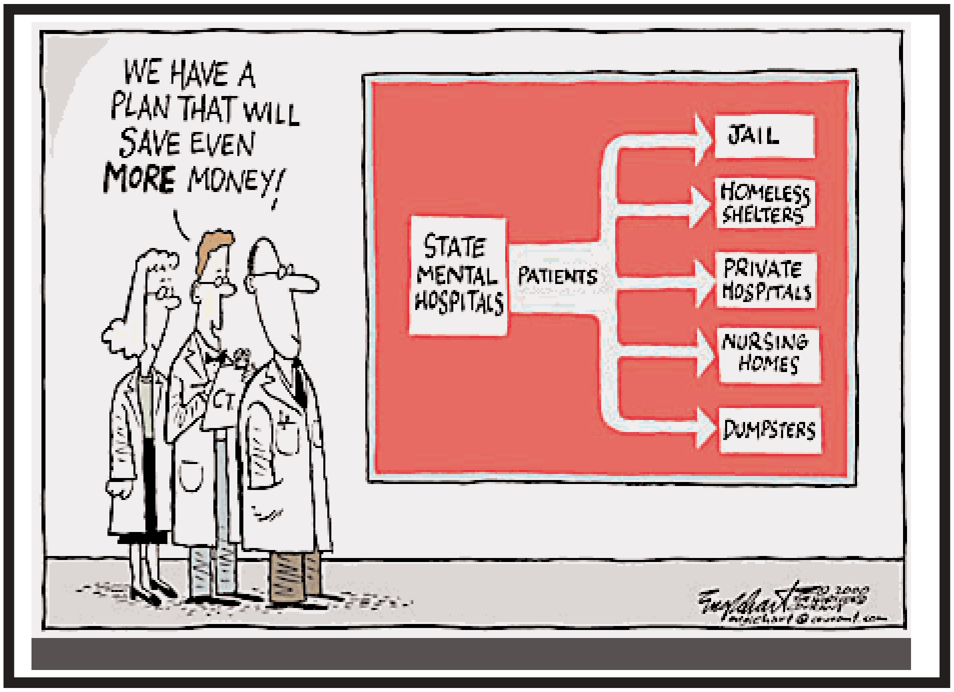
Catalyst

TREATMENT ADVOCACY CENTER Volume 2, No. 2 March/April 2000

True Parity Means Eliminating MEDICAID'S IMD Exclusion

By Bruce Rheinstein, J.D., Policy Analyst

If you get sick today with a disease in your heart, liver, or any other organ but are unable to pay for appropriate treatment, federal Medicaid funds will help pay for your care. But if you are between the ages of 21 and 65, have a severe mental illness and require hospitalization in a psychiatric hospital, the federal Institutions for Mental Disease (IMD) Exclusion bars the use of Medicaid funds for your treatment.[1] If, on the other hand, you are hospitalized in the psychiatric ward of a general hospital or in a nursing home--where you likely will receive a lower quality of care for your illness--Medicaid pays.



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The Surgeon General's recent report on mental health views the crisis through rose-colored glasses. For example, the Surgeon General criticizes private insurance companies for failing to provide "parity" in their coverage of mental illnesses, but is totally silent on the failure to provide parity in Medicaid, the federal government's insurance program. For the most severely mentally ill, private insurance is essentially meaningless. Many are indigent because of their illnesses and private insurance is a luxury they cannot afford and are not in a position to obtain through employment.

While the federal government is a relatively new player in the mental illness treatment arena--getting involved in 1965 with the advent of Medicaid and Medicare--it plays a major role in funding care for those with the severest of psychiatric disorders. In 1962, for example, federal dollars comprised just two percent of the total funds in the mental illness treatment system, with state and local government contributing the remaining 98 percent. By 1994, however, the federal share had increased to 62 percent of the total money spent.[2]

The IMD exclusion precludes states from using those federal funds for most of the care provided in state psychiatric hospitals, making the IMD exclusion a gigantic economic carrot feeding the process of deinstitutionalization. States started locking the front door and opening the back in an effort to get patients out of state funded hospitals and into settings where the federal government would help pay the tab. As a result, it has become increasingly difficult for the most severely ill to get inpatient treatment. Hospitals are discharging patients sicker and quicker in a mad long dash to make them Medicaid eligible by ending their inpatient residency. The primary question that drives the system today is not, "What does the patient need?" but rather, "What will federal programs pay for?"

The consequences of Medicaid's discriminatory nature are staggering for the severely mentally ill, their families, and the communities in which they live. The United States has lost effectively 93% of its state psychiatric hospital beds since deinstitutionalization began in 1955,[3]

(IMD Exclusion page 8)

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Catalyst

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(the Center).

