

WORK GROUP # 2 - CONTINUUM OF CARE

Joint Subcommittee to Study Mental Health Services in the Commonwealth in the 21st Century

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Thursday, September 24, 2015, 9:00 am

Suffolk City Hall

442 W. Washington Street, Suffolk, Virginia

- I. Introductions and Opening Remarks**
- II. PRESENTATION: Mandatory Outpatient Treatment** - Brian Stetting, Policy Director, Treatment Advocacy Center
- III. Discussion**
- IV. Adjourn**

An Advocate's Observations on Research Concerning Assisted Outpatient Treatment

Brian Stettin

Current Psychiatry Reports

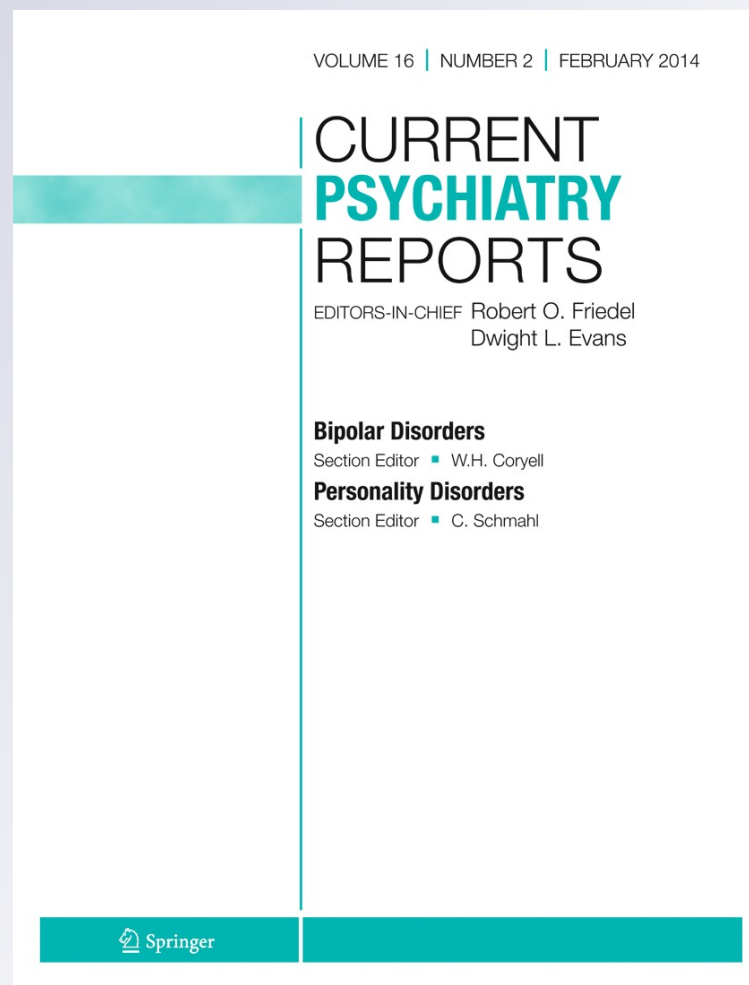
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An Advocate's Observations on Research Concerning Assisted Outpatient Treatment

Brian Stettin

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Introduction

“Assisted outpatient treatment” (AOT) is a practice designed to improve treatment outcomes for people with severe mental illness whose difficulties adhering to voluntary outpatient care have left them trapped in the revolving door of the mental health and criminal justice systems. Under AOT, an individual found to meet strict eligibility criteria is placed under court order to comply with an approved treatment plan as a condition of remaining in the community and receives intensive case management and monitoring. A patient's substantial violation of the court order typically leads to short-term evaluative detention to determine whether hospital commitment has become necessary.

In my work for the Treatment Advocacy Center promoting AOT across the United States, I am often puzzled by the wide gulf between the perceptions of AOT among intelligent and dedicated mental health professionals and the findings of researchers on the effectiveness of AOT in improving treatment outcomes for the most challenging subset of psychiatric patients. The research is good enough to lead one to expect a near-universal embrace of AOT within the mental health field, and yet this is hardly the case. While 45 states and the District of Columbia have laws authorizing local mental health systems to practice AOT, implementation of these laws remains spotty in all but a few. Many professionals I encounter seem to have absorbed anti-AOT messages emanating from various mental-health consumer organizations who reflexively oppose any infringement on patient autonomy.

