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To: Senate Health Committee

From: John Monahan, President & CEO

Date: September 27, 2005

Re: Testimony in Support of S-2760

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Enclosed is my testimony in support of S-2760 that I was unable to provide directly yesterday. In addition to the attached, I would like to add the following:

(1) Personal Experience with IOC in Texas – My Sister, who has had a serious mental illness, was the beneficiary of involuntary outpatient commitment (IOC) when she lived in Texas. Within a week of her divorce from her physician husband, she went from living in an upper class Houston neighborhood to poverty and the Salvation Army shelter. All her money was lost on a futile legal battle to win custody of her daughter, while she was psychotic. When symptomatic and refusing medication, my sister does not think she is ill.

She continued to refuse medication, was hospitalized against her will, and, fortunately, ***placed by the Texas Mental Health System on IOC*** upon discharge. For the next seven years she lived with my mother in New Jersey, ***voluntarily continued her treatment*** for schizophrenia, got her teaching credential with straight A's, and was substitute teaching. She was doing so well that no one anticipated her refusal to continue medication. She soon returned to symptoms that afflicted her in Texas, and quickly became unreachable. Because New Jersey did not have IOC, she did not have the support for recovery that she had found in Texas. Instead, she received "support" from her Public Defender and others for her "right to refuse treatment". She was discharged from a county psychiatric hospital to Boston, where she spent the next seven years poor, on the street, actively psychotic, living in homeless shelters, and subject to victimization and assault.

We have very sketchy information about her. Since moving to Boston, she has refused both medication and contact with my family, except for periodic calls to my 92 year old mother from the depths of her psychosis. No one in Boston will provide any information about her due to confidentiality laws. Although a devout Catholic, she was not allowed in the local Catholic Church because of her symptoms and appearance. The only people who looked after her in Boston were members of a Black Pentecostal Church, who presumably were the ones who helped her get the subsidized room, where she currently lives and from which she is soon to be evicted. Some might say her "civil liberties" were protected by the New Jersey mental health system, but I would not wish such "protection" on any person with mental illness or their family.

(2) Time to End the Suffering – There will never be agreement on IOC. Some consumers, who are already in treatment and are not the focus of IOC, oppose IOC on principle. They want the right to refuse treatment even if they will never exercise that right. Other consumers take a more pragmatic stance, and see it as an option that saves lives. In many states, IOC is a catalyst that helps many with mental illness enter voluntary recovery. It's time to give those who need such a catalyst the same second chance that Texas granted to my sister, but New Jersey denied her.

Promoting Voluntary Recovery

through Involuntary Outpatient Commitment

Testimony to
New Jersey Senate
Health, Human Services & Senior Citizens Committee

September 26, 2005

Contact Information: **John Monahan, LCSW**
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My name is **John Monahan.** I am the President and CEO of **Greater Trenton Behavioral Healthcare**. I have **4 documents** for you: (1) an outline of why Involuntary Outpatient Commitment (IOC) is needed; (2) my testimony provided at the last hearing showing how IOC will promote voluntary recovery for those refusing treatment in a much safer and less traumatic manner than current practice; (3) the New York State Report on implementing IOC, showing dramatic improvements in outcomes.; and (4) the rest of this page – highlighting NY Outcomes and recommending improvements to S-2760.

Dramatic Improvements in NY State Outcomes Due to IOC

By intervening before the individual sinks to the depths of his/her illness, IOC will improve the prognosis for recovery, and prevent high-cost hospitalizations, arrests, incarcerations and homelessness. The results in New York State are dramatic:

Changes in Incidence of Significant Events for Persons Under AOT* (Percent of all AOT Recipients)

	Prior to Onset of a Court Order	During AOT	**% Improvement**
Psychiatric Hospitalization	87%	20%	77%
Homelessness	21%	3%	85%
Arrests	30%	5%	83%
Incarcerations	21%	3%	85%

Source of data: Assisted Outpatient Treatment Report, Kendra's Law, March 2005 http://www.omh.state.ny.us/omhweb/Kendra_web/finalreport/)
***AOT = Assisted Outpatient Treatment = Involuntary Outpatient Commitment**

Recommended Improvements to S-2760

1. Family Involvement – The bill should authorize the presumptive involvement of family and/or significant others in treatment planning, unless the consumer specifically states that he does not want them involved.

