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How PAIMI and SAMHSA funded groups provided false information to Dem E&C Members thereby misleading them.

Summary: Several E&C Democrats addressed a letter to Representatives Upton and Pallone expressing concern with provisions in HR-2646 that are targeted to help people with serious mental illnesses.[1] Their letter contains numerous falsehoods provided by PAIMI and SAMHSA proponents which if relied on, will prevent people with schizophrenia and bipolar from receiving treatment. The fact that PAIMI and SAMHSA groups are misleading members of Congress, in and of itself, shows the need to overhaul those two programs.

Letter contains unsupported, and likely untrue HIPAA claim

The letter asserts that allowing families who provide care out of love access to medical information paid providers already receive would "deter individuals from seeking treatment they need." We believe the signatories were told that, but research shows the opposite. The major NIMH First Episode Psychosis study published last week, found those who had their medications complemented with talk therapy **and family support** did better than those who didn't.[2] They were not "driven from care".

Without access to information about the diagnosis, medications, and next appointments of seriously mentally ill loved ones, parents are powerless to get prescriptions filled, see medications are taken, and transportation to appointments arranged. Having an unmedicated psychotic child at home, screaming at voices only he can hear 24/7 often creates an untenable situation, and causes the needs of other family members to go unaddressed. Parents are forced to get orders of protection and stop providing housing. A homeless person is created who often moves on to become an incarcerated person.

The solution HR-2646 proposes is minimal. It would allow families who provide housing, case management, and support out of love, to receive a small subset of the information those who provide those services for money already receive. And even then, family caretakers can only receive the information if it is needed to "protect health safety and welfare". Case notes are excluded. Far from infringing rights, the disclosures will enable more persons with serious mental illness to avoid incarceration and involuntary hospitalization, truly massive deprivations of rights. It is important to understand that the fix only applies to a very tiny group. Only 4% of population has serious mental illness.[3] The fix only applies to a small subset of those.

SAMHSA and PAIMI group provided signatories erroneous information on the efficacy of AOT

The letter questions the efficacy of AOT laws by stating the 'necessity, effectiveness, and impact of each such laws vary dramatically nationwide." We have no doubt that the signatories were told that, but it is untrue.

The research on the efficacy of AOT is overwhelmingly positive and consistent in every jurisdiction that has used it including OH, NJ, NC, IA, AZ, CA, NY and others.[4] The fact that federally funded PAIMI and SAMHSA groups have denied that to Congress is an important example of why we need to rein them in. They are preventing evidence based programs from being implemented. [5]

After formal review of the nationwide research, AOT was declared an "Evidence Based Practice" by

SAMHSA[6], an "Effective Crime Prevention Program" by the Department of Justice[7]; and HHS's Agency for Healthcare Research and Quality said AOT "lead(s) to significantly fewer emergency commitments, hospital admissions, and hospital days as well as a reduction in arrests and violent behavior."[8] After reviewing the nationwide research, AOT was endorsed by the National Alliance on Mental Illness,[9] National Sheriff's Association,[10] and International Association of Chiefs of Police.[11] Like HIPAA provisions, AOT provisions apply to a very small group. It is only available to those with serious mental illness who *already accumulated multiple episodes* of arrest, incarceration, hospitalization and homeless due *refusal or inability to comply with treatment* that was offered to them. This group is the sickest of the sick:

- In **North Carolina**, AOT reduced the percentage of persons refusing medications to 30%, compared to 66% of patients not under AOT.[12]
- **Ohio** found "During the first 12 months of outpatient commitment, patients experienced significant reductions in visits to the psychiatric emergency service, hospital admissions, and lengths of stay compared with the 12 months before commitment."[13]
- **Arizona** research found "71% [of AOT patients] . . . voluntarily maintained treatment contacts six months after their orders expired" compared with "almost no patients" who were not court-ordered to outpatient treatment."[14]
- **Iowa** researchers found "it appears as though outpatient commitment promotes treatment compliance in about 80% of patients… After commitment is terminated, about 3/4 of that group remain in treatment on a voluntary basis."[15]
- The **New Jersey** Violence Commission just reported, " "Outpatient commitment has proven to be a valuable tool in treating mental illness in the community and reducing inpatient hospitalization."[16]
- In **Nevada County, California** the number of days hospitalized decreased 46.7%; number of days incarcerated decreased 65.1%, number of days homeless decreased 61.9%; number of emergency interventions decreased 44.1%. Implementation saved $1.81-$.2.52 for ever dollar spent and "receiving services under Laura's Law caused a reduction in *actual* hospital costs of $213,300 and a reduction in *actual* incarceration costs of $75,600[17] This is consistent with other research in that county.[18]
- In **Los Angeles, California,** AOT reduced incarceration 78%; reduced hospitalization 86%; and reduced hospitalization 77% even after discharge. It cut taxpayer costs 40%.[19]

The signatories are correct that New York has the "most widely implemented, funded and studied AOT laws.[20] Here's what that research found.

