Prepared Statement by
DJ Jaffe
Executive Director, Mental Illness Policy Org
to be delivered at a briefing by
Energy and Commerce Oversight and Investigations Subcommittee Majority Staff
on
Subcommittee's Investigation of Federal Programs Addressing Severe Mental Illness
Thursday May 29, 2014

My name is DJ Jaffe and in early 1980s my wife and I become guardian for my sister-in-law who has perhaps the most serious mental illness: schizophrenia. Trying to get care for her led me to see how horrible the mental health system is and led to 30 years of pro-bono service to organizations trying to improve carel[1].

Our position is consistent with the majority report. It differs from some in the SAMHSA funded mental health industry. The reason is, we are not mental health advocates or advocates for the highest functioning. We are advocates for the most seriously mentally ill, the ones most likely to become headlines. Not all mental illness is serious.[2] Twenty percent of adults over 18 have a diagnosable mental illness. But only 4% have a serious mental illness including the 1.1% with schizophrenia and the 2.2% with severe bipolar disorder.[3]

We have to stop ignoring these most seriously ill. Until the early 1960s virtually all mental health expenditures were spent on the most seriously ill in state psychiatric hospitals. Today federal dollars are instead spent improving the mental health of all citizens including people without any mental illness. As a result, 164,000 are homeless[4] and over 300,000 incarcerated[5, 6]. A disproportionate number are people of color.[7, 8] Parents who beg for treatment for adult children known to have serious mental illness can not get it. Meanwhile the system funds everything else.

We know how to help the most seriously ill. We have to prioritize federal spending. Send the seriously ill to the head of the line rather than jails shelters prisons and morgues. Replace mission creep with mission control. Reform HIPAA so parents can get the information about seriously mentally ill loved ones they need to help them. Create more hospital beds for the few who can not survive safely in the community, require SAMHSA to focus on serious mental illness[9] and PAIMI to stop working to prevent that[10].

We have to recognize that some seriously mentally ill are so sick, they don't know they are sick and therefore will not accept treatment that is offered to them. It's called anosognosia[11]. Perhaps most importantly, we need to expand the use of Assisted Outpatient Treatment. AOT is only used after voluntary treatment has failed.

AOT has been extensively studied and proven to work on the hardest to treat. It is only for a tiny subset who have accumulated multiple episodes of homelessness, hospitalization, arrest, incarceration or violence associated with going off treatment. After full due process including the right to an attorney, it allows judges to order them into six months of mandated and monitored community treatment. AOT reduces serious violence 66%. It reduced homelessness, arrest, hospitalization, and incarceration over 74% each[12] . Neither peer support nor Trauma informed care have been proven to do that. Consistent with the spirit of Olmstead AOT prevents the use of restrictive and inhumane inpatient commitment and incarceration. It saves taxpayers 50% of the cost of care.[13]

It is perhaps the most humane thing we can do. It provides an off-ramp before incarceration…a fence by the edge of a cliff, rather than an ambulance at the bottom.

The committee heard from police chiefs, sheriffs, judges, homeless advocates, parents and children of the most seriously ill in support of AOT. The only opposition comes from vocal SAMHSA funded groups who raise objections not based on the facts. AOT does not take away everyone's rights; allow force treatment or drive people from care. 80% of those enrolled said AOT helped them get well and stay well. It does not cause stigma. Those who received AOT felt less stigma than those who didn't.[14]

We have to stop ignoring the seriously ill. Police Chief Biasotti said it best when he told the committee[15]:

> *"We have two mental health systems today, serving two mutually exclusive populations: Community programs serve those who seek and accept treatment. Those who refuse, or are too sick to seek treatment voluntarily, become a law enforcement responsibility. …(M)ental health officials seem unwilling to recognize or take responsibility for this second more symptomatic group. Ignoring them puts patients, the public and police at risk"*

I thank the committee and Representative Murphy who introduced the Helping Families in Mental Health Crisis Act and especially my fellow Democrats who supported this bill. We Dems have too often and for too long been unwilling to admit unpleasant truths like not everyone recovers, sometimes hospitals are needed; and left untreated a small subset of the most seriously ill do become violent.

