosis, to be treated for the good of others: why shouldn't we require the same thing of psychiatric patients?

Pro: Giving patients the right to refuse medication is consistent with the direction of the future. It is giving consumers greater control over the things in their lives. No longer can they be controlled by an impersonal medical and psychiatric bureaucracy. The right to refuse medication is progressive.

Kahn: If most psychiatric patients have the right to refuse medications, then psychiatric hospitals will revert simply to preventive detention. They will be merely jails for the mentally ill. That will return us to the asylums of the 1920s. That is not progressive; it is regressive.

Pro: But the potential for abuse of involuntary medication is too great. Look at the abuses that have taken place in the Soviet Union, where political dissidents are often labeled psychiatric patients and then drugged.

Kahn: That is perfectly true, and the potential for abuse is real. However, they abuse jails in the Soviet Union, too, but we don't abolish jails here because of it. No, we must build in legal safeguards, strengthen patient advocates, and insure the availability of public defenders for the patients, but we do not need to abolish involuntary medication.

Pro: What about the psychiatric patients who do not wish to get well? Don't they have the right to keep their sickness if they want to? R.D. Laing and others have said that psychosis is a creative growth experience: by forcing medication on patients you are depriving them of this opportunity.

Kahn: Most mental-health professionals agree that there are very few psychiatric patients who enjoy their illness or view it as a growth experience. On the contrary, it is usually seen as psychically painful and very unpleasant. Laing may be a good poet, but he is a poor psychiatrist.

At this point in the proceedings, the justices conferred and then adjourned for the weekend. They were strongly divided in their opinion and troubled by the many conflicting rights that had to be resolved.

When the justices returned on the following Monday, they rendered an immediate and unanimous decision: Judge Tauro's 1979 decision was overturned. Involuntary medications could be used "whenever two qualified psychiatrists agree that it is needed to treat a patient who suffers from a true psychosis, since the psychiatric profession agrees that such people no longer have normally functioning brains and have lost contact with 'reality.'" For patients whose symptoms are not

diagnosed as stemming from psychosis, such treatments would be an unconstitutional invasion of liberty.

The justices ruled that any patient given such medication was entitled to a court hearing within a reasonable amount of time after commitment (three days was suggested as "reasonable" in most circumstances). The patient would also have the right to representation by a lawyer and to call expert witnesses at the hearing who might dispute the need for medication in his or her case.

The Court also recommended the creation of outside review panels for all psychiatric hospitals: such panels would include laypersons and professionals not directly connected with the hospital and would automatically review randomly selected cases of involuntary medication for appropriateness. The findings of such panels would be public documents (although the names of patients would be deleted to protect confidentiality). The justices acknowledged the need for constant review and monitoring of the "ongoing creative tension" between the need to medicate persons with true psychoses and the possibility that the practice can be abused.

The unanimous decision on Monday, so different from the divided opinions of the justices on the previous Friday, was a source of much speculation. Several weeks passed before the full story was known. One of the justices, it turned out, had spent the weekend living on a psychiatric ward where patients were allowed to refuse medication. The justice had been overwhelmed by the chaos, by the intrusions of untreated patients on other patients, by patients' manipulation of the ward staff members (one threatened to refuse his medication if he wasn't given a second dessert), and by the irrational and delusional reasons given by the patients when refusing medication (for example, one patient refused because he thought that Martians were trying to poison him). To this justice's opinion, most of the patients were sick and in need of treatment, yet they had little insight into their condition. He immediately persuaded his colleagues. In fact, they went even further: they also suggested that any lawyer who wished to argue similar cases in court should first spend a full weekend on a psychiatric ward for newly admitted patients. ⁵⁷⁰

New study evaluates the impact of intensive case management on violence in severe mental illness

[Walsh, E., Gilvarry, C., Samele, C. et al. Reducing violence in severe mental illness: Randomised controlled trial of intensive case management compared with standard care. *British Medical Journal* 323:1093-1096 (2001)]

The study, conducted in England, was a randomized controlled trial of intensive case management in patients with psychosis to assess whether intensive case management reduced the prevalence of violence in comparison with standard case management. The two-year study involved 708 patients with a diagnosis of psychosis and at least two inpatient admissions for psychotic illness, with one in the previous two years. The intervention group had intensive case managers with caseloads of 10-15 patients versus the control group that had standard case managers with 30 or more patients.