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

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

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

The Courage to Effect Change

By Mary T. Zdanowicz, Executive Director

Two remarkable individuals contributed their personal stories for this issue of the Catalyst. We are grateful for their willingness to share with others their experiences that so effectively illustrate the need for assisted treatment reform. Donnie Buchanan was diagnosed with schizophrenia fourteen years ago. His non-compliance with treatment nearly cost him his life. He is a role model for others not only because of what he has learned about his illness, but because he is brave enough to share his story in order to help others. Unfortunately, those most vocal in the "consumer movement" tend to oppose assisted treatment. But, studies reveal that the majority of those who receive assisted treatment retrospectively agree that they needed it. Donnie is among those who give a voice to that silent majority whose lives have been enriched or even saved by assisted treatment.

Dick Taylor's testimony chronicles the tireless battle that he and his wife Judy waged in order to save their son. Although I hear similar stories repeated every day by other families across the country, I was literally reduced to tears by their story. The account of their son's descent into psychosis illustrates the madness of a system that withholds treatment from those who cannot realize their need for it. They must become dangerous to get help. It also illustrates how difficult and painful it really is for families to help loved ones who do not realize that they are ill. Clearly, it would have been easier for the Taylors to do nothing than to exert the tremendous effort that was required to get help for their son. Anyone who asserts that families derive perverse pleasure from hospitalizing a loved one has no inkling of the torture that is involved in making these decisions. The Taylors' perseverance probably saved their son's life. It may be even easier for mental health professionals to do nothing when a client refuses treatment. Too often we hear the mantra "it is his choice to refuse treatment" when the client is not even aware he needs help. Thankfully, some truly caring professionals do not use such excuses and, like the Taylors, do everything in their power to get their clients the treatment they need.

Donnie and the Taylors hope that others will learn from their experience. Last month Dick Taylor told his story to a Delaware commission of lawmakers, policymakers and administrators. He and a myriad of other families across the country are finally sharing their stories because they know that they must do so if they are ever to have any hope of effecting change. We thank Donnie and the Taylor family for their courage.

Donnie's story

Commitment to Recovery

By Donnie Buchanan

Editor's note: Donnie's story previously appeared in the NAMI Advocate.

My name is Raymond "Donnie" Buchanan. I'm 39 years old, and I've had schizophrenia since I was 25. I live in the Atlanta area and grew up there. I also have an identical twin brother with schizophrenia. He got sick at age 21. I have another brother (younger) with severe epilepsy and a mother with bipolar disorder. My dad and one sister, who is the oldest sibling, seem to be the only "normal" people in the family.

I was thinking to myself the other day that I've suffered through fourteen years of pure hell; that I feel like I've lost a large part of my life to schizophrenia. I feel like these years have been taken away from me by this illness. Sometimes it feels like I'm trapped by this spirit so strong inside of me that I don't know what it is at times. I was raised fundamentalist in the South, where people sometimes associate unusual behavior with demons and the devil. I don't want to think my problem is demonic, and yet I don't want to think it's mental--but it is. One thing I have to accept is that I have a mental illness; that doesn't mean I'm different from anybody else. But I think sometimes that if I hadn't become ill, I'd be working full time somewhere.

My illness started in 1985 when I was working in Houston, Texas, driving a truck for some soft drink companies and serving machines. I began to feel very paranoid about the Teamsters Union, and thought that they were threatening me and going to hurt me. I might have misinterpreted things, but the paranoia and fear felt very real. Shortly afterward I started to hear things like "I hate your g_damn guts," "You're going to die," etc. I also had religious delusions, like thinking I was Jesus.

I was hospitalized in Atlanta a couple months after the symptoms started. This was to be the first of about 30 to 40 hospitalizations I've had in the last fourteen years. I've also been put in jail for symptoms of my illness. Fortunately, in the last few years I've been on Clozaril (the highest dose possible), which hasn't controlled all of my symptoms, but worked better than other antipsychotics. I take about four other medications too.

I was put on outpatient commitment because of an incident that happened about a year after getting schizophrenia. I experienced an auditory command hallucination that told me to get a gun and kill myself. However, I shot myself in the chest and didn't die. It was at this point that I was sent before the county probate judge and was ordered into treatment (outpatient civil commitment). The judge required me to attend day treatment on a daily basis and take medication regularly. The judge offered to help me obtain a lawyer/advocate that would help me follow through with the outpatient commitment plan and help me report progress back to the judge.

The day I first went to see the judge, I was nearly a vegetable from the illness. I hadn't been participating regularly in treatment, including taking medication. I could barely function. At the first review in front of the judge a year later, when the lawyer saw me, she told me that I looked a lot better. I continued to get better over the next few years. After about five years, I think, I was participating in treatment so regularly that the outpatient commitment order was discontinued.

Almost all the time I got sick I ended up in the state hospital, but there was one time I remember where I ended up in jail. A voice commanded me to go to a part of Atlanta to look for Dorothy Stratten, and I was arrested for criminal trespassing at a hotel. Instead of taking me to the hospital, they took me to the county jail, where I was beat up twice by other inmates and taken advantage of.

The outpatient commitment order helped me a lot. It prevented me from getting into trouble and got me on a regular schedule. I knew I had to take medication and become involved in some type of daily activity to deal with the voices and paranoia. Since I've been on Clozaril and the other medications, I've been able to work part-time and attend day treatment. I've worked at a restaurant now for about six months, which is about the longest time I've held a job. The voices don't tell me what to do anymore. I ignore them and tell them to go to hell and leave me alone, especially if they're bad voices.