Pass HR 3717 so we can start moving from a system that requires tragedy, to one that prevents it.

I've attached to my statement a comparison of HR 3717 with HR 4574 and other fact sheets

---

[1] DJ Jaffe has served on the boards of directors for NAMI/Metro NYC, NAMI/NYS and NAMI National in Arlington, VA. He wrote their policy on "Involuntary and Court Ordered Treatment" available at http://www.nami.org/Content/ContentGroups/Policy/Updates/Involuntary_Commitment_And_Court-Ordered_Treatment.htm. He was on the Advisory board of the Brain and Behavior Research Foundation (formerly NARSAD). In 1988, he co-founded the Treatment Advocacy Center and in 2010 started Mental Illness Policy Org. a non-partisan independent science-based think-tank on serious mental illness. MIPO does not accept funds from the mental health industry, pharmaceutical companies or government and is funded by small donations from the mothers of severely mentally ill adult children who are unable to secure care for them.

[2] While the boundary between serious mental illnesses and all others is clearly debatable, the extremities are clear. We are quoting the statistics used by most government agencies. See SAMHSA, National Survey on Drug Use and Health, Revised Estimates of Mental Illness from the National Survey on Drug Use and Health, 2013. Available at http://www.samhsa.gov/data/2k13/NSDUH148/sr148-mental-illness-estimates.htm and Center for Disease Control and Prevention, Mental Illness Surveillance Among Adults in the United States, Morbidity and Mortality Weekly Report (MMWR), September 2, 2013. Available at http://www.cdc.gov/mmwr/preview/mmwrhtml/su6003a1.htm?s_cid=su6003a1_w

[3] Three major disorders account for the bulk of people with serious mental illness, but other rare disorders can also be serious at various points in time. See NIMH Schizophrenia statistics at http://www.nimh.nih.gov/statistics/1SCHIZ.shtml. See NIMH, Bipolar Disorder statistics at http://www.nimh.nih.gov/statistics/1BIPOLAR_ADULT.shtml. See Severe major depression statistics at http://www.nimh.nih.gov/statistics/1MDD_ADULT.shtml.

[4] Homelessness: Estimates of homeless mentally ill vary. In January 2012, the Annual Homeless Assessment Report determined 633,782 people were homeless on a single night in the United States. Sixty-two percent of them (390,155) were sheltered (living in emergency shelter or transitional housing) and thirty-eight percent (243,627) were unsheltered (living in places not meant for human habitation, such as the streets, abandoned buildings, vehicles, or parks. (Alvaro Cortes, et al. 2012) These estimates do not include homeless "couch-surfers" who camp out on the sofas of friends and families, move every few days and have no permanent address. Estimates of the percentage of homeless who have mental illness range from 25% to 46% (National Alliance to End Homelessnes). Depending on the age group in question, and whether it includes all mental illness or just serious mental illness, the consensus estimate seems to be that at minimum 26% of homeless are seriously mentally ill. (U.S. Department of Housing and Urban Development 2010) Therefore, 164,783 seriously mentally ill are homeless at any given point in time as are 291,539 with any mental illness.

[5] More than 50% of those in jails and prisons have a mental health problem (James and Glaze 2006). However only about 16 or 17% of individuals in federal prisons and 17% of those in jails have serious mental illness. (Osher, et. al. 2012) There were 1,504,150 in prisons and 735,601 in jail. (Glaze and Parks 2012) Therefore there were 240,664 seriously mentally ill in prisons and 125,052 seriously mentally ill in jails, or 365,716 adults with serious mental illness in jails and prisons.

[6] That's ten times as many as are hospitalized. The Treatment of Persons with Mental Illness in Prisons and Jails: A State Survey. Treatment Advocacy Center. April 2014. Available at http://www.tacreports.org/treatment-behind-bars

[7] 55% of African Americans in state prisons and 63% of those in jails have mental health problems. Bureau of Justice Statistics, Mental Health Problems of Prison and Jail Inmates. September 2006, Available at http://www.bjs.gov/content/pub/pdf/mhppji.pdf.