Intensive case managers had an average of 4.41 contacts per month with intervention group patients compared with the standard case managers, who had 1.94 contacts per month with the control group. Using three data sources, the number of assaults for study participants was recorded, although it should be noted that the frequency and seriousness of assault was not recorded. There was no significant difference in violence between the two groups — 80 (23%) of the intervention group and 78 (22%) of the control group committed physical assault.

While the British study showed that intensive services alone did not reduce violence, the most comprehensive study of assisted outpatient treatment (AOT) conducted at Duke University showed that intensive services (termed "regular services") combined with long term AOT cut the probability of violent behavior in half [Swanson, J.W., Swartz, M.S., Borum, R. et al. Involuntary outpatient commitment and reduction of violent behaviour in persons with severe mental illness. *British Journal of Psychiatry*, 176: 224-231 (2000)]. In the Duke study, regular services were considered to be three or more contacts per month (comparable with the British study's intensive case management contact frequency). The Duke researchers found that regular services combined with long term AOT reduced the probability of violence from 48% to 24%.

The significant difference 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% more likely to be violent than those who complied.

This new research shows that assertive community services alone do not reduce violence. But, when coupled with long-term AOT the probability of violence is cut in half. For the population that we are concerned with (i.e., those who may become violent) the argument could be made that laws should be reformed to allow for AOT before adding more intensive services for this population.



My View: A personal story about mental illness

by Chip F. Correll

I live with schizophrenia and obsessive-compulsive disorder (OCD). Some consider this to be a terrible thing to have to live with. I am coming to accept the fact that I have mental illnesses and will have to take medications to fight these disorders for the rest of my life.

As part of coming to accept this, I went through a cathartic experience of writing my first autobiography, "Overcoming OCD and Schizophrenia with God in My Life." My book is a personal story about my struggles with mental illnesses. The style is that of a personal journal, allowing readers into my mind and soul.

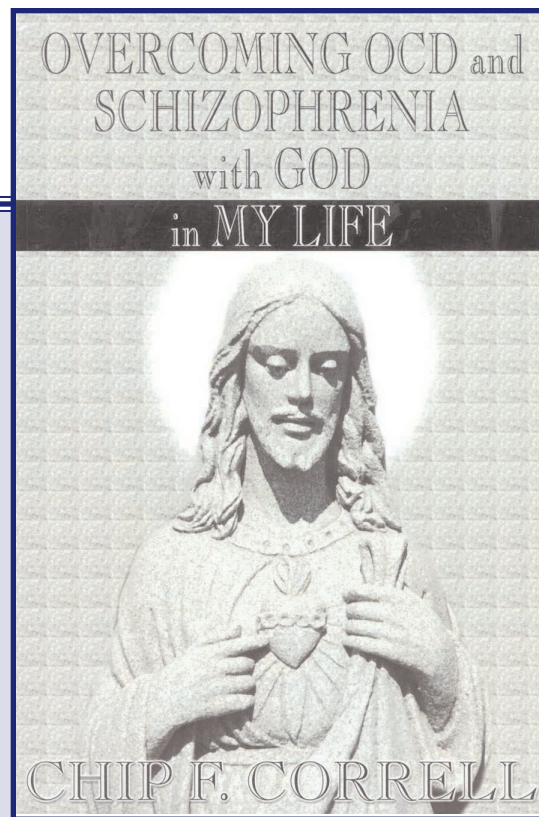
I was 24 years old when I had my first "break" and was hospitalized for a paranoid episode. I was immediately diagnosed as having paranoid schizophrenia, as I thought my grandmother and the hospital workers wanted to kill me.

My book details the importance of getting one's symptoms under control by taking the right medications, having a strong support system, and partaking in therapy on a consistent basis. I am taking Geodon and Clozaril to combat my paranoid schizophrenia and Luvox for my OCD. I also write about the process of getting Social Security, Medicare, Medicaid and food stamp benefits in my book.

It is important that consumers, loved ones and the general public realize that mental illnesses are biological brain disorders just like diabetes. Mental illnesses are chemical imbalances in the brain. It is critical to take medications in order to control these illnesses.

I have also advocated to get the Ticket to Independence Bill passed on the federal and state levels. The bill passed on Dec. 17, 1999, but now must pass individually in each state to do any good. I am lobbying in my home state of Florida to see this important legislation passed, so that the mentally ill such as myself can return to part-time work without losing one's benefits. I feel that it is God's will for my life right now to advocate for the mentally ill.