As far as advice to someone facing an outpatient commitment, I think the best thing for him or her to do is to use it to become educated. They need to realize that they have a chemical imbalance; that they DO have a brain disease. It's not just their fault--they were genetically born with it, or that it came on through age, or whatever.

If people don't take their medication, they're going to get into trouble. As a person who's had bizarre thoughts and feelings, I know what people are going through--I've been through the same thing. Some people who deny that they're ill become either homicidal, suicidal, or both. I haven't been homicidal but I've been suicidal, and I got help. I learned that when those feelings started, it was part of my depressive part of my illness, and I needed to seek help before I got worse and reacted again. I learned this largely through outpatient commitment, and the education I got through treatment. Sometimes outpatient commitment is needed--I would say in limited circumstances--it would be based on what the person did or what they do.

I hope that people realize that individuals with severe mental illnesses need help before they get into trouble and commit a violent act like homicide or suicide. To wait until a violent act occurs often can be too late, and isn't a compassionate approach for people who have severe mental illnesses like mine.

Testimony of Dick Taylor (Wilmington, Delaware)

Editors note: Mr. Taylor presented this testimony on February 28, 2000, before a commission of Delaware state legislators, policymakers and mental health administrators.

Four years ago my wife and I did not know anything about mental illness. We began to learn in an agonizingly slow and emotionally-draining process with the onset of our then 29-year-old son's first psychotic break. Our son was making plans to attend Tulane Law School, when he began talking about satellites in his head, the sick American Society, the F.B.I., and later, voices.

Because he was convinced there was nothing wrong, my wife and I signed a complaint to have him involuntarily committed based on a threatening statement he made to us. We successfully got court-ordered commitment and medication to be given at Rockford Center. We thought we were on our way to helping our son have a chance for a normal life. We were at best naïve and had no idea what the next four years would have in store for our family.

After 10 days our son's private insurance refused to cover him. After being diagnosed with schizophrenia, not given any medication or neurological tests, he was discharged into our care. The doctor's last words to us were, "Your son is a tragedy waiting to happen." It was the next day that our son became a missing person--his 30th birthday.

He turned up three weeks later in the Philadelphia railroad station after having spent a night in jail and living in a car in the Philadelphia International Airport parking lot.

After two more years of psychotic episodes and small periods of time where he could actually keep a job for about three weeks, we thought an opportunity presented itself to get him help again. On a complaint of violence directed at me, the police came to our house, but viewed it as a domestic dispute since our son did not pose a threat of danger to himself or others. Since our son had only the choice of jail or signing himself into Meadowood, he chose to go to Meadowood. Before, we could even think about feeling good about our son's

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chances for treatment, he was diagnosed with a mild personality disorder and discharged after five days because the HMO would no longer cover inpatient treatment.

Another year passed before we attempted to have our son committed for treatment again, but despite his statements about satellites in his head and the sick American Society, the crisis counselor and police told us that since he did not pose a danger to himself or others, that they could not take him for commitment. He was left once again to struggle with his voices that degraded him, talking about the evil American Society and calling every embassy in DC to have his citizenship changed and asking if they could give him money.

Our son continued to divide his time between living at our house in Riverdale, and our home in Montclare. He could no longer hold a job longer than two weeks because "people were being mean to him." Eventually, he could not work at all. His sister who is fighting breast cancer, his brother, Judy and I continue to grieve for our son every day--a son who is alive, but has no life. Until Saturday morning, February 12th at 3:30 a.m., our biggest barrier to getting our son help was Delaware State Law. Our son was committed to Rockford Center, but it was not pleasant, and it was not easy.

At 3:00 a.m. my wife and I were awakened by screams. We knew it was our son, and I left our bedroom to see if I could help calm him down. He was screaming about "interdictal" satellites and that they were coming through his eyes. He wanted me to stop them.

When I told him I could not, but was there anything else I could do, he became more irritated and pushed me. I continued to try to calm him down, but then he picked up a chair and threw it at me. He ran for the phone and pulled it out of the wall so I could not call the police. I ran into the bedroom, locked the door and told Judy to call 911 from our bedroom phone, while my son was banging on our door trying to get in to stop us from making the call. After he heard us place the 911 call, he grabbed his belongings and took off in a car that virtually had no brakes.

With the help of the state police and the Milton police, our son was apprehended and taken to Beebe Hospital at about 4:30 a.m. After a psychiatric evaluation, it was determined he needed to be transported to Delaware State Hospital and arrived there about 9:00 a.m. At 10:00 a.m. my wife called to check on the status of our son and was told by Delaware State Hospital that he had escaped from the security guards and was never admitted to Rockford Center. My son was listed on the police report as psychotic, delusional, and violent, yet no measures were taken to be sure he was delivered successfully and safely into a locked facility at Rockford by Delaware State Hospital.

