Treatment Advocacy Center

Modernizing New Jersey's Civil Commitment Law

New Jersey needs assisted outpatient treatment

Assisted outpatient treatment (AOT), also known as involuntary outpatient commitment (IOC), allows a judge to issue a court order mandating that a person who meets specific criteria adhere to a prescribed community treatment plan, using the possibility of hospitalization as leverage. The main goal of AOT is to foster more consistent adherence to treatment for people whose severe mental illnesses impair their ability to seek and voluntarily comply with treatment.[1] Non-compliance with treatment, specifically non-adherence to medication, is strongly associated with hospitalization,[2] arrest,[3] and violence[4] among people with severe mental illnesses.

Based on New York's experience with Kendra's Law, AOT would be used to help a relatively small number of people in New Jersey – an estimated average of 337 individuals per year.[5] As the Mental Health Association of New Jersey explains, "a majority of [the mentally ill] can make their own decisions about care."[6] AOT would not apply to the majority of people with severe mental illnesses, and would in no way adversely affect the rights of those who are able to make their own decisions regarding treatment.

New Jersey is one of only eight states that does not provide for AOT as an alternative to involuntary hospitalization for people with severe mental illnesses. The practical result of New Jersey's failure to do so is that community mental health services are only available to people who are able to accept services voluntarily. The rest are left untreated until their condition deteriorates to the point where they are "in need of involuntary commitment" because their mental illness causes them to "be dangerous to self or dangerous to others or property."[7] New Jersey essentially forces people who lack insight into their illness to hit rock bottom before they can be helped – and then the only option is one of the state's scarce remaining hospitals beds.

AOT addresses the most common reason for refusing treatment - lack of insight (anosognosia)

Extensive research since the early 1990s has revealed that some people with schizophrenia and bipolar disorder experience a neurological deficit called "anosognosia," a condition also commonly found in people suffering other brain disorders such as Alzheimer's or stroke.[8] Anosognosia impairs a person's ability to recognize that their symptoms are caused by a brain disorder.[9] A leading researcher detailed the severe consequences of this condition:

> [P]oor insight in schizophrenia is associated with poorer medication compliance, poorer psychosocial functioning, poorer prognosis, increased relapses and hospitalization and poorer treatment outcomes.[10]

The most common reason that people with severe mental illnesses are not being treated is that they do not believe that they need treatment.[11] A severe lack of insight into illness can "seriously interfere with [a patient's] ability to weigh meaningfully the consequences of various treatment options."[12]

New York has seen dramatic success in its first five years using AOT

Among individuals in first five years of New York's assisted outpatient treatment program (Kendra's Law), far fewer experienced hospitalizations (77 percent), episodes of homelessness (74 percent), arrests (83 percent), and incarceration (87 percent) and significantly more individuals had improved medication compliance (50 percent) and participation in substance abuse treatment (65 percent).[13] Participants also had marked reductions in harmful behavior; and individuals who were in AOT for longer periods had greater reductions in violent behavior. Hospital days were reduced dramatically from an average of 50 days over a six-month period before starting AOT, to an average of 22 days during the six months of AOT, to an average of only 13 days in the six-month period after AOT. That is a full 74 percent reduction in hospital days six months after termination of the court order when compared with the six months prior to AOT.

In July of 2005, the New York Legislature recognized the success of Kendra's Law and voted (204-1) to extend the benefits it provides. As Governor Pataki explained, "The results are clear. Kendra's Law works."[14]

People with severe mental illnesses report improved quality of life with AOT

More than 75 face-to-face interviews have been conducted with participants in New York's AOT program to assess their opinions about AOT including their perceptions of coercion or stigma associated with the court order and their quality of life as a result of AOT. When asked about the impact of the pressures and other measures that people took to get them to stay in treatment:

- 75 percent of interviewed recipients reported that AOT helped them gain control over their lives,
- 81 percent said that AOT helped them to get well and stay well, and
- 90 percent said AOT made them more likely to keep appointments and take medication.