- AOT in NY reduces homelessness, hospitalization.[21]
- AOT in NY reduces arrest and incarceration in the 70-80% range. [22, 23]
- AOT in NY reduces suicidal behavior.[24]
- AOT in NY reduces the cost to taxpayers by 60% in rural areas and 50% in urban by replacing the use of expensive jails and hospitals with community services.[25]
- Far from being costly, the savings generated by AOT allow states to expand their mental health services.[26]
- 81% of consumers (peers) in AOT in NY (as opposed to those who purport to speak for them) say AOT helped them get well and stay well and contrary to what PAIMI and SAMHSA-funded opponents claim, the research shows far from driving people from care, or causing stigma, consumers in AOT perceived less stigma than those who were not.[27]

Nothing in HR2646 requires states to use or have AOT laws or homogenize their law to a national standard. AOT Laws can be successfully implemented with or without additional funding. Because the laws cut down on the use of expensive hospitals and jails, they let counties do more with less. They free up funds that can be used to increase services for all. [28], [29]

SAMHSA and PAIMI group provided signatories erroneous information on the racial neutrality of AOT

The letter claims AOT has "disparate impact…on minorities." We have no doubt that the PAIMI and SAMHSA groups told the signatories this, but it is untrue. The fact that they convinced the members of this shows the need to rein in those groups.

The claim of lack of racial neutrality dates back to when the New York recipient of PAIMI funds (NY Lawyers in the Public Interest) wanted to stop New York from making AOT (Kendra's Law) permanent. They used their PAIMI funds to create a faux internal study purporting to prove that Kendra's Law was not being applied in a racially neutral matter.[30] The legislature was appropriately concerned, so spent taxpayer money for an independent study. The independent study found "no evidence of racial bias" and readily identified the statistical tricks used in the PAIMI-funded faux study.[31] Nonetheless, nationwide PAIMIs still use faux-study to convince legislators to oppose AOT, without telling legislators there exists an independent study that was published in a peer review publication that proved the internally generated faux study false.[32] The independent study declared:

- "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."
- "Parallel analyses for Hispanics and other minority populations show this same pattern and no appreciable racial disparities are evident in selection of these groups for AOT."
- "Defining the target population as public-system clients with multiple hospitalizations, the rate of application to white and black clients approaches parity."

Publicly available demographic data confirms AOT is applied in a racially neutral manner roughly consistent with the number of people of color living in the counties who are using public sector services. (Source: NYS OMH Racial Demographics, Oct. 2015.) [33]

Region	White	Black	Hispanic	Asian	Other
Central	94%	2%	4%		1%
Hudson River	84%	6%	10%	0%	0%
Long Island	79%	11%	10%	0%	
NYC	32%	25%	41%	2%	0%
Western	80%	13%	6%		0%
Statewide	**49%**	**19%**	**30%**	**1%**	**0%**

The Harlem Chapter of the National Alliance on Mental Illness (NAMI/Harlem), made up almost entirely of African Americans, wrote to Representatives Tim Murphy, Eddie Bernice Johnson, and Charlie Rangel urging the AOT provisions of HR2646 be included in any final legislation.

> "AOT dramatically reduces homelessness, arrest, hospitalization and incarceration of the seriously ill. A 2009 study found it is one of the few community programs that does not discriminate based on race. **Our members in the New York version of AOT (Kendra's Law) receive case management, housing, medication maintenance and other important services they would otherwise not be able to avail themselves of.**" (NAMI/Harlem)[34]

Dr. Stephanie Le Melle Co-Director of Public Psychiatry at NYS Psychiatric Institute told a SAMHSA forum that any racial bias within the mental health system--of which there may be a lot--is not taking place within the Kendra's Law program. She is a psychiatrist and African American New Yorker intimately familiar with Kendra's Law.

SAMHSA's 2011 investigation of PAIMI found PAIMI has a long history of using federal funds to mislead legislators on AOT:[35]

- "collaborat[ing] with…a consumer advocacy organization to block passage of a proposed expansion of an outpatient commitment law."
- "PAIMIs reported joining other advocates in activities such as: Ad hoc partnerships focused on specific

issues (e.g., opposing outpatient commitment)."

- "At the state level, PAIMIs have been involved in systemic issues including outpatient civil commitment."
- "A number of PAIMIs worked to prevent the enactment of state laws creating outpatient commitment systems."

Signatories were provided one-sided information about the utility of the PAIMI program

The signatories express concern about provisions they claim "would weaken the Protection and Advocacy System for individuals with mental illness." We have no doubt they were told that, but requiring PAIMI to focus on it's core mission would strengthen PAIMI, not weaken it.

PAIMI's mission has become terribly unfocused and often antithetical to helping the seriously ill. Funds are used primarily to defend an ideology that believes being psychotic is a right to be protected rather than an illness to be treated. PAIMI does some good work. For example, they work to improve treatment in jails. But is their defense of the right to be psychotic that puts people in jail in the first place.

The anti-treatment activities of PAIMI were studiously documented in "Lawyers Who Break the Law: What Congress Can Do to Prevent Mental Health Patient Advocates from Violating