Among these messages are patently false claims that the research on AOT is “mixed or inconclusive,” or that the research only suggests AOT might be worthwhile in an exceedingly well-funded system of community-based care. In this article, I hope to set straight the record on the AOT research by summarizing the mountain of positive data, placing the purportedly inconclusive or negative findings in a more intellectually honest context, and putting to rest the pervasive myth that impressive results achieved in New York are rooted in anomalies of that state.

Studies of New York's Kendra's Law

2003/2005 OMH Reports

When New York enacted its landmark AOT law known as “Kendra's Law” in 1999, lawmakers sought to quell swirling controversy and the dire predictions of opponents by attaching a “sunset” provision, providing that the new law would expire on June 30, 2005 if not re-enacted before then. To guide the future determination of the law's fate, counties were directed to report to the state Office of Mental Health (OMH) certain data relating to their frequency and results in utilizing AOT, and OMH was directed to compile and analyze this and other independently-gathered data in a 2003 “interim report” [1] and a 2005 “final report” [2] to the legislature.

Upon their respective releases, these reports delighted Kendra's Law supporters and annoyed the doomsayers. In addition to offering a wealth of fascinating data on the demographics of AOT patients and the use that counties were making of the new law, the OMH report provided the first glimpse into the law's effectiveness in improving access to and engagement with treatment for the most challenging patients in the public mental health system, reducing harmful behaviors, and enhancing public safety. Across the

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board, the findings were extraordinarily positive. Among the highlights:

- The most troubling consequences of non-treatment decreased dramatically during the time that patients spent under AOT, as compared to each patient's three-year period prior to AOT initiation. This included an 87 % decline in incarceration, an 83 % decline in arrests, a 77 % decline in psychiatric hospitalization, and a 74 % decline in homelessness.
- AOT led to dramatic increases in participation in critical services, including an 89 % increase in receipt of case management, a 47 % increase in receipt of medication management services, and a 63 % increase in receipt of housing or housing support over the first six months of AOT.
- The percentage of individuals demonstrating good or excellent adherence to medication more than doubled, from 34 % at onset of court order to 69 % after six months of AOT.
- Face-to-face interviews with AOT recipients revealed that most patients saw AOT as a positive factor in their lives. While about half reported feeling angry and embarrassed when first placed under AOT, 62 % of the AOT recipients interviewed agreed that, all things considered, AOT had been good for them.

In light of these and other findings, the OMH report recommended that Kendra's Law be reauthorized permanently in 2005, noting that "[f]or the people who have benefited from participation in services mandated under an AOT order – individuals who, without Kendra's Law, had limited experience of success in using mental health services – these positive outcomes are more than statistics; they are tangible evidence that the system of care has been responsive to their needs."

2009 Independent Evaluation

In 2005, the opponents of Kendra's Law recognized that lawmakers were unlikely to allow Kendra's Law to expire in the wake of the stellar OMH report and opted instead to seek another sunset and study.

First, it was argued that OMH's reported findings were inherently suspect, since the agency had a political interest in seeing a program supported by New York Governor George Pataki judged successful. The opponents called for a new study to be conducted by an independent research organization with no stake in any particular outcome.

Second, opponents noted that the OMH report shed no light on *why* AOT patients saw such dramatic improvements in treatment outcomes. It was, after all, undeniable that AOT led to better coordination of care and case management and a higher quality of outpatient services. From the beginning, opponents had argued that better care could be delivered just

as effectively to the AOT-targeted population on a voluntary basis. From their perspective, the positive results were entirely attributable to the improvements in service quality, and might even have been better without "coercion" interfering with the bond of trust between patient and caregiver. And in truth, there was nothing in the OMH report to prove them wrong (or, for that matter, right).