There was a search but he was not found. My wife and I drove to our home in New Castle County because we were sure our son would go there. When we arrived, our son was indeed in the house, but when he saw us, he grabbed his back pack and ran out the door on foot. I called 911, and they said they would send someone immediately. After 5 minutes I called again and they assured me someone was coming. No one ever came. After checking with the state police later, we were told they never got either of these 911 messages from dispatch.

My wife and I drove around for two hours looking for our son, but with no success. Our son was missing again. It seemed like there was a state conspiracy to keep my son from getting the treatment he needed.

My son eventually called my brother in Allentown, Pennsylvania to come and pick him up. My brother saw this as an opportunity to have my son apprehended. He called me, and we set up a meeting time for 10:30 a.m. on Sunday, February 13th in the St. James Church parking lot. My son thought that his uncle would take him over the Delaware state line and live with him at his home in Allentown.

Afraid to trust dispatch again, my wife and I called the state police directly and went to Troop 6 to explain our plan. Arrangements were made to have state police pick up our son. My son's paranoid antennae was up. He saw a state police car and ran through the church parish house, where he had broken into the night before and stayed. The state police gave chase and the search continued in the nearby neighborhood with the state police helicopter, five police cars and seven troopers. They finally apprehended my son at about 11:30 a.m.

After some medical treatment for cuts and abrasions at Christiana Care, the state police transported our son to Rockford Center at about 1:00 p.m.

Chad began taking medication on February 14th and receiving psychiatric care. On Wednesday, February 16th in a session with the social worker we were told that the insurance company was putting pressure on them to discharge him by Friday February 18th. This would have been prior to a court hearing scheduled for Wednesday February 23rd to have court-ordered medication and outpatient care for our son.

Having been through this twice before, we knew it was time to hire a lawyer. Our attorney sent three letters on February 18th: one to the center's executive director, one to the doctor treating our son, and one to the insurance company's case worker. The letter made each one aware that if our son was discharged prior to getting enough treatment to rid him of his psychosis that we would hold them responsible and major contributors to any harm that came to our son. On February 21st we were assured by the doctor that he would appear at the court hearing to recommend further inpatient care and court-ordered medication and outpatient care.

I will have flashbacks for the rest of my life to serve as painful reminders of how my son has suffered, and how we have suffered as a family. It has been one long nightmare of instant replays of court hearings, my son being led away in handcuffs, and waking to screams in the middle of the night.

We will have memories of panic each time he was missing and wondering if he was safe, memories of a father's tears caused by love for a tortured son who is unable to recognize his illness, memories of deep despair each time an attempt to get my son treatment was thwarted by Delaware Law and an ineffective Health Care System--all memories that did not have to be repeated over and over again.

Judy and I are asking the state legislature to pass the kind of legislation that would allow parents like us to get help for their children, as adults on a **Need For Treatment Basis**. It is ironic that the present law protects my son's right to accept or refuse treatment, but that because of my son's inability to recognize his illness, he is unable to practice the most precious of our civil liberties--the right to pursue happiness and success and lead a productive life in society.

State Updates

West Virginia

West Virginia's Commission on Mental Hygiene Reform Reaches Consensus on a "Need for Treatment" Standard

By Mary T. Zdanowicz, Executive Director

In February 1999, the Supreme Court of Appeals of West Virginia appointed the Commission on Mental Hygiene Reform for the express purpose of updating and improving the State's assisted treatment laws.[1] In making its recommendations for reform, the Commission recognized that there have been profound changes since the enactment of West Virginia's mental hygiene laws. In 1974, the average length of stay in a West Virginia psychiatric hospital was 15.91 years; today the average stay is 15 days. There were thousands of individuals in the state's psychiatric hospitals 25 years ago, while today there are less than 250. Most significantly, "there has been a revolution in the understanding and treatment of mental illness, including the use of modern medications that can dramatically ameliorate the symptoms of many mental illnesses."

The Treatment Advocacy Center was honored with an invitation to make a presentation to the Commission at its first meeting on April 7, 1999. The Commission also collected information about the need for reform by conducting public hearings, surveying jail officers and court personnel, polling other stakeholders in the system, conducting telephone interviews of consumers of mental health services and consumers' families, and accepting submissions via mail and e-mail.

On December 15, 1999, the Commission issued its Final Report that contained thirteen recommendations falling into three categories: 1) standards and procedures; 2) services; and 3) accountability, oversight and education. Most notably, the Commission unanimously recommended modifying the "dangerousness" standard for assisted treatment with a "need for treatment" standard. West Virginia law currently requires proof that an individual is "likely to cause serious harm to himself or herself or to others if allowed to remain at liberty." The Commission recognized that the "dangerousness" standard "drives the 'criminalization' of the involuntary commitment process. ... Many persons with mental illness ... do not recognize the existence or extent of their illness. Before receiving treatment, persons with mental illness must often spiral to the depths of their illness, to a level that they are declared, in a legal proceeding, likely to cause serious injury to themselves or others." The Commission recognized the benefits of early intervention in preventing further deterioration that can occur if symptoms are left untreated and in being cost-effective by treating the illness at a less advanced stage.