[8] See a summary of the study, "Racial Disparities In Involuntary Outpatient Commitment: Are They Real?", Health Affairs, Vol. 28, No 3, May 2009 at http://mentalillnesspolicy.org/kendras-law/research/no-racial-disparities-kendras-law.html where there is also a link to the complete study.

[9] SAMHSA uses block grant funds to coerce states to replace the medical model with SAMHSA's recovery model, which leaves out those who are psychotic and delusional can not self direct their own care. SAMHSA funds groups that joined the "Occupy Psychiatry" movement by declaring that "psychiatric labeling is a pseudoscientific practice of limited value in helping people recover" and conduct SAMHSA funded workshops to teach persons with mental illness how to go off treatment. SAMHSA refuses to certify programs that help the seriously ill. See http://mentalillnesspolicy.org/samhsa for further discussion of problems at SAMHSA.

[10] Lawyers Who Break the Law: What Congress Can Do to Prevent Mental Health Patient Advocates from Violating Federal Legislation. Amanda Peters. Oregon Law Review. Vol 89. 133. 2010. Available at http://mentalillnesspolicy.org/myths/mental-health-bar.pdf

[11] When you see someone walking down the streets eating out of dumpsters arguing with voices only they can hear. When they scream "I am the Messiah", it is not because they believe they are the Messiah, it is because they know it. As the Messiah, they see no need for treatment. See anosognosia studies at http://mentalillnesspolicy.org/medical/anosognosia-studies.html.

[12] See a summary of research on Kendra's Law in "Research from the ten independent studies conducted over ten years on NYS Assisted Outpatient Treatment" available at http://mentalillnesspolicy.org/kendras-law/research/kendras-law-studies.html which also links to many of the actual studies.

[13] "The Cost of Assisted Outpatient Treatment: Can It Save States Money?" Jeffrey W. Swanson, Ph.D.; Richard A. Van Dorn, Ph.D.; Marvin S. Swartz, M.D.; et. al. American Journal of Psychiatry. Summary and link to study available at http://mentalillnesspolicy.org/aot/aot-cuts-costs-in-half.html

[14] Phelan, Sinkewicz, Castille and Link. Effectiveness and Outcomes of Assisted Outpatient Treatment in New York State Psychiatric Services, Vol 61. No 2 February 2010. Version presented to NYS/OMH available at http://mentalillnesspolicy.org/kendras-law/research/kendras-law-study-2009.pdf

[15] Testimony of Chief Michael C. Biasotti Immediate Past President New York State Association of Chiefs of Police to Energy and Commerce Subcommittee on Oversight and Investigations hearings March 26, 2014. Available at http://mentalillnesspolicy.org/imd/biasottipsychhospitaltestimony.pdf

Comparison of provisions related to serious mental illness in adults in the Helping Families in Mental Health Crisis Act (HR 3717) and in the Strengthening Mental Illness in our Communities Act (HR 4574)

(Draft 5/21/14 based on initial analysis. Prepared by Mental Illness Policy Org.)

	Helping Families in Mental Health Crisis Act (HR-3717)	Strengthening Mental Health in Our Communities (HR-4574)
Co-sponsors	54 Republican 30 Democrat	4 Democrat
Starts to address hospital bed shortage that prevents seriously ill from getting care when needed	**Yes**	No
Provides funds for Assisted Outpatient Treatment Pilot Programs (last off ramp before jail).	**Yes**	No
Gives states incentive to implement need for treatment/grave disability standards so mentally ill loved ones can be treated before becoming danger to self or others.	**Yes**	No
Writes exceptions into HIPAA/FERPA so parents can get information about diagnosis, what prescriptions need filling, and pending appointments of their loved ones to help them	**Yes**	No
Funds NIMH research into reducing violence by untreated seriously mentally ill	**Yes**	No
Requires government to prioritize the most seriously ill rather than least ill	**Yes**	No
Inhibits SAMHSA from giving grants to non-evidenced based programs and funding anti-treatment advocacy (ex. eliminating hospitals, banning ECT, opposing AOT…)	**Yes**	No
Inhibits PAIMII from overruling parents involved in care of loved ones	**Yes**	No
Focuses on medical model of treatment	**Yes**	No
Gives law enforcement and people with a medical background an important role on advisory boards	**Yes**	No
Cuts funding of programs that are not working	**Yes**	No
Eliminate the 190 day lifetime limit On inpatient psychiatric hospital care under Medicare	No	**Yes**
Reauthorizes Garrett Lee Suicide Programs	**Yes**	**Yes**
Support for Mental Health Courts	**Yes**	**Yes**
Train police to handle mental illness calls better	**Yes**	**Yes**
Protects Classes of medicines	**Yes**	**Yes**
Increases data collected by DOJ on mental illness	**Yes**	**Yes**