In deference to these concerns and others, in 2005 Kendra's Law was renewed with a June 2010 sunset date. The reauthorizing legislation directed OMH to contract with an independent research organization to conduct a new "external evaluation" of the effectiveness and impacts of Kendra's Law. Among the many issues ordered to be addressed in the study were "the outcomes for people with mental illness who receive enhanced outpatient services and for those people who are mandated into outpatient treatment."

The contract to conduct the new study was awarded the following year to a team of researchers led by Marvin Swartz and Jeffrey Swanson of Duke University School of Medicine. In June 2009, the team submitted its "New York State Assisted Outpatient Treatment Program Evaluation" – by far the most multi-faceted, exhaustive and well-known AOT study to ever appear [3]. (The various components of the report were later separated into a collection of more detailed articles published in the October 2010 issue of *Psychiatric Services*) [4–9].

Most critically, the external evaluation confirmed and expanded upon the earlier OMH findings on the effectiveness of New York's AOT program in improving treatment outcomes, improving service engagement and averting harmful behaviors among its target population. Among the findings:

- During a six-month study period, AOT recipients were hospitalized at less than half the rate they were hospitalized in the six months prior to receiving AOT. Among those admitted, average length of hospitalization dropped from 18 days prior to AOT to 11 days during the first six months of AOT and 10 days for the seventh through twelfth months of AOT.
- Receipt of intensive case management services jumped dramatically under AOT, from 11 % in the pre-AOT period to 28 % in the first six months and 33 % during the 7-12 month period. Receipt of *any* case management services (not necessarily intensive) increased from 18 % in the pre-AOT period to 44 % in the first six months and 53 % during the 7-12 month period.
- Medication receipt (defined as having a filled prescription for an appropriate medication and having a sufficient supply during at least 80 % of days in a given month) increased from 35 % in the pre-AOT period to 44 % in the first six months and 50 % during the 7-12 month period.

Assessing the role of involuntariness in achieving good results under AOT presented a challenge for the research

team. The classic empirical method to test the question would be to create a randomized controlled trial with two groups of AOT-eligible outpatients, one group placed under AOT court orders and the other group permitted to decide individually whether to receive or reject the treatment offered. But in practice, there are obvious ethical barriers to setting up such a trial. Few psychiatrists would be comfortable having a patient with schizophrenia who does not believe he has an illness – with a long history of incarcerations and hospitalizations resulting from treatment non-adherence – join the control group and lose any possibility of benefiting from the “black robe effect” of an AOT order.

But if a definitive study on the value of involuntariness in AOT was not to be, a regional difference in the use of the law still made it possible for the New York evaluation team to address the question. The researchers discovered that in New York City, the general practice was to petition for AOT automatically upon determining that a patient about to be discharged from a hospital met AOT criteria. In upstate counties, the practice tended to be quite different. There, patients deemed court order-eligible by their doctors were approached and asked to agree to participate in AOT voluntarily, with the understanding that, if they refused, the county would pursue a court order and almost certainly prevail in obtaining one. Most patients accepted the opportunity to avoid court proceedings, meaning that, unlike their New York City counterparts, most of the upstate AOT patients were not actually under court order to adhere to treatment.

This dichotomy presented the researchers with an opportunity to compare a large number of patients under court order to adhere to treatment with a large number of comparable patients who were not. It was acknowledged that the upstate patients were not truly “voluntary” participants in the program, since their cooperation was secured through application of leverage. But, if anything, that fact would only make it *less* likely that researchers would find differences in outcomes between the groups.

And yet even in this imperfect comparison, there were several measures by which the court-ordered patients were found more successful and no measures by which the quasi-voluntary patients were more successful. To be sure, patients in both groups were found to benefit greatly from enhancements in service quality and care coordination. But beyond that baseline, the researchers found that the court-ordered patients were less likely to be hospital-admitted during AOT by a “highly statistically significant” margin, less likely to be arrested, and showed a substantially higher level of personal engagement in their treatment. These findings led the study team to conclude: “The increased services available under AOT clearly improve recipient outcomes. However, the AOT court order, itself, and its monitoring do appear to offer additional benefits in improving outcomes.”