The Commission recommended that the Legislature amend the standard for assisted treatment so that it encompasses persons with mental illness whose judgment is impaired and those who exhibit similar behavior to that which previously resulted in court-ordered treatment. The proposed "need for treatment" statutory language includes the following criteria:

> “the person has behaved in such a manner as to indicate that the person is unable, without supervision and the assistance of others, to satisfy the person's need for nourishment, personal or medical care, shelter, or self-protection and safety, so that it is probable that death, substantial physical bodily injury, serious mental decompensation or serious physical debilitation or disease will ensue unless adequate treatment is afforded.”

The Commission's Report provides a comprehensive review of West Virginia's civil commitment process and a thoughtful and thorough model for reform. Included among the Commission's other recommendations were the need for: procedures to improve medication compliance in and out of the hospital; strengthening of the continuum of services for severe mental illness from preventive services in the community to long-term care; accountability and monitoring of services providers, courts

(State Updates page 7)

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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Treatment Advocacy Center Board of Directors. Front left to right: Gerry Tarutis, Ed Francell, Carla Jacobs. Back left to right: DJ Jaffe, E. Fuller Torrey, Ray Coleman, Fred Frese. Missing from picture is James Copple.

New Board Member

The Treatment Advocacy Center is pleased to announce that Ray Coleman has joined the Center's Board of Directors. Mr. Coleman is the Facility Commander and Deputy Director for the King County Department of Adult Detention, Regional Justice Center-Detention Facility in Kent, Washington. He has held a leadership position in a number of key organizations including Charter President of the American Jail Association, Past Treasurer of the National Coalition for the Mentally Ill in the Criminal Justice System and Past President of Community Action for the Mentally Ill Offender. He holds an M.A. degree in psychology and has worked for more than 15 years on diversion programs for the mentally ill offender. Eleanor Owen, Executive Director of Washington Advocates for the Mentally Ill, has known Ray Coleman for many years. Eleanor says that "he has been the single most effective and knowledgeable voice in the state of Washington on the criminalization of individuals with severe mental illness. He raised the level of awareness of this travesty with state lawmakers and policymakers and was a vital contributor to establishment of the jail diversion program and mental health court in King County." We are exceedingly pleased to welcome Ray Coleman to the Board of the Treatment Advocacy Center.

(State Updates from page 5)

and state agencies; and education. The Final Report can be viewed on the Treatment Advocacy Center's web site (www.psychlaws.org) or West Virginia's web site (www.state.wv.us/wvsca/mental hyg/finalmh.pdf).

The Treatment Advocacy Center is grateful to Chief Justice Larry V. Starcher of the Supreme Court of Appeals of West Virginia and his staff, particularly Staff Attorney Tom Rodd, for their dedication to improving treatment for individuals with severe mental illness in West Virginia. The Center commends the Commission for its insightful report and recommendations.

Connecticut

HB 5699
Introduced 02/23/00

(Note: The Board of Directors of NAMI-CT issued a statement that the bill is "an ill-conceived solution to the problems in the Connecticut mental health system." In reaching that conclusion, the NAMI-CT Board relied on an invalid interpretation of the study of the New York pilot outpatient commitment program and apparently ignored the other studies that demonstrate that assisted outpatient treatment works.)

♦Creates assisted outpatient treatment for persons with psychiatric disabilities having a propensity for violence.

♦Authorizes court to order assisted outpatient treatment if: when caused by psychiatric disability, respondent has threatened or inflicted serious physical injury on another on one or more occasions; history of noncompliance; without medication respondent likely to relapse/deteriorate and pose danger to others; and likely to benefit from treatment.

♦Order can be for no longer than 180 days.

♦Noncompliance can be reported to court; upon reasonable cause to believe person is danger to self/others or gravely disabled, the court can order that a person be taken for examination.

Minnesota

HB 3107/ SB 2634
Introduced 02/10/00
Introduced 02/07/00

(Note: The bill is sponsored by Minnesota State Representative Mindy Greiling who was unable to get treatment for her son who was psychotic until he became dangerous.)

♦Modifies provisions related to early intervention mental health treatment; further relaxes criteria in existing law; adds "the proposed patient is in need of treatment to prevent progression of the illness" as alternative criterion of early intervention standard.

♦Provides stay order mechanism for outpatient early intervention.

♦Provides notice to certain relatives.

♦Modifies consent provisions for minors.

South Dakota

HB 1036
Signed into law 02/15/00

♦Revises definitions of danger to self and danger to others: removes imminence requirement by deleting "very" from "very near future."

♦Provides that treatment history and recent acts/omissions can be used as evidence.

♦Expands "gravely disabled" provision to include a reasonable expectation of serious physical harm due to a person's inability to take care of essential medical care.

Utah

SB 200
Introduced 01/29/00

(Note: SB200 passed in the Senate on 02/22/00, but was not brought up for a vote in the House because the fiscal note tied to the bill to fund additional services did not make the Legislature's priority funding list.)