MENTAL ILLNESS POLICY ORG.
UNBIASED INFORMATION FOR POLICYMAKERS + MEDIA
50 EAST 129 ST., PH7 NEW YORK, NY 10035
OFFICE@MENTALILLNESSPOLICY.ORG
MENTALILLNESSPOLICY.ORG

9 Independent Kendra's Law Studies Show it works

Independent Study	Findings
May 2011 Arrest Outcomes Associated With Outpatient Commitment in New York State Bruce G. Link, et al. Ph.D. Psychiatric Services	For those who received AOT, the odds of any arrest were 2.66 times greater (p<.01) and the odds of arrest for a violent offense 8.61 times greater (p<.05) before AOT than they were in the period during and shortly after AOT. The group never receiving AOT had nearly double the odds (1.91, p<.05) of arrest compared with the AOT group in the period during and shortly after assignment."
October 2010: Assessing Outcomes for Consumers in New York's Assisted Outpatient Treatment Program Marvin S. Swartz, M.D., Psychiatric Services	Consumers who received court orders for AOT appeared to experience a number of improved outcomes: reduced hospitalization and length of stay, increased receipt of psychotropic medication and intensive case management services, and greater engagement in outpatient services.
February 2010 Columbia University. Phelan, Sinkewicz, Castille and Link. Effectiveness and Outcomes of Assisted Outpatient Treatment in New York State Psychiatric Services, Vol 61. No 2	Kendra's Law has lowered risk of violent behaviors, reduced thoughts about suicide and enhanced capacity to function despite problems with mental illness. *Patients given mandatory outpatient treatment - who were more violent to begin with - were nevertheless four times less likely than members of the control group to perpetrate serious violence* after undergoing treatment. Patients who underwent mandatory treatment reported higher social functioning and *slightly less stigma*, rebutting claims that mandatory outpatient care is a threat to self-esteem.
March 2005 N.Y. State Office of Mental Health "Kendra's Law: Final Report on the Status of Assisted Outpatient Treatment. "	**Danger and Violence Reduced** • 55% fewer recipients engaged in suicide attempts or physical harm to self • 47% fewer physically harmed others • 46% fewer damaged or destroyed property • 43% fewer threatened physical harm to others. • Overall, the average decrease in harmful behaviors was 44%. **Consumer Outcomes Improved** • 74% fewer participants experienced homelessness • 77% fewer experienced psychiatric hospitalization • 56% reduction in length of hospitalization. • 83% fewer experienced arrest • 87% fewer experienced incarceration. • 49% fewer abused alcohol • 48% fewer abused drugs **Consumer participation and medication compliance improved** • Number of individuals exhibiting good adherence to meds increased 51%. • The number of individuals exhibiting good service engagement increased 103%. **Consumer Perceptions Were Positive** • 75% reported that AOT helped them gain control over their lives • 81% said AOT helped them get and stay well • 90% said AOT made them more likely to keep appointments and take meds. • 87% of participants said they were confident in their case manager's ability. • 88% said they and case manager agreed on what is important to work on. **Effect on mental illness system** · **Improved Access to Services.** AOT has been instrumental in increasing accountability at all system levels regarding delivery of services to high need individuals. Community awareness of AOT has resulted in increased outreach to individuals who had previously presented engagement challenges to mental health service providers. · **Improved Treatment Plan Development, Discharge Planning, and Coordination of Service Planning**. Processes and structures developed for AOT have resulted in improvements to treatment plans that more appropriately match the needs of individuals who have had difficulties using mental health services in the past. · **Improved Collaboration between Mental Health and Court Systems.** As AOT processes have matured, professionals from the two systems have improved their working relationships, resulting in greater efficiencies, and ultimately, the conservation of judicial, clinical, and administrative resources. o There is now an organized process to prioritize and monitor individuals with the