A randomized control study of AOT showed similar results. Researchers assessed the impact of AOT on quality of life of people with severe mental illnesses, covering a range of areas including social relationships, daily activities, finances, residential living situation, and global life satisfaction. They found remarkable evidence that subjects who underwent sustained periods of AOT had measurably greater subjective quality of life at the end of the study year. It appears that AOT exerts its effect largely by improving treatment adherence and decreasing symptomatology.[15]

A randomized control study shows that AOT significantly reduces the consequences of nontreatment

The most comprehensive, randomized control study of AOT, referred to as the Duke Study, involved people who "generally did not view themselves as mentally ill or in need of treatment."[16] The study compared people who were offered community mental health services with people who were offered the same services *combined* with a court order requiring participation in those services (i.e., the difference was the court order). The Duke Study showed that combining a court order with services for a long term (at least six months) reduced hospitalization (up to 74 percent), reduced arrests (74 percent), reduced violence (up to 50 percent), reduced victimization (43 percent) and improved treatment compliance (58 percent).[17]

Studies in other states also demonstrate that AOT works

- In Washington, D.C., hospital admissions decreased from 1.81 per year before to 0.95 per year after outpatient commitment.[18]
- In Ohio, the number of hospital admissions decreased from 1.5 to 0.4 per year. Outpatient commitment increased patients' compliance with outpatient psychiatric appointments from 5.7 to 13.0 per year and attendance at day treatment sessions from 23 to 60 per year.[19]
- In Iowa, the number of hospital admissions were reduced from 1.3 to 0.3, total number of hospital days from 33.3 to 4.6, and length of stay from 26.7 to 18.6.[20]
- In North Carolina, admissions for patients on outpatient commitment decreased from 3.7 to 0.7 per 1,000 days.[21]
- In North Carolina, only 30 percent of patients on outpatient commitment refused medication during a six-month period compared to 66 percent of patients not on outpatient commitment.[22]
- In Arizona, among patients who had been outpatient committed, "71 percent of the patients voluntarily maintained treatment contacts six months after their orders expired" compared to "almost no patients" who had not been put on outpatient commitment.[23]

Caregivers and people with severe mental illnesses report improved quality of life after sustained AOT

Families and friends who are caregivers for people with severe mental illnesses experience significant strain, particularly when their loved ones refuse treatment. In a study of the effect of AOT on caregivers, extended outpatient commitment contributed significantly to reduced caregiver strain.[24]

Consumers believe the benefits of AOT outweigh the potential disadvantage of perceived coercion

In a survey of people with schizophrenia concerning preferences related to AOT, "being free to participate in treatment or not" was the least important outcome. When asked to rank their preferences, they answered that reducing symptoms, avoiding interpersonal conflict, and avoiding re-hospitalization outranked avoidance of outpatient commitment.[25] Studies show that a majority of people with severe mental illnesses who received mandatory treatment later agreed with the decision.[26] An informal survey of consumers of services for people with severe mental illnesses by a fellow consumer revealed that a majority supported outpatient commitment.[27] A formal survey published in July 2004 found that a majority of consumers regard mandated treatment as effective and fair.[28] One prominent consumer advocate who has schizophrenia explained that those "who have been primarily interested in consumer rights and liberties ... focus ... on opposing the use of forced treatment. ... On the other hand, consumer advocates who place a high value on the need for psychiatrically disabled persons to receive treatment tend to support [AOT]."[29]

New Jersey cannot afford *not* to have AOT

New Jersey's state psychiatric hospitals are severely overcrowded, with a readmission rate estimated to be as high as 35 percent at one of the state hospitals.[30] In its analysis of the FY 2005 state budget, the New Jersey Office of Legislative Services (OLS) warned that, "the actual census at Ancora, Greystone, and Trenton [New Jersey's psychiatric hospitals] has historically exceeded the estimates included in the recommended budget" and"[t]he actual census of the three facilities has been between 5.3 percent and 14.1 percent greater than the estimates included in the recommended budgets between FY 2000 to FY 2004."[31] Two hundred and fifty-three individuals, almost ten percent of individuals between the ages of 18-64 admitted to a state hospital, are readmitted within 30 days of discharge. The readmission rate jumps to 22 percent in the six-month period following discharge.[32]

County budgets are being adversely impacted by high hospital readmission rates as well, because counties are responsible for 50 percent of the cost of care that their residents receive in state psychiatric hospitals.[33] AOT reduces hospital readmissions significantly and is needed to reduce overcrowding and budget shortfalls.