♦Removes "imminent" danger requirement, replaces with "substantial" danger.

NAMI--2000 CONVENTION!

Visit the Treatment Advocacy Center at the NAMI 2000 Convention.

The Treatment Advocacy Center will be attending the NAMI 2000 Annual Convention June 14 - 18 in San Diego, California. Be sure to visit our booth and attend the Treatment Advocacy Center's workshop:

"What is it Like To Be Sick and Not Know It?"

IT IS BEWILDERING!-Many suffering from mental illness refuse treatment because they don't realize they are sick. Hear why from one of the nation's leading experts, Dr. Xavier Amador. Then Dr. Fred Frese, and four others who have been there, will take you inside the mind of a person who is desperately ill but doesn't know it.

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[1] Members of the Commission included consumers of mental health services, consumers' family members, consumer advocates, mental hygiene commissioners, a magistrate, a circuit court judge, a prosecuting attorney, a public defender, a sheriff, service providers, representatives from the Department of health and Human Resources, a representative from the Governor's cabinet on children and families, and members of the West Virginia delegates and the West Virginia Senate.

You can help end Medicaid discrimination against persons with severe mental illnesses by contacting your representatives in Congress and telling them to support repeal of the IMD Exclusion.

For info on how to help:

Call us at
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info@psychlaws.org

Or, go to our web site at

www.psychlaws.org

♦Amends danger to self to include "currently relevant historical pattern indicating that without treatment…will suffer severe and abnormal mental or emotional distress, and will experience deterioration of his ability to function…"

(IMD Exclusion from page 1)

resulting in increased rates of incarceration, homelessness, victimization and violence. The race for Medicaid dollars has, in fact, reduced the total number of state psychiatric hospital patients to less than 60,000 today, compared to 500,000 in 1965 when Medicaid was enacted.

For many people with severe mental illness, deinstitutionalization has meant nothing more than transinstitutionalization from a hospital ward to a prison cell--a grim reality indeed.

A recent study by Steven Raphael at the Goldman School of Public Policy at Berkeley established a causal connection between deinstitutionalization of the severely mentally ill from state psychiatric hospitals and increases in rates of incarceration in jails and prisons.

According to the Department of Justice's (DOJ) statistics, 275,900 persons (16% of all prisoners) in state jails and prisons are mentally ill. With some 3,500 and 2,800 mentally ill inmates respectively, the Los Angeles County Jail and New York's Riker's Island are currently the two largest psychiatric inpatient treatment facilities in the country.[4]

With many states still closing hospitals, the trend to criminalize the mentally ill continues. More hospitals closed between 1990 and 1997 than in the previous two decades combined.[5] While New York has instituted a one-year moratorium on further hospital closures, closings continue in other states. For example, Virginia proposes to close Eastern State Hospital and plans on closing most of the remaining state psychiatric hospitals, Hawaii is closing its only state psychiatric hospital, and Vermont is converting much of its state hospital into a prison.

You can help end Medicaid discrimination against persons with severe mental illnesses by contacting your representatives in Congress and telling them to support repeal of the IMD Exclusion. Information on the IMD Exclusion and how to contact Congress is available on our web site at www.psychlaws.org <http://www.psychlaws.org> under "Hospital Closures." For more information, please call the Treatment Advocacy Center at 703-294-6001, or send an email to info@psychlaws.org.

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[1] 42 USC 1396r-4

[2] E. Fuller Torrey, Out of the Shadows: Confronting America's Mental Illness Crisis, 99 (1997)

[3] In 1955 the U.S. had a population according to the Census Bureau of some 164 million. By 1996 the population had increased to 265 million. Meanwhile the number of patients in state and county mental hospitals dropped from 558,239 to 61,722. U.S. Dept. of Health Education and Welfare, Pub. Health Service Publication No. 574. Patients in Public Hospitals for the Mentally Ill, (1956) Substance Abuse and Mental Health Services Admin., Ann. Survey of State and County Mental Inpatient Services, U.S., 1996 (1998)

[4] Fox Butterfield, Prisons Replace Hospitals for the Nation's Mentally Ill, NY Times, March 5, 1998 at A1

[5] According to information provided by the NASMHPD (National Association of State Mental Health Policy Directors) Research Institute, some 40 state psychiatric hospitals closed their doors between 1990 and 1997.

Crises Intervention Training (CIT): A Catalyst for Consumers and Cops

By Donald G. Turnbaugh, Chair, NAMI Florida Decriminalization Committee

"Sometimes, I'm afraid of you," were the words spoken by a consumer when greeting a deputy sheriff at an assisted living facility (ALF). "I'm afraid of you sometimes, too," was the deputy's response. This friendly exchange occurred when neither was afraid, nor in crisis, as on this day, both were participants in a discussion group consisting of persons with mental illness, case managers, and law enforcement officers, who were on all-day visits to various facilities ranging from day-treatment programs to ALF's. These visits, in March and August 1999, were part of Florida's first-ever 40-hour training courses entitled: Crisis Intervention Training (CIT) for Law Enforcement Officers conducted in Pinellas County (Clearwater, Largo) and attended by 95 deputies and police officers from 15 agencies encompassing four counties in the Tampa Bay area. During the five consecutive days of specialized training, they are instructed how to professionally and properly deal with persons with mental illness in crisis.