	greatest need; o AOT ensures greater access to services for individuals whom providers have previously been reluctant to serve; o Increased collaboration between inpatient and community-based providers.
July 2013: The Cost of Assisted Outpatient Treatment. Can it Save States Money? American Journal of Psychiatry	• In New York City n**et costs declined 50%** in the first year after assisted outpatient treatment began and an additional 13% in the second year. In non NYC counties, costs declined 62% in the first year and an additional 27% in the second year. This was in spite of the fact that Psychotropic drug costs increased during the first year after initiation of assisted outpatient treatment, by 40% and 44% in the city and five-county samples, respectively. The increased community based mental health costs were more than offset by the reduction in inpatient and incarceration costs. Cost declines associated with assisted outpatient treatment were about twice as large as those seen for voluntary services
October 2010: Changes in Guideline-Recommended Medication Possession After Implementing Kendra's Law in New York, Alisa B. Busch, M.D Psychiatric Services	In all three regions, for all three groups, the predicted probability of an M(edication) P(ossesion) R(atio) ≥80% improved over time (AOT improved by 31–40 percentage points, followed by enhanced services, which improved by 15–22 points, and "neither treatment," improving 8–19 points). Some regional differences in MPR trajectories were observed.
October 2010 Robbing Peter to Pay Paul: Did New York State's Outpatient Commitment Program Crowd Out Voluntary Service Recipients? Jeffrey Swanson, et al. Psychiatric Services	In tandem with New York's AOT program, enhanced services increased among involuntary recipients, whereas no corresponding increase was initially seen for voluntary recipients. In the long run, however, overall service capacity was increased, and the focus on enhanced services for AOT participants appears to have led to greater access to enhanced services for both voluntary and involuntary recipients.
June 2009 D Swartz, MS, Swanson, JW, Steadman, HJ, Robbins, PC and Monahan J. New York State Assisted Outpatient Treatment Program Evaluation. Duke University School of Medicine, Durham, NC, June, 2009	We find that New York State's AOT Program improves a range of important outcomes for its recipients, apparently without feared negative consequences to recipients. • **Racial neutrality**: We find no evidence that the AOT Program is disproportionately selecting African Americans for court orders, nor is there evidence of a disproportionate effect on other minority populations. Our interviews with key stakeholders across the state corroborate these findings.**Court orders add value:** 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. • **Improves likelihood that providers will serve seriously mentally ill:** It is also important to recognize that the AOT order exerts a critical effect on service providers stimulating their efforts to prioritize care for AOT recipients. • **Improves service engagement:** After 12 months or more on AOT, service engagement increased such that AOT recipients were judged to be more engaged than voluntary patients. This suggests that after 12 months or more, when combined with intensive services, AOT increases service engagement compared to voluntary treatment alone. • **Consumers Approve**: Despite being under a court order to participate in treatment, current AOT recipients feel neither more positive nor more negative about their treatment experiences than comparable individuals who are not under AOT.
1999 NYC Dept. of Mental Health, Mental Retardation and Alcoholism Services. H. Telson, R. Glickstein, M. Trujillo, Report of the Bellevue Hospital Center Outpatient Commitment Pilot	• Outpatient commitment orders often assist patients in complying with outpatient treatment. • Outpatient commitment orders are clinically helpful in addressing a number of manifestations of serious and persistent mental illness. • Approximately 20% of patients do, upon initial screening, express hesitation and opposition regarding the prospect of a court order. After discharge with a court order, the majority of patients express no reservations or complaints about orders. • Providers of both transitional and permanent housing generally report that outpatient commitment help clients abide by the rules of the residence. More importantly, they often indicate that the court order helps clients to take medication and accept psychiatric services. • Housing providers state that they value the leverage provided by the order and the access to the hospital it offers.