Medication non-adherence is a significant factor in hospital readmissions. A study of Medicaid recipients with schizophrenia in California revealed that "individuals who were [medication] non-adherent were two and one-half times more likely to be hospitalized than those who were adherent."[34] The same study found that those who are non-adherent incur 43 percent more in service costs than those who adhere to medication. AOT can help reduce such costs by improving medication compliance.

New Jersey has made substantial investments in community mental health services in recent years. Under Phase I of New Jersey's Redirection Plan, Marlboro Psychiatric Hospital was closed in 1998 and $50 million has been invested annually in community psychiatric services.[35] In FY 2005, the state appropriated an additional $30 million for the second phase of the plan (Redirection II) to redirect money from state psychiatric hospitals to community services.[36] Redirection I & II created a variety of intensive services, including thirty-one PACT teams, considered the most comprehensive form of community treatment. Unfortunately, the effectiveness of those services is compromised because New Jersey does not have AOT. The PACT Model recognizes that sometimes a court order may be required to ensure that clients benefit from these services.[37] New Jersey currently does not have that option. As a consequence, nearly one thousand people who have been enrolled in PACT services are not actively participating.[38] New Jersey's citizens have made a strong investment in PACT services; they deserve to know their programs are benefiting those in need.

ENDNOTES

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[5] As of March 2005, 3,908 individuals received treatment orders under Kendra's Law. This translates to an average of 747 individuals per year. According to the U.S. Census Bureau, New Jersey's population is approximately 45 percent of New York's (19,190,115 vs. 8,638,396 persons). Based on the experience in New York, it is estimated that New Jersey will have an average of 337 people receiving court orders per year.

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> some clients who enter PACT treatment voluntarily later refuse treatment and may become candidates for involuntary services if they relapse… In this case the PACT team first tries to stay involved with the client who declines treatment … If the client's behavior … meets the commitment law criteria, the PACT team participates in the commitment process.

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Treatment Advocacy Center

Modernizing New Jersey's Civil Commitment Law:

New Jersey's Current Community Service Programs are Unavailable to a Significant Number of Individuals with a Severe Mental Illness

Is assisted outpatient treatment constitutional?

No court in the United States has ever declared an assisted outpatient treatment (AOT) law to be unconstitutional. Forty-two states and the District of Columbia have already enacted AOT. Various provisions have been tested and found constitutional by state courts throughout the country. New York's courts, including the state's highest court, have repeatedly upheld AOT as constitutional. Standards much broader than those proposed in New Jersey have been upheld in states such as Hawaii, Wisconsin, and Washington.

Doesn't New Jersey already have outpatient programs set up?

All of New Jersey's current outpatient programs are voluntary. Thus, they cannot help those most in need of treatment – people with a severe mental illness who refuse treatment because they are unable to understand they are sick. This small segment of those with mental illnesses will not seek treatment and, in New Jersey, are left to deteriorate until they become so ill that they pose a danger to themselves or others. AOT provides effective treatment to these individuals, something that redirecting funds to the community is simply not designed to do.

How many people would AOT cover?

The most accurate indicator is experiences from other states – and New York has the best documented experience with AOT. As of March 2005, 3,908 individuals received treatment orders under Kendra's Law. An average of 62 individuals per month, or 747 individuals per year, have been ordered to maintain treatment under the program. Adjusting for population, New Jersey should have approximately 337 orders per year.

Hasn't New Jersey already addressed this problem by creating PACT teams?

With the closing of Marlboro Psychiatric Hospital in 1998 and the substantial investment in community mental health services of Redirection I & II, New Jersey was able to establish 31 PACT teams – at least one team in each county. Programs in Assertive Community Treatment (PACT) teams comprise the most progressive community service model and provide 24-hour, seven-day-a-week mobile treatment to the most severely ill individuals.

Unfortunately, unlike most other states that use PACT teams, New Jersey cannot require clients to take medication. PACT teams are powerless to help someone who refuses treatment. Yet, refusing clients remain with PACT, as it is designed to provide long-term care for its clients. Thus, under the current program, New Jersey citizens are paying for people to refuse the most expensive services the state has to offer. AOT is not an alternative to PACT teams; it is a change in the law that would drastically improve PACT teams' ability to provide treatment in the community.

New Jersey already has conditional release. Why should we enact a similar program?