What is the CIT course like?

As the officers first arrive for this intensive training, some appear apprehensive, skeptical, or mostly curious. By the time they depart, five days later, they are confident, knowledgeable, and, in most cases, compassionate. This metamorphosis is caused by the scope of the material, the depth of instruction, and the interest of the officers themselves. The first day is filled with information about the signs, symptoms, medications and side-effects, of these illnesses. Accurate and specific examples of delusions, hallucinations, and paranoia, are provided and fully explained, including why so many persons go off their "meds" even though they seem to be working.

Then, after the previously described all-day field-trips, the Family and Consumer Perspective session captures everyone's undivided attention. Here a mom and two consumers take the class on a virtual roller-coaster ride describing their personal experiences with mental illness and the criminal justice system. Although every session is well received, these two are, by far, the most popular. The course is rounded out with various other related topics: de-escalation techniques, suicide risk assessment, involuntary commitment laws and procedures, dual diagnosis, street encounters (7 videoed role-playing scenarios), and mental illness in children, adolescents, and the elderly .

Evaluations of the two CIT courses by participants were extremely positive. Now, veterans of the course, after putting the lessons learned to use, return to instruct other officers. They describe CIT with words like, "I've received a lot of training that I sometimes use; e.g., SWAT and pursuit driving; but, I use CIT everyday!"

Who should receive CIT?

Law enforcement will continue to be the first responding "care-givers" to the scene of persons in crisis. Unfortunately, when the paranoia and delusions of one encounter the fears and ignorance of the other, an all-too-often combustible situation results. A symbiotic relationship is inevitable, whether either likes or wants the contact. These encounters draw upon inner personal strengths not every officer possesses and the specialized training not every officer needs. The very nature of CIT is contrary to general law enforcement "crime fighting" techniques. Experience indicates that officers who volunteer for CIT perform best.

Does CIT work?

CIT may not be a panacea, but it is a vital step in the decriminalization effort. It is one of the best ways for persons who need help to get to treatment and not to jail. For some, an encounter with law enforcement is their only opportunity for treatment and the significant first step up the treatment ladder. Hopefully, CIT will be the end of the former and the beginning of the latter. The law enforcement community does its part by providing officers for the training. The training ensures that officers learn how to treat persons with brain disorders with dignity and the importance of delivering them for treatment. It is the availability of effective treatment that remains in question.

One comparison study of the Memphis Police Department's successful twelve-year CIT program and two other programs indicates the answer is a resounding--Yes! CIT has proven itself as a time-saving, money-saving, and life-saving program. In

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Pinellas County, a Florida Highway Patrol Trooper, and CIT graduate, was recently recognized for his exemplary action in "talking-down" four persons in separate incidents from jumping from a known "suicide site." Additional anecdotal examples abound.

What is the future of CIT?

At the national level, NAMI (formerly National Alliance for the Mentally Ill) established, as part of its policy, a strategy of “adopting programs such as the Memphis Police Crisis Intervention Team (CIT) program." An encouraging sign is that a number of police departments around the nation have implemented the Memphis model CIT program.

NAMI Florida has embarked upon a statewide endeavor to spread the word about CIT by: encouraging local NAMI affiliate presidents to contact their sheriffs and police chiefs; conducting workshops; writing articles; and attending law enforcement conferences. CIT courses have been conducted, or are being scheduled, in several of the major metropolitan areas; e.g., Clearwater, Tampa, Orlando, Jacksonville, and Miami.

How can a community get CIT off the ground?

An existing group, the Pinellas County Mental Health Coalition, comprised of advocates, consumers, providers, practitioners, law enforcement officers, and others interested in improving mental health services, designed, developed, and delivered the CIT course with no cost to tax-payers. All presenters donated their time and talent! Community Partnerships such as this can be replicated in almost every city and county nationwide.

Information about how to form a Community Partnership to establish CIT is available by contacting NAMI Florida's Decriminalization Committee at: 727-942-8140; fax: 727-937-8512; e-mail: turnj@aol.com.

About the author: Donald Turnbaugh, retired from the U.S. Customs Service as Special Agent in Charge in 1995 after 30 years of service. Prior to that, he served five-years with the Baltimore Police Department in the early 1960's. He was President, NAMI Pinellas County, Florida for two terms (1998, 1999). Currently, he is the Chairperson of NAMI Florida's Decriminalization Committee.

Your Voice -- Will Make a Difference

Thanks very much! I would definitely like extra copies of all future issues. The Catalyst is such a good tool for family members in my Family-to-Family classes-especially since we're trying to pass legislation here in California.