2. Clarify the Expansion of the Current Standard – The current standard for involuntary hospitalization is "danger to self or others in the reasonably foreseeable future". Current practice by screening centers, however, in most communities is imminent dangerousness. The language of the bill should clarify: (1) "reasonably foreseeable future" as the unitary standard in multiple sections of the bill for both involuntary hospitalization and involuntary outpatient treatment; and (2) specify the conditions and due process requirements for moving clients between levels of care.

3. Clarify Role of Screening Centers & Courts – The bill should specify that consumers who do not comply with the court order for outpatient treatment should be brought to the screening center in their community for re-evaluation of clinical status and disposition. All orders and/or changes to orders for involuntary outpatient treatment should mirror the due process requirements for court review and hearings currently in place for involuntary inpatient treatment.

Why We Need involuntary Outpatient Commitment (IOC)

A. Need for timely treatment for people with mental illness who
   - need treatment to avert harm to themselves or others or
   - who cannot care for themselves/make treatment decisions;

B. Current Law on Court-ordered Treatment
   - only authorized when a person becomes dangerous
   - only provided in most restrictive setting

C. Consequences of Current Law: Untreated mental illness leads to
   - exacerbation of illness
   - unnecessary hospitalizations that could have been prevented
   - psychotic behavior – criminal behavior – incarceration
   - homelessness and victimization on the streets
   - family cut-offs and loss of community ties
   - much worsened prognosis: more intense and costly treatment;
   - diversion of vast resources into inpatient care
   - impoverishment of continuing care systems leading to
     - overwhelmed community mental health agencies
     - acute care versus rehabilitation focus
     - limited services: housing, case management, employment, etc
     - low salaries causing labor market crisis
   - impoverishment of state psychiatric hospital system
     - overcrowding, limited staffing and treatment
     - premature discharge into community leading to
       - predictable failure in the community and readmission
   - revolving door between hospitals, prisons and the street
   - underserving of lower risk clients
     - parents at risk of abuse or neglect
     - individuals/parents transitioning off welfare
     - people with serious, debilitating but non-dangerous disorders
       - 8 – 12 week wait for medication appointment
   - violent offenses committed by untreated persons with mental illness
     - victimizing both the now imprisoned perpetrator and the victim
     - media coverage linking violence and mental illness
     - stigmatizing as violent all persons with mental illness
       - leading to discrimination and societal neglect
   - symptomatic clients disempowered leaving them with
     - lesser voice in treatment decisions
     - reinforcing power differential between consumer/provider

III. <u>What About Civil Liberties?</u>

A. Whose civil liberties are currently being protected?
   - Those with untreated mental illness now in prison? Their families?
   - Their victims' families? Those homeless, victimized, or worse?
   - Those with treated mental illness who want the option to refuse meds?
     - this option to be exercised when?

B. Civil liberties, as currently defined, sacrifices too many for too little reward.

Promoting Recovery Through Involuntary Outpatient Commitment

My name is John Monahan. I am the President and CEO of Greater Trenton Behavioral Healthcare. We provide services to people with serious mental illness and their families. Many of our clients become hospitalized or incarcerated because of symptom-induced behavior caused by their refusal of treatment. My testimony focuses on how Involuntary Outpatient Commitment (IOC) will benefit these consumers and their families.

The overwhelming support of families for IOC is understandable. Sixty per cent of those leaving public psychiatric hospitals are discharged to families. Families often shoulder an unfair and at times dangerous burden, when we expect them to provide shelter to a family member who refuses treatment. Such families see IOC as long over-due.

The benefit to consumers is also clear. Though some consumers oppose IOC, the vast majority of those opposing do not even meet IOC's eligibility criteria. They are too healthy. IOC focuses on much more ill, high-risk consumers.

Limited Focus of the Proposed IOC Legislation

The proposed IOC legislation targets a very tiny segment of those with serious mental illness in New Jersey – approximately 400 persons or .1% of the roughly 400,000 with schizophrenia, bi-polar disorder or major depression. But, though very small, this group consumes a vastly disproportionate share of public mental health resources, primarily in the form of high cost emergency and inpatient care. They also pose the greatest danger to themselves, to their families, and to the community.

Some argue that if the state would provide more funding for services, there would be

no need for IOC. I agree there is a need for more services. But, even if we had twice as many services as we need, the vast majority of those targeted for IOC would still refuse treatment. Why? Because these high-risk consumers are so ill with an untreated brain disorder that distorts their perceptions and judgment, they do not recognize they are ill.

Prevents Trauma of Hospitalization

The IOC target population is already in crisis, and based on repeated history, is headed toward involuntary hospitalization or incarceration in the "reasonably foreseeable future". By then, they will be beyond reach, sunk to the depths of their illness, terrified and a danger to themselves or others. Once institutionalized, they will be physically controlled in ways that are traumatizing to those who are ill. They will also be required to take medication against their will, just like under IOC, but the outcomes and the prognosis will be far worse.

By intervening before high-risk consumers reach the point of dangerousness, as the IOC legislation proposes, they will be spared an ordeal that both those in favor and those opposed to IOC agree is horrible and traumatizing. By comparison, IOC provides a much less intrusive intervention than what lies ahead of them. It also sets the stage for recovery.

Promotes Voluntary Recovery

There are two routes into recovery for those with serious mental illness. Most enter treatment voluntarily. Before treatment, they see how symptom-induced behavior could cause them to lose what they hold dear at home, at work or at school. They also watch their health begin to deteriorate. They enter recovery to avoid these losses.

It would be wonderful if the 400 people targeted by IOC were less impaired and could perceive the losses caused by their illness. But they cannot. The normal way into recovery is not an option for them. Those who do enter recovery, do so by a very different and much more difficult route, based on having their liberty wrested from them, again and again, through numerous hospitalizations and incarcerations over many years. By the time they're ready for voluntary treatment, their minds and bodies have been so chronically stressed from all their past crises and institutionalizations that a very steep and difficult road lies ahead of them. But, they are the lucky ones. Others never make it.

Because IOC intervenes before high risk consumers become so ill they are dangerous, they respond more quickly to medication and treatment than when institutionalized and in the depths of their illness. If we replace multiple episodes of institutionalization with multiple episodes of IOC, high risk consumers will have a much safer route into recovery than current practice. As they gradually learn about how mental illness affects them, and gradually learn to feel more in control of their symptoms, recovery becomes an option.

IOC also has a "multiplier effect" that supports recovery. Its mere presence vastly improves the ability of case managers to persuade consumers to remain in recovery. This allows IOC to be used only as a last resort that targets very small numbers, but with an
impact that extends far beyond those who require it to remain safe.
The question is not whether IOC is a good or bad thing for consumers in general, but is it a better or worse way to help *specific* consumers with *specific* needs than what is currently available. When New York State implemented a version of IOC, it reported dramatic reductions in homelessness, incarceration, involuntary hospitalization, violent and suicidal behavior, etc. We owe it to those in danger and to their families to implement IOC now.

New York State Outcomes for AOT Recipients

AOT was designed to ensure supervision and treatment for individuals who, without such supervision and treatment, would likely be unable to take responsibility for their own care and would be unable to live successfully in the community. For persons under AOT the goal is to increase access to the highest intensity services and to better engage them in those services. An additional goal is to reduce the incidence of behaviors harmful to themselves or others. Participation in AOT should result in improved adherence with prescribed medication and decreased hospitalization, homelessness, arrests and incarceration. In addition, individuals under AOT should bene fit through improved functioning in important community and personal activities.

Table 4
Services Received by Persons Under AOT in New York State
Rates Prior to AOT and While Enrolled in AOT

	Percentage of Persons Under AOT	
Service	Prior to AOT	While Enrolled in AOT
Case Management	52%	100%
Medication Management	63%	94%
Individual or Group Therapy	51%	75%
Day or Partial Hospitalization	15%	35%
Substance Abuse Services	26%	52%
Housing and/or Housing Support Services	23%	41%
Urine or Blood Toxicology (adherence to medication)	17%	27%
Urine or Blood Toxicology (substance abuse)	16%	25%
Other	4%	9%

Increased Participation in Case Management and Other Services

Table 4 compares participation in services by AOT recipients prior to and subsequent to the court order. For all categories of service, a greater percentage of individuals are participating in the service while under court order than were receiving it prior to the court order. The most dramatic example is in the area of case management. As prescribed by the legislation, all individuals receiving a court order are enrolled in case management. However, prior to AOT, only 52% of these individuals were receiving this service.

In addition, the percentage of AOT individuals who are receiving substance abuse services doubled as a result of their court-ordered treatment plan, increasing from 26% to 52%. Similarly, the percentage of persons under AOT who receive housing services as a result of their court-ordered treatment plan nearly doubled, increasing from 23% to 41%. Substantial increases are also seen for urine or blood testing used to assess adherence to medication or substance abuse.

Reduced Incidence of Hospitalization, Homelessness, Arrest and Incarceration

After six months of participation in AOT, the incidence of hospitalization, homelessness, arrest and incarceration had all declined significantly from their pre-AOT levels. Table 5 summarizes change in the occurrence of these events.

Table 5
Changes in Incidence of Significant Events for Persons Under AOT
(Percent of all AOT Recipients)

	Prior to Onset of a Court Order	During AOT
Psychiatric Hospitalization	87%	20%
Homelessness	21%	3%
Arrests	30%	5%
Incarcerations	21%	3%

Increased Engagement in Services and Adherence to Prescribed Medication

An important goal of AOT is increased engagement, i.e., active and regular participation in services; and increased adherence to prescribed medication, i.e., taking medications necessary to manage psychiatric symptoms as directed by the treating physician. To assess engagement, case managers were asked to rate the engagement of persons under AOT using a scale ranging from “not at all engaged in services” to “independently and appropriately uses services.” Data collected since the onset of AOT show the percent of individuals who exhibit poor engagement dropped significantly from 59% to 34% at six months.

To assess medication adherence, case managers were asked to rate adherence of persons under AOT using a scale ranging from “taking medication exactly as prescribed” to “rarely or never taking medication as prescribed.” The resulting data show that the percent of individuals with poor medication adherence dropped significantly from 67% to 22% after six months. Figure 3 displays the improvement in engagement in services and medication adherence after six months of AOT participation.

Improved Community and Social Functioning

The evaluation database also documents changes in AOT recipients’ day-to-day functioning. Measures that are used for this assessment are the Global Assessment of Functioning (GAF) and three sets of items that assess individuals’ abilities in specific functional areas: self-care, social and community living skills, and task performance. The case manager serving the individual under AOT completes all functional assessment measures.

Figure 3

Changes in Service Engagement and Adherence to Medication

	At onset of court order	After 6 months receiving court-ordered services
Individuals exhibiting poor engagement	59%	34%

Individuals exhibiting poor adherence to medication	67%	22%

The GAF is a commonly used measure of overall functioning. It includes social, occupational, academic, and other areas of personal performance and results in an overall numerical rating score which can range from 0 to 100. A score of 50 or below denotes serious impairment in social, occupational or school functioning. At the onset of an AOT court order 38% of individuals had a GAF score below 50. After receiving services under an AOT court order for six months, the percentage of persons with a GAF score below 50 dropped to 31%.

AOT recipients' functioning in the area of self-care and community living also improved after six months of program participation. Figure 4 displays the change in these measures. The figure compares the percentage of persons under AOT who were reported as having difficulty at the onset of their court-ordered treatment with the percentage reported as having difficulty six months later. For all items, there were fewer individuals rated as having difficulty, and in 12 of the 13 measures the change was statistically significant.

In the area of social, interpersonal and family skills and task performance, similar improvements in functioning were seen. On all measures for these areas, the changes between the onset of the court order and at six months were statistically significant. Figures 5 and 6 display the social, interpersonal and family skills and task performance data.

Decreased Incidence of Harmful Behaviors

Case managers also reported reductions in the incidence of harmful behaviors for persons under AOT. All 11 harmful behaviors rated showed declines in the percentage of individuals for whom an occurrence was reported. The reductions in 10 out of 11 harmful behaviors were statistically significant. Figure 7 presents these data.

Figure 4
Improvement in Self Care and Community Living
(Percent of Persons Reported Having Severe Difficulty)

	Onset of AOT	Six Month Follow-Up
Manage Medication *	9%	5%
Follow Through on Health Care Advice *	11%	8%
Access and Use Available Transportation	8%	6%
Handle Personal Finances*	33%	19%
Shop for Food, Clothing, etc*	33%	20%
Access and Use Community Services*	44%	29%
Make and Keep Necessary Appointments*	18%	12%
Prepare/Obtain Own Meals*	16%	9%
Take Care of Own Possessions*	36%	25%
Take Care of Own Living Space*	17%	13%
Recognize and Avoid Common Dangers*	9%	6%
Maintain Adequate Personal Hygiene*	18%	14%
Maintain Adequate Diet*	29%	16%
*Statistically significant change		

Figure 5
Improvement in Social, Interpersonal and Family Functioning
(Percent of Persons Reported Having Severe Difficulty)

	Onset of AOT	Six Month Follow-Up
Effectively Handle Conflicts *	15%	11%
Engage in Social and/or Family Activities*	36%	19%
Manage Assertiveness Effectively*	23%	16%
Form and Maintain a Social Network*	43%	35%
Manage Leisure Time to Personal Satisfaction*	39%	25%
Respond to Other's Initiation of Social Contact*	56%	35%
Ask for Help When Needed*	48%	30%
Communicate Clearly*	26%	21%

*Statistically significant change

Figure 6
Improvement in Task Performance
(Percent of Persons Reported Having Severe Difficulty)

	Onset of AOT	Six Month Follow-Up
Perform within a Schedule, Maintain Regular Attendance*	23%	15%
Perform in Coordination with or in Close Proximity to Others*	31%	21%
Sustain an Ordinary Routine*	39%	28%
Maintain Attention and Concentration Spans*	35%	22%
Complete Task without Assistance*	40%	27%
Perform at a Consistent Pace Without Unreasonable Rest Periods*	32%	23%
Complete Task without Errors*	31%	23%
Understand and Remember Instructions*	33%	23%

*Statistically significant change

In summary, individuals receiving AOT court orders showed improved functioning in the areas of self care, community living, interpersonal functioning and task performance during the first six months of court-ordered treatment. Incidence of psychiatric hospitalization, homelessness, arrests and incarceration decreased from pre-AOT levels. Statistically significant reductions also occurred in harmful behaviors such as substance abuse, suicide attempts, and physical harm to self.

Figure 7
Improvement in Incidence of Harmful Behaviors
(Percent of Persons for Which One or More Events in the Past 90 Days is Reported)

	Onset of AOT	Six Month Follow-Up
Express Suicide Threat*	33%	26%
Make Suicide Attempt*	32%	27%
Do physical Harm to Self*	20%	11%
Damage or Destroy Property*	35%	20%
Take Property without Permission*	40%	23%
Do Physical Harm to Others*	32%	18%
Abuse Alcohol*	19%	11%
Abuse Drugs*	13%	10%
Make Threat of Physical Violence to Others*	11%	7%
Verbally Assault Others*	16%	9%
Create Public Disturbances*	19%	13%
*Statistically significant change		

Source: Assisted Outpatient Treatment Report, Kendra's Law, March 2005 http://www.omh.state.ny.us/omhweb/Kendra_web/finalreport/)