AOT and conditional release are different programs, although both can expedite the recovery of someone in need of treatment. The main difference is timing. Conditional release can occur only after someone has

already been admitted to a treatment facility. AOT serves as a preventative alternative to involuntary hospitalization, allowing someone who is in need to get treatment before they require inpatient care.

In addition, recent court cases have called into question the effectiveness of the already limited conditional release provisions. Under current judicial interpretation, individuals on conditional release may not be returned to a facility unless they meet the initial inpatient standard. Even if an individual has completely disregarded the conditions specified in his or her discharge plan, the court must still find that the individual is dangerous to himself, others, or property before recommitment may take place, just as with someone who is not on conditional release. The release conditions are essentially meaningless.

Isn't the real problem that there aren't enough services?

AOT seeks to help those individuals whose illness has rendered them incapable of understanding that they are ill. For this small subset of the most mentally ill, no amount of money spent on services will ever be enough to induce their compliance with treatment.

These individuals suffer from a condition known as anosognosia – literally "to not know a disease." Studies show approximately 50 percent of individuals with schizophrenia and 40 percent of individuals with bipolar disorder have some impaired ability to recognize their condition. For these individuals, the delusions (e.g. the woman across the street really is being paid by the CIA to spy on him/her) and the hallucinations (e.g. the voices really are instructions being sent by the President) are real – and no amount of voluntary services will suffice.

Why isn't the solution simply more voluntary programs?

The reality is that, for some individuals, voluntary treatment is simply impossible. Their illness has robbed them of the ability to understand their need for care. AOT allows loved ones and treatment providers to provide treatment to those who need care, until they reach the point that they are able to make rational decisions for themselves.

How will AOT address our current psychiatric hospital bed shortage?

AOT allows providers to ensure consistent treatment for individuals with a history of repeatedly stopping their treatment and requiring inpatient hospitalization. Under New Jersey's current system, providers cannot intervene for these individuals until they've deteriorated to the point that they again require hospitalization. Research shows that each time an individual is allowed to deteriorate in this manner, treatment is more difficult and expensive, and the prospects of a full recovery are reduced. AOT ensures that these individuals are not allowed to repeatedly deteriorate, without requiring expensive and ultimately ineffective hospitalizations.

AOT allows individuals who would otherwise be committed to an inpatient facility to receive treatment in the community – reducing treatment costs while limiting the upheaval inherent in an inpatient hospitalization. Every dollar saved by helping an individual to be an active member of society is a dollar that can be reinvested in other areas of psychiatric care in New Jersey.

Doesn't AOT put too much focus on violence by mentally ill persons? How would this program address the issue of stigma?

Violence is just one of many repercussions of New Jersey's outmoded treatment law, but it is one that resonates among the general public. Providing consistent treatment to individuals in need and preventing the tragedies that too often accompany nontreatment is the most cogent way to address stigma. The reality is that until New Jersey has a law that ensures treatment for the most ill, tragedies will continue to occur and continue to color society's perception of the most severely mentally ill.

But focusing solely on AOT's role in reducing violence is also a mistake. AOT has also been shown to reduce homelessness, incarceration, substance abuse, suicide and victimization – all very real consequences of untreated severe mental illness.

Does New Jersey have enough services available to ensure the success of AOT?

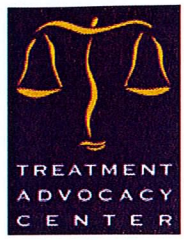
AOT legislation should include specific provisions mandating that courts may not order an individual into assisted outpatient treatment if the services are not available in the community.

But the services are available. Authoritative studies on the effectiveness of AOT published by Duke University showed that the service level required was three or more outpatient visits per month, with a mean of seven service events per month. Most counties in New Jersey will be able to provide this level of services to the limited number of individuals who would qualify for AOT.

New Jersey currently has over 31 PACT teams that far exceed the services standard utilized in the Duke studies. These teams are already tasked with serving a number of severely ill individuals who repeatedly refuse the services offered to them. AOT would provide these teams with another tool to provide effective mental health treatment.

In addition, New Jersey currently provides a minimum of 18 months of Integrated Case Management Services to all consumers discharged from state and county hospitals. The state has recently expanded this program to include consumers coming out of short-term care facilities who have a history of two or more hospitalizations within a 12-month period; these services could be made more effective with the addition of a program shown to help ensure consistent treatment adherence.