Camille Callahan
Hemet, CA

I've seen the www.psychlaws.org web site and I do NOT support Treatment Advocacy Center and its policies. You believe if someone is diagnosed with a mental illness they should be immediately committed or as you refer to it "assisted treatment." Even if the person is competent and not in any way a danger to themselves or others, you think involuntary treatment should be used as a first priority. Not only that, you want laws to make it easier to forcibly drug people and keep them on certain drugs under the threat of punishment. How more dehumanizing and degrading can you get?. It's no wonder so many people are afraid to seek treatment. Would you want to lose all your rights regarding your personal health care decisions? and possibly be taken into custody (locked up) against your will just because you are diagnosed with a specific medical disorder?

I think this kind of big brother coercive philosophy is part of the problem, not the solution. I believe in civil rights, and all people's civil rights should be protected, and I know the ACLU and various human rights organizations would and will protect people from these kinds of measures.

If you believe in this form of approach, then what makes you any different than a Nazi !!

Curtis Eugene

Response from Mary Zdanowicz:

Dear Mr. Eugene:

I am afraid you must have been visiting some other organization's web site because we certainly do not believe in the approach that you describe.

The Treatment Advocacy Center does not, never has, and will never advocate that a person be committed simply because of having been diagnosed with mental illness.

However, if a person with mental illness who is in need of treatment refuses it because they do not believe they are ill, then assisted treatment is appropriate, because the illness has rendered him or her unable to make an informed decision about treatment. You express concern about civil rights, but you must realize that a person in the throes of psychosis is not really free to exercise his rights. Assisted treatment may be necessary to alleviate symptoms such as delusions, hallucinations and disordered thinking and once again enable people overcome by mental illness to participate meaningfully in their personal health care decisions.

We believe in protecting individual rights, particularly the right to be well. Should it be any other way, I doubt that so many people who have psychiatric disabilities--including two of our Board Members and our Assistant Director--would support our mission. Sincerely,

Mary T. Zdanowicz
Executive Director

I am very much in support of what you are trying to accomplish. As you probably know, your most outspoken opponents are the very high functioning, so-called mentally ill.

Betty W. Smith
Holt, Michigan

I was fortunate to receive a copy of your article titled "Reinventing Mental Health Care"--and totally agree!! It is unfortunate that the organization titled "Protection & Advocacy" sounds so similar to yours!! Yet does a disservice to clients by NOT approving medications for those who are not able to recognize that they need the medication!

Kathy Porovich
Clearlake Oaks, CA

I am delighted to learn of TAC--a move in the right direction. This is of great interest to me as I am the mother of a daughter who has suffered from schizophrenia for over 40 years. If I may be of help in writing letters or making telephone calls to legislators or congress persons, just let me know.

Mary H. Main
Dallas, TX

Can I have 10-20 copies of Catalyst? The Catalyst articles hit the nail on the head!

Patricia Spoerl
Milwaukee, WI

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

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

Thank you, thank you, for your wonderful work!

Alice Fitzcharles
Media, PA

The first issue of your publication meant so much to me. I read with profound empathy the story by the mother of Kenneth Scott Hardman. We too, have a personal experience very similar in nature.

Our youngest son died by suicide only eight months after he had graduated cum laude from college. His case is being litigated in N.C. Our attorney is from your area, Bryant Welch, J.D., Ph.D., a marvelous advocate.

The enclosed check is a memorial to our son, Stephen Kemp Pettyjohn (Dec. 14, 1971-August 27, 1997). He was beautiful and bipolar.

If I am entitled to receive any future issues of your Catalyst publication I will appreciate each one. I will subscribe as necessary. The first copy came to me through our local chapter of NAMI - VA.

Thank you for your efforts on behalf of us all.

Sydney S. Pettyjohn
Chatham, VA

I just received my copy of the Catalyst and enjoyed reading it very much. My husband is president of our local NAMI chapter, and I would love to have about 30 copies of your publication to distribute at our next meeting.

Yvonne Starr
Marietta, GA

PLEASE HELP THE TREATMENT ADVOCACY CENTER TO ACHIEVE ITS MISSION TO ELIMINATE THE LEGAL AND PRACTICAL BARRIERS TO TREATMENT FOR MILLIONS OF AMERICANS WHO SUFFER FROM, BUT ARE NOT BEING TREATED APPROPRIATELY FOR SEVERE BRAIN DISORDERS, SUCH AS SCHIZOPHRENIA AND MANIC-DEPRESSIVE ILLNESS, AND TO PREVENT THE DEVASTATING CONSEQUENCES OF NON-TREATMENT: HOMELESSNESS, SUICIDE, VICTIMIZATION, WORSENING OF SYMPTOMS, HOMICIDE, AND INCARCERATION.

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STANDARDS SHOULD BE BASED ON THE NEED FOR TREATMENT

Several states have abandoned dangerousness as the sole standard upon which inpatient treatment decisions are based. The states that have done so have incorporated the following factors into their standards in different combinations:

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

Standards based on the need for treatment allow for a medical intervention before an individual spirals to the depths of his illness.

MEET TAC BOARD MEMBERS!