On May 2, 1998, I participated in "Walk the Walk," held in the nation's capitol to join voices for the mentally ill. The annual event drew thousands and thousands of consumers and advocates to unite as a powerful force for lives touched by



mental illness. This event, which I attended with my brother John, will live on in my heart and mind as an historical event with far-reaching and life-enhancing progress for lives touched by mental illness.

In 1999 I bought a condo in a quiet area of the county I live in. It's a two-bedroom apartment. I enjoy the balcony at my condo. I like to sit out there and listen to beautiful birds. It's fun to sit on my balcony with a stereo headset on or simply read a good book out there. I spend a lot of my time reading and listening to music. It's very peaceful and quiet where I live, and I relish these peaceful moments which help to clear my mind of a busy day's activities.

My family and I are active members in the National Alliance for the Mentally Ill. I have a bi-monthly column called Consumers' Corner in each of our county newsletters and in my column I write about the accomplishments of our local consumers. I have represented my local chapter at National Conventions in Chicago, San Diego and Washington, D.C. I have an A.A. degree in Journalism and a Bachelor's degree in English. I earned both degrees before my first psychotic episode. At 30 years old, I currently volunteer for a local magazine, where I do proofreading and write news-feature articles.

My book may be ordered by sending a check or money order for \$11.95 (includes tax and shipping/handling) to Dee Nelson, P.O. Box 16542, Clearwater, FL 33766. Allow about a week for delivery.

**TREATMENT ADVOCACY
CENTER HONORARY
ADVISORY COMMITTEE**

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

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**"The system is not only
overburdened by sheer numbers of
clients; it is also burdened by its
insistence that people whose mental
capacity is impaired weigh their
options and make informed choices."**

— Beth Barber

**Victims of laws that were
made to save them**

*by Beth Barber, Cleveland Plain Dealer,
Jan. 20, 2002*

Outraged as many people were by the death of Margaret Bolling, hers was not a simple case of neglect by officialdom.

Hers was one of many cases complicated by the law and the difficulties often inherent in offering assistance.

Margaret died at age 55 in a house fire probably started by the candles she was using for light. She had lost her job, her house had been sold in foreclosure and her utilities had been cut off.

That is, by law, essentially all the public is entitled to know about this woman.

So journalists call neighbors, relatives, whomever to find out more about Margaret. And they call attorneys to find out more about society's laws on helping Margarets.

The answers I've gotten so far may or may not be definitive, particularly about that Silly Putty code called the law: It takes the shape of the person or agency pressed to interpret it. But spurring discussion is my purpose here — discussion of what the law is and what shape it should take when its current form hurts those it was passed to protect.

From neighbors, we learn that Margaret had been to the Center for Families and Children for treatment of mental illness, but she had recently refused any more mental-health services.

From Commissioner Tim McCormack, we learn that she had applied to the state for disability payments because of her mental illness. From the county coroner, we learn that Margaret had cirrhosis of the liver, though Dr. Elizabeth K. Balraj carefully, rightly noted that she doesn't have the "clinical information" to say whether alcoholism was involved.

Many people are both substance abusers and mentally ill, and their disability may be traced more to one than the other.

Currently in this county, the treatment of substance abusers falls more to the Board of Alcohol and Drug Addiction; of the mentally ill, to the Mental Health Board. Both say they cannot confirm that Margaret was a client.

The Center for Families and Children put it this way in a statement released Tuesday:

"Individuals who seek treatment from mental health providers, such as CFC, have rights protecting the confidentiality of their consultations. Ohio law prohibits mental health providers from discussing or releasing information about a patient's treatment, or even identifying an individual as a patient.

"While public interest in stories relating to individuals who have received treatment is understandable, that public interest does not outweigh the protection afforded to mental-health patients under Ohio law."

Maybe so, maybe no. Few rights are so absolute that the public interest never counts. But to the professional mental health community, absolute confidentiality is unquestionable writ. To laypeople, it's debatable.

Confidentiality rules intended to protect the mentally ill from being "stigmatized" by the label could not keep Margaret's illness a secret from her neighbors. Some, according to McCormack, gave her rides to treatment sessions.