Assisted outpatient treatment also saves resources that are currently wasted on ineffective treatment. AOT reduces hospitalizations, episodes of homelessness, incarceration, arrest, and victimization, and significantly improves medication compliance and participation in substance abuse treatment. These freed up resource monies can be used to fund other areas of the New Jersey mental health system, such as community services and voluntary treatment programs.



Treatment Advocacy Center Briefing Paper

Assisted outpatient treatment: Results from New York's Kendra's Law

SUMMARY: Kendra's Law is New York's law for assisted outpatient treatment. The New York State Office of Mental Health released its "Final Report on the Status of Assisted Outpatient Treatment" on March 1, 2005, which details the outcomes for the first five years of Kendra's Law. Assisted outpatient treatment drastically reduced hospitalization, homelessness, arrest, and incarceration among the people with severe psychiatric disorders in the program, while at the same time increasing their adherence to treatment and overall quality of life. The adoption of assisted outpatient treatment also resulted in fundamental changes to the overall New York mental health system, leading to enhanced accountability and improved treatment plan collaboration for all service recipients – effectively committing the system to the patient, not just the patient to the system.

* * *

Kendra's Law helps those who need it most

As of March 1, 2005, 3,908 individuals received treatment orders under Kendra's Law.[1] An average of 62 individuals per month, or 747 individuals per year, were ordered to maintain treatment under the program.[2] That is approximately 39 per year per million people in the state population.[3]

As intended, the individuals placed in assisted outpatient treatment (AOT) were among the most severely ill. In the three years prior to the court order, almost every participant – 97 percent – had at least one psychiatric hospitalization (with an average of three hospitalizations per recipient). When compared with a similar population of mental health service recipients, those placed in AOT had been twice as likely to have been homeless, 50 percent more likely to have had contact with the criminal justice system, and 58 percent more likely to have a co-occurring mental illness and substance abuse condition.

Kendra's Law reduces the severest consequences from lack of treatment

During the course of court-ordered treatment[4], when compared to the three years prior to participation in the program, AOT recipients experienced far less hospitalization, homelessness, arrest, and incarceration. Specifically, for those in the AOT program:

- 74 percent fewer experienced homelessness;
- 77 percent fewer experienced psychiatric hospitalization;
- 83 percent fewer experienced arrest; and
- 87 percent fewer experienced incarceration.

Kendra's Law reduces costs for the most expensive services

Inpatient hospitalization is by far the most expensive form of psychiatric treatment available today. One of the most dramatic benefits to individuals participating in the Kendra's Law program was a marked reduction in the total number of days spent hospitalized. On average, AOT recipients spent 50 days in the hospital for psychiatric care during the six months prior to AOT, a number that was reduced 56 percent for participants during a matched period. Even after the termination of the court order, the decline continued – during the first six months following the end of the AOT order, total hospital days were reduced to an average of 13, a 73 percent reduction from the pre-AOT total. Individuals who meet Kendra's Law strict eligibility standard typically already consume significant inpatient and outpatient treatment dollars. The majority received case management, medication management, and/or individual or group therapy prior to AOT. Assisted outpatient treatment can reduce costs by reducing the ineffective use of existing services.

Kendra's Law reduces harmful behavior

Kendra's Law also resulted in dramatic reductions in the incidence of harmful behaviors for AOT recipients at six months in AOT as compared to a similar period of time prior to the court order:

- 55 percent fewer recipients engaged in suicide attempts or physical harm to self;
- 49 percent fewer abused alcohol;
- 48 percent fewer abused drugs;
- 47 percent fewer physically harmed others;
- 46 percent fewer damaged or destroyed property; and
- 43 percent fewer threatened physical harm to others.

Overall, the average decrease in harmful behavior was 44 percent.

Kendra's Law improves treatment compliance

Individuals in the Kendra's Law program were also much more likely to regularly participate in services and take medication as prescribed by the treating physician.

- The number of individuals exhibiting good adherence to medication increased by 103 percent (from only 34 percent to 69 percent).
- The number of individuals exhibiting good service engagement increased by 51 percent (from 41 percent to 62 percent).