More Recent Studies of Kendra’s Law

Since the release of the 2009 independent evaluation of Kendra’s Law, more studies have continued to advance our understanding of the impact of AOT in New York.

In 2010, a research team led by faculty of Columbia University’s Mailman School of Public Health published striking findings on the contribution of Kendra’s Law to public safety [10]. Over a three-year period, 76 New York City AOT patients were compared with a control group of mentally ill outpatients enrolled in the same clinics who did not meet criteria for AOT due to insufficient history of treatment non-adherence leading to violence or repeated hospitalizations. Tracking these patients in the community, the researchers found the AOT patients — despite being *more* violent than the control group historically — were four times *less* likely than control group patients to commit acts of serious violence.

In 2013, Jeffrey Swanson of Duke Medical School led a team of researchers in delving into administrative, budgetary and service cost data collected in the course of the 2009 independent evaluation of Kendra’s Law to answer a critical question not previously examined: does AOT result in cost savings to public mental health systems [11]? The recent study published in the *American Journal of Psychiatry* found that service costs for frequently hospitalized patients with severe mental illness declined 43 % in New York City in the first year participants received AOT after hospital release and an additional 13 % the second year. In a studied group of five counties outside New York City, the savings were even greater: 49 % in year one and an additional 27 % in year two. These findings led researchers to conclude that “[a]ssisted outpatient treatment requires a substantial investment of state resources but can reduce overall service costs for persons with serious mental illness.”

Pre-Kendra’s Law Studies of AOT

While the Kendra’s Law studies have understandably dominated academic discourse on AOT over the last decade, it is worth keeping in mind that a good number of studies of AOT were released prior to New York’s deep plunge into AOT. A few examples:

- A study performed in Tucson, Arizona, published in *Hospital and Community Psychiatry* in 1988, compared a group of AOT patients committed just after the enactment of Arizona’s AOT law in 1983 with a comparable group that received outpatient treatment just before the law became effective [12]. In addition to shorter inpatient stays for the AOT group, the study found that 71 percent of AOT patients voluntarily maintained treatment contacts

six months after their orders expired, compared with “almost none” in the non-AOT sample.

- A study performed in Summit County (Akron), Ohio, published in *Psychiatric Services* in 1996, reported that during the first 12 months of AOT, patients experienced significant reductions in psychiatric emergencies, hospital emergencies and length of stay compared to the 12 months prior to commitment [13].
- A randomized controlled trial performed in North Carolina, published in the *American Journal of Psychiatry* in 1999, initially revealed little difference in hospital admissions and total hospital days between the AOT and control groups [14]. However, when the results were refined by diagnosis and length of time under AOT, critical distinctions emerged. Among patients with nonaffective psychotic diagnoses, those under AOT experienced 72 % fewer hospital admissions and an average of 28 fewer hospital days. Moreover, patients who received AOT for more than 180 days were admitted to hospitals less than half as often as the control-group patients.

As with the more recent studies of Kendra’s Law, this earlier string of AOT studies is notable for its consensus in finding that AOT can markedly improve outcomes for people with severe mental illness who struggle with treatment adherence. The one study to sing a different tune – bringing us back again to New York – is perennially cited among AOT opponents and merits further scrutiny.

The Myth of “Mixed” or “Inconclusive” Results

1998 Bellevue Study

Claims that research has delivered a “mixed” or “inconclusive” verdict on AOT usually rely heavily on a single study concerning an AOT pilot program launched in 1995 at Bellevue Hospital in Manhattan [15]. The mandated external evaluation of the program was performed by Policy Research Associates and delivered to the state legislature and governor in December 1998. Comparing a group of AOT patients to a control group receiving treatment voluntarily, and with both groups receiving intensive, enhanced services, the study found “no significant statistical difference between the two groups on any outcome measure.” It concluded that “legal coercion may not play a significant role in keeping individuals in treatment.”

As a member of the team that drafted the original proposal of Kendra’s Law in January 1999 (serving at the time as an assistant New York State attorney general), I was certainly mindful of the Bellevue report released in the prior month. But before we allowed ourselves to dismiss the idea of expanding AOT statewide, we took a hard look at the structure of the

Bellevue pilot and asked whether the disappointing study results might be attributable to fatal flaws in the model employed. From our conversations with program staff, it quickly became clear the pilot had suffered greatly from its failure to attach any meaningful consequence to non-compliance with a court order.