Nor did "confidentiality" protect Margaret from what may well have been the ultimate result of her illness: her inability to protect herself from circumstances that contributed to her death.

And "confidentiality" laws, according to the mental-health community, kept the county's \$90 million-plus apparatus for assisting the mentally ill from doing more than it did.

So strict is this interpretation of the law that a year or so ago attorneys told the Mental Health Board not to mail letters to some 900 clients of an agency that abruptly closed its doors to let them know where else to go for services. Some average Joe might deduce that the recipient is mentally ill.

Worse things could happen — such as the world watching a severely mentally ill client slide into dysfunction even though help was available.

If there's a better way to sustain the stigma of mental illness — and exacerbate any doubt about the effectiveness of treatment and the law — may officialdom never stumble upon it.

Margaret could have gotten help with the foreclosure proceedings, other housing, the utility shutoff, even a smoke detector, had she known whom to call and had she been capable of doing so — or had somebody else called on her behalf.

Whether neighbors called a mental-health agency on her behalf is in dispute, but indisputably, some had no idea whom to contact. And some undoubtedly did not know, or did not want to decide, at what point their intervention would cross that line between busybody and lifesaver.

The person presumably most aware of Margaret's dire circumstances would have been her caseworker. But she had told her caseworker to scram, which the law

allows absent a court finding that she was an immediate danger to herself or to others, could not care for herself, or would benefit from treatment.

Apparently, there was no such finding in Margaret's case. That might surprise laypeople. It won't surprise mental-health professionals.

The system is not only overburdened by sheer numbers of clients; it is also burdened by its insistence that people whose mental capacity is impaired weigh their options and make informed choices. By that reasoning, freezing on the street, stopping medication that enables the ill to function and depending instead on public largess are decisions society must accept. Even if those decisions kill them. Or someone else.

From this insistence comes the profession's reluctance to "commit" clients to institutions or to mandated outpatient care, except in the most extreme situations and then only for the briefest periods — a reluctance the professionals and the courts in this county have only recently begun to reconsider.

Under law, I'm told by a mental-health professional, an agency that kept sending a caseworker to offer Margaret services she kept rebuffing would not be paid for those unproductive visits. Nor could the caseworker breach her privacy by calling an agency that could get her electricity turned back on.

So Margaret Bolling lost her mental-health services, her job, her house, her utilities, her beloved dog and ultimately her life.

And it really was nobody's "fault."

It was simply the operation of law.

If that's not reason enough to question the law and its prevailing interpretation, what is?

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Your Voice— Will Make a Difference

Mary,

Thank you so much for the article, "Committing Crime Is Fastest Ticket to Treatment of Mental Illness."

It is a wonderful article and I am sure it will help to raise the level of awareness about our antiquated commitment laws. You and your group are wonderful as always. Thank you,

Jeff Kuehn

President

Salt Lake Chapter, NAMI

Dr. Torrey,

This gift is because I believe in you and the cause you represent. Thank you so much for speaking up for the untreated SMI [severely mentally ill] population. You are indeed a good crusader.

Jesse and Martha Stinson

Birmingham, Alabama

Dear Ms. Zdanowicz,

Recently, I learned about the Treatment Advocacy Center through my lawyer. I wish I had known about it long ago.

My son, who was diagnosed with schizophrenia, died this past July at the age of 39. I struggled so often trying to get treatment for Mark when he refused treatment and was headed for an "episode" which I was often the brunt of. One mental health professional said to me, "Why don't you go to his apartment and let him hit you so we can get him committed." At the time, I wondered who actually needed to be committed more, my son or his "professional."

Well, I need not go into any more of these scenes because I'm sure these are the reasons you started the Center. I'm so glad this Center exists.

Sincerely,

Marianne Tampanello

(a grieving mother)

King of Prussia, Pennsylvania

THE FOLLOWING MEMORIALS AND TRIBUTES WERE RECEIVED BY TREATMENT ADVOCACY CENTER SINCE OUR LAST ISSUE WAS PUBLISHED. PLEASE ACCEPT OUR DEEP APPRECIATION FOR CHOOSING TO SUPPORT OUR MISSION IN MEMORY OR IN HONOR OF SOMEONE VERY SPECIAL TO YOU.

—TREATMENT ADVOCACY CENTER BOARD AND STAFF.

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THANK YOU FOR YOUR SUPPORT!