Kendra's Law recipients value the program

Researchers with the New York State Psychiatric Institute and Columbia University conducted face-to-face interviews with 76 AOT recipients to assess their opinions about the program, perceptions of coercion or stigma associated with the court order and, most importantly, quality of life as a result of AOT. While the interviews showed that the experience of being court-ordered into treatment made about half of recipients feel angry or embarrassed, after they received treatment, AOT recipients overwhelmingly endorsed the effect of the program on their lives:

- 75 percent reported that AOT helped them gain control over their lives;
- 81 percent said that AOT helped them to get and stay well; and
- 90 percent said AOT made them more likely to keep appointments and take medication.

Additionally, 87 percent said they were confident in their case manager's ability to help them – and 88 percent said that they and their case manager agreed on what is important for them to work on. AOT had a positive effect on the therapeutic alliance.

Kendra's Law improves the system's ability to help those in need

Not only is Kendra's Law helping the individuals in the program, it is also helping the system better provide treatment to all those in need. The New York Office of Mental Health detailed some of these systemic benefits in its final report: "Counties and stakeholder groups statewide have reported that the implementation of processes to provide AOT to individuals under court orders has resulted in beneficial structural changes to local mental health service delivery systems... The implementation of AOT has also supported the development of more collaborative relationships between the mental health and court systems. AOT has been instrumental in increasing accountability at all system levels regarding delivery of services to high need individuals."

The increased accountability led to a shift in the manner in which treatment to high need individuals was viewed: "Local mental health systems began to identify the potential risk posed by not responding to individuals in need, and as a result, those systems improved their ability to respond more efficiently and effectively."

ENDNOTES

[1] This statistic and all others cited in this summary, unless otherwise noted, are from the following source: N.Y. State Office of Mental Health (March 2005). *Kendra's law: Final report on the status of assisted outpatient treatment. New York: Office of Mental Health.*

[2] 3,908 individuals over the first 5.23 years of the program (11/8/99 – 2/1/05) = 747.7 individuals per year, or 62.3 per month. This is notably fewer people than the 10,000 people per year that Kendra's Law opponents predicted would be swept into the "dragnet" of the law.

[3] New York's population is approximately 19 million. See http://quickfacts.census.gov/qfd/states/36000.html.

[4] The average timeframe for court orders was 16 months, and ranged from six months to more than 30 months.

Treatment Advocacy Center Briefing Paper

Consequences reduced – But not in New Jersey

Mark and Kathy Katsnelson, along with countless New Jersey families who are struggling to get treatment for their loved ones suffering from severe mental illnesses, are leading the effort to reform the state's inadequate mental health law. The Katsnelsons recognized the deficiency in New Jersey's law after the death of their 11-year old son Gregory, at the hands of a young man with an untreated mental illness. They and other families know that New Jersey needs assisted outpatient treatment to keep those with an untreated mental illness who are too ill to know they need help from becoming trapped in a revolving door of short-term hospitalizations, incarcerations, victimization, and violence.

You only have to pick up a newspaper to confirm that such reform is long overdue. Newspaper accounts provide stark evidence of the tragedies resulting from New Jersey's outdated law. Most other state laws allow for assisted outpatient treatment to reduce hospitalization, homelessness, arrests, incarceration, harmful behavior and victimization (42 other states already have assisted outpatient treatment laws). But in New Jersey, only individuals willing and able to access treatment voluntarily can get service in the community. The result is, unfortunately, all-too predictable…

Arrests reduced - But not in New Jersey

IN NEW YORK 83% fewer individuals were arrested (Kendra's Law statistics).

IN NORTH CAROLINA Arrests reduced by 74% (Duke Studies).

IN NEW JERSEY Elio Pintado had been committed to hospitals at least three times, but each time he stopped taking his medication his family had to wait until he became "dangerous." Pintado, 30, now faces 17 criminal charges stemming from a March 12, 2004 incident in which he is accused of holding two employees of a limousine company hostage in Roselle Park, NJ and claiming he had a bomb-rigged suitcase. After a 10-hour standoff, a SWAT team stormed the building and found there was no bomb. Pintado has bipolar disorder and was not taking medication. He had a prior history of minor offenses. After hearing of the hostage situation, a Chatham police officer who arrested Pintado for disorderly conduct in 2002 said he "wasn't surprised in the least. I could have forecast this." (*New York Times*, Mar. 13, 2004; *Star Ledger*, Mar. 13 and Nov. 9, 2004; *Bergen County Record*, Mar. 13, 2004; WNBC.com, Mar. 16, 2004)

Incarceration reduced - But not in New Jersey

IN NEW YORK 87% fewer individuals experienced incarceration (Kendra's Law statistics).