To be clear, the point of AOT should *never* be to punish or sanction a patient for violating the terms of his or her court order. The pilot legislation stated explicitly that non-compliance would not be grounds for automatic hospital commitment or a finding of contempt of court, and we readily adopted that language into our draft of Kendra’s Law. But it is certainly important for non-compliance to have a consequence – typically, short-term detention of the patient to determine whether inpatient commitment has become necessary. (As many practitioners have explained to me, even if the non-adherent patient is found not to meet criteria for hospital commitment and must be released back into the community, the opportunity to bring him back into a clinical setting, remind him of his duty to the court, and identify the underlying issues that led to non-adherence is ordinarily enough to get the patient back on track.) To accomplish this, the AOT program must have a clear protocol for a treating physician to trigger detention and transportation of the patient by a peace officer or mobile crisis team.

In this regard, it is fair to say that the Bellevue AOT pilot program was an abject failure. The authorizing legislation required a treating doctor to seek approval to recall a patient from the hospital director and authorized only the New York City sheriff’s office to effectuate detention and transportation. As it turned out, these specifics led to enormous difficulties in establishing a workable procedure for responding to non-compliance, which were never fully resolved despite numerous interagency attempts. In a 1999 memorandum responding to the Bellevue study, Dr. Howard Telson, director of the AOT pilot, expressed his frustration [16]:

“It is important to note that during most of the [AOT] pilot, and throughout the entire study period, there has been no procedure in place to transport patients with outpatient commitment orders who are noncompliant and who may be dangerous, to the hospital for evaluation. The [clinical team] has continually received questions, comments and complaints about this issue. Some clinicians and family members stated that since the [AOT] did not have an operational enforcement mechanism, it had “no teeth” and its value was therefore limited. Although it was generally felt that the hospital transport procedure would rarely be used, many expressed the concern that the lack of the procedure very significantly affected the meaning of the court order to patients, judges and everyone else involved. It certainly made the experimental and control conditions

in the study seem much more similar than had originally been contemplated.”

In the drafting of Kendra’s Law, we were determined to avoid extending these difficulties across the state. Our legislation established a straightforward and flexible procedure for detaining non-compliant patients and obligated law enforcement officers to carry out detention directives. This led to much workable AOT programs than the one Dr. Telson oversaw.

It was far from the only lesson learned at Bellevue that we drew from in crafting Kendra’s Law. With the wealth of impressive studies we have today on the AOT law that replaced and corrected the flawed Bellevue model, the 1998 study has been rendered irrelevant.

2005 / 2010 Cochrane Review

And yet the ghost of Bellevue lives on – not only in direct citations to it, but also in the enormous role it plays in a 2005 literature review [17] (nominally updated in 2010 [18]) conducted by The Cochrane Collaboration, an esteemed non-profit organization that promotes evidence-based medical practice through its authoritative literature reviews. At first glance, the conclusion of the Cochrane reviewers seems devastating:

“Based on current evidence, community treatment orders may not be an effective alternative to standard care. It appears that compulsory community treatment results in no significant difference in service use, social functioning or quality of life compared with standard care. There is currently no evidence of cost effectiveness.”

To reconcile this conclusion with the body of research recounted here, it is helpful to understand a bit about the Cochrane ethos. The Cochrane Reviews are a series of studies utilizing *only* data that meets the highest scientific standards, i.e., trials in which patients are randomized to the active treatment or a control group. Randomized controlled studies are rarely done in non-pharmacological studies of psychiatric treatment because they are expensive, difficult, and arguably unethical, if there is clear evidence that the treatment being studied is effective. Thus, by definition, the Cochrane team had almost no AOT studies to examine. Studies in which patients were compared before and after being placed on AOT, for example, were excluded.

The authors begin by identifying 71 published papers on the efficacy of AOT. These were “subjected to strict quality and eligibility assessment” that eliminated 61 of the 71. The remaining 10 papers covered only two studies: the 1999 North Carolina study and the 1998 Bellevue pilot study.