IN NEW JERSEY Miklos Nagy was in Passaic County Jail on January 15, 2002 when he suffered a heart attack and died at Paterson hospital. He had threatened suicide and was put in restraints after a manic episode a few days before his death. Nagy had been incarcerated since the previous Thursday, when police arrested him for allegedly attacking his mother with pepper spray. Nagy's mother said her son had suffered from manic depression for years, and had a history of medication non-adherence. Nagy's mother said that despite the attack, she begged officials not to incarcerate him. "I told the police, 'He's a sick man. He needs hospitalization, not jail," she said. (*The Record*, Jan. 17, 2002.)

Homelessness reduced - But not in New Jersey

IN NEW YORK 74% fewer individuals experienced episodes of homelessness (Kendra's Law statistics).

IN NEW JERSEY As many as 11,000 people in New Jersey who suffer from mental illness are homeless, according to estimates by the Department of Human Services. The quality of life for the mentally ill homeless is abysmal. Valerie Fox, who has schizophrenia and spent two years in the 1980s living on the streets, said she wished someone had forced her to get back on her medication. "There was absolutely no good reason for me to be out there, except for the mental illness. I have license to say this, because I've lived it," Fox said. (*Asbury Park Press*, July 24, 2000, *Star Ledger*, Oct. 26, 2004).

Violent episodes reduced - But not in New Jersey

IN NEW YORK 47% fewer recipients physically harmed others (Kendra's Law statistics).

IN NORTH CAROLINA Violence reduced up to 50% (Duke Studies).

IN NEW JERSEY On October 17, 2002, Ronald Pituch, 27, bludgeoned his 56-year-old mother to death because she refused to buy him a pack of cigarettes. He then tied up his niece and assaulted an elderly woman he passed in his neighborhood. He later encountered 11-year old Gregory Katsnelson on his bike and stabbed him with a kitchen knife. Gregory's body was found in a shallow pond near the bike trail behind his Evesham, NJ home. Pituch was not taking medication for schizophrenia and had become so verbally abusive in the weeks prior to the attacks that his family wanted to have him "committed in some way to a mental-health facility." Family members say mental-health professionals assured them that Pituch was not homicidal or suicidal. Family members also said Pituch denied he was sick. (*Courier-Post* Oct. 21, 2002 & Sept. 28, 2003; *Philadelphia Inquirer*, Nov. 13, 2002 & Dec. 7, 2002, *Burlington County Times*, Oct. 14, 2003).

Threats of harm to others reduced - But not in New Jersey

IN NEW YORK 43% fewer individuals made threats of physical harm to others (Kendra's Law Statistics).

IN NEW JERSEY On October 10, 2004, a 34-year-mentally ill lunged at a Mount Olive, NJ police officer with a knife and was killed while his father screamed, "Don't shoot him!" The shooting occurred moments after 72-year-old Sumandor Alli had called 911, just as he had done before whenever his son, Gregory, stopped taking his medication and acted out. This time, Alli had turned violent, stabbing his father with a blunt knife. When the patrolman arrived at the Budd Lake home, Alli charged at him, waving a knife and ignoring the officer's demands to drop it. The officer then fired three shots, killing Alli. Police had been called to the house before because of his erratic behavior. Sumandor Alli said his son was diagnosed with schizophrenia at age 18. The month before his death, police had taken Gregory Alli to Saint Clare's Hospital for treatment. (*Newark Star-Ledger, October 11, 2004; Mt. Olive Chronicle, October 13 & 20, 2004*)

Medication adherence improved – But not in New Jersey

IN NEW YORK Individuals exhibiting good adherence to medication increased by 51% (Kendra's Law Statistics)

IN NEW JERSEY In May 2004, Edward Herringer, who lived in a supervised residence for people with mental illnesses in Ewing, NJ, had been off his medication and displaying symptoms for three weeks when neighbors called police because he was speaking incoherently and threatening suicide. When police arrived, he lunged at a police officer with a kitchen knife and mentioned a hand grenade. Dozens of police officers, including the New Jersey State Police SWAT Team, responded to what became a seven-hour standoff. Police evacuated about two-dozen homes in the neighborhood. No one was seriously hurt. (*Trentonian*, May 7, 2004)

Victimization reduced – But not in New Jersey

IN NORTH CAROLINA Victimization reduced 43% (Duke Studies).

IN NEW JERSEY In January 2004, 65-year-old Joel Seidel, who had a long history of mental illness, was stomped to death by a cellmate in the Camden County jail's mental health wing. His assailant, Marvin Lister, 35, an inmate with a long history of mental illness and violence, had also savagely beat another man with mental illness in 1993, while in the jail's psychiatric unit. When Mr. Seidel was released from psychiatric institutions, he refused to take his medication. Seidel's family decided against paying the $150 bond, hoping he would receive treatment while incarcerated. (*Philadelphia Inquirer*, Feb. 21, 2004; *Courier-Post*, Feb. 19 & 21, Mar. 21, 2004.)

Treatment Advocacy Center Briefing Paper

Anosognosia (impaired awareness of illness): A major problem for individuals with schizophrenia and bipolar disorder

SUMMARY: Anosognosia is the single largest reason why individuals with schizophrenia and bipolar disorder do not take their medications. This impaired awareness of illness is caused by damage to specific parts of the brain, and affects approximately 50 percent of individuals with schizophrenia and 40 percent of individuals with bipolar disorder. Medications can improve awareness in some patients.

* * *

What is impaired awareness of illness?

People with impaired awareness of illness may not recognize that they are ill. Instead, they believe their delusions are real (e.g., the woman across the street is being paid by the CIA to spy on him) and that their hallucinations are real (e.g., the voices are instructions being sent by the President). Impaired awareness of illness is the same thing as lack of insight. The term used by neurologists is "anosognosia," which comes from the Greek word for disease (nosos) and knowledge (gnosis). It literally means "to not know a disease."

How big a problem is it?

Many studies of individuals with schizophrenia report that approximately half of them have moderate or severe impairment in their awareness of illness. Studies suggest that approximately 40 percent of individuals with bipolar disorder have impaired awareness of illness; this is especially true if the person also has delusions and/or hallucinations.[1, 2]

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

Impaired awareness of illness has been known for hundreds of years. In 1604 in his play "The Honest Whore," Thomas Dekker has a character say: "That proves you mad because you know it not." Among neurologists, unawareness of illness is well known since it also occurs in some individuals with strokes, brain tumors, Alzheimer's disease, and Huntington's disease. The term "anosognosia" was first used by a French neurologist in 1914. However in psychiatry impaired awareness of illness has only become widely discussed since the late 1980s.[3]

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

No. Denial is a psychological mechanism that we all use, more or less. Impaired awareness of illness, on the other hand, has a biological basis and is caused by damage to the brain, especially the right brain hemisphere. The specific brain areas that appear to be most involved are the frontal lobe and part of the parietal lobe.[4, 5]

Can a person be partially aware of their illness?

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

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

Studies suggest that approximately one-third of individuals with schizophrenia improve in awareness of their illness when they take antipsychotic medication. Studies also suggest that a larger percentage of individuals with bipolar disorder improve on medication.[6]

Why is impaired awareness of illness important?

Impaired awareness of illness is the single biggest reason why individuals with schizophrenia and bipolar disorder do not take medication. They do not believe they are sick, so why should they? Without medication, the person's symptoms become worse. This often makes them more vulnerable to being victimized and committing suicide. It also often leads to rehospitalization, homelessness, being incarcerated in jail or prison, and violent acts against others because of the untreated symptoms.[7, 8, 9]

It is difficult to understand how a person who is sick would not know it.

Impaired awareness of illness is very difficult for other people to comprehend. A person's psychiatric symptoms seem so obvious that it's hard to believe the person is not aware he or she is ill. Oliver Sacks, in his book *The Man Who Mistook His Wife for a Hat*, noted this problem: "It is not only difficult, it is impossible for patients with certain right-hemisphere syndromes to know their own problems... And it is singularly difficult, for even the most sensitive observer, to picture the inner state, the 'situation' of such patients, for this is almost unimaginably remote from anything he himself has ever known."

ENDNOTES

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