Enough has already been said here about the questionable post-Kendra’s Law relevance of the Bellevue study. The North Carolina study, by contrast, clearly indicates value in AOT for

patients with psychotic disorders and for patients who receive it for longer than six months. Unfortunately, these valuable findings were lost in Cochrane’s rigid analysis. For one thing, Cochrane’s standard methodology reduces all study data to a binary outcome, i.e., something worked or it did not. Thus, a 40 percent improvement in outcome would be recorded as a failure. Even worse for the North Carolina study is that it was not possible to randomly assign patients on the basis of the total length of their court orders, as this could only be dictated by the application of statutory criteria. This made it impossible for the Cochrane reviewers to take account of the positive findings specific to patients who received AOT for more than six months.

In sum, the Cochrane Review of AOT studies should not be mistaken for a true appraisal of the vast body of peer-reviewed AOT research literature. Its relevance rests on the dubious premise that randomized controlled trials are the only useful means to assess the effectiveness of AOT.

The Myth of New York’s Extreme Spending

Since the release of the 2009 independent evaluation of Kendra’s Law, AOT opponents have sought to neutralize the positive findings by insisting they rest upon unique aspects of New York’s mental health system. We are told that the most critical component of Kendra’s Law was in fact an attached funding stream to bolster community-based care in New York generally and that other jurisdictions must be willing to replicate such efforts before they can even consider implementing AOT.

Those who make the argument invariably quote a paragraph of the 2009 New York report:

“The introduction of New York’s AOT Program was accompanied by a significant infusion of new service dollars and currently features more comprehensive implementation, infrastructure and oversight of the AOT process than any other comparable program in the United States. It is, therefore, a critical test of how a comprehensively implemented and well-funded program of assisted outpatient treatment can perform. However, because New York’s program design is unique, these evaluation findings may not generalize to other states, especially where new service dollars are not available. This report addresses whether AOT can be effective and under what circumstances, not whether it will always be effective wherever or however implemented.”

While the logic of this statement is unassailable, the same cannot be said of the conclusion that some would draw from it, i.e., that any thought of passing a state AOT law or launching a local AOT program must be held in abeyance until the

underlying system of community-based care is brought up to the level of resource that we all might wish it to reach.

There is no denying that most of the funding attached to Kendra's Law has gone to improve community-based systems of care across the state. But the characterizations I often hear of New York as a Shangri-La for outpatient services would surely shock mentally ill New Yorkers and their families, who struggle and scrape for their precious resources just like others across the U.S. While it is true that the state ranks near the top in mental health funding per-capita [19], this is mostly a function of how crushingly expensive it is to provide *anything* in New York. And those who look only at the dollar amount attached to Kendra's Law may not be giving adequate consideration to how far below average in outpatient resources New York was prior to 1999.

AOT cannot be used to paper over the defects of a local mental health system lacking the basic resources people with severe mental illness need to maintain safety and sanity. It is not a magical stone that turns a pot of water into nourishing soup to feed a village. What I believe research and experience tell us about AOT is that it adds value to whatever resources happen to be available in a community, by enhancing the likelihood that insight-deficient outpatients will avail themselves of those resources. If the resources offered are woefully inadequate, adding the value of AOT still won't provide enough. But if I had a severely mentally ill, insight-lacking family member stuck in a town where resources were fair-to-middling, I would certainly want AOT added to the mix. As the Kendra's Law researchers note, it probably wouldn't lead to results as good those achieved in New York. But there is every reason to think it would lead to better results than would be possible through fair-to-middling services alone, which my loved one would be free to avoid altogether.

The point here is not that we should consider abandoning the fight for ample, high-quality community-based services. We certainly should not. But it hardly serves the interests of people with severe mental illness to put the fight for AOT on hold until we reach the mental-health resource promised land. The research could not be more clear: AOT helps people who desperately need all the help they can get.

Compliance with Ethics Guidelines

Conflict of Interest Brian Stettin declares that this article advances the mission of the Treatment Advocacy Center, a non-profit organization by which he is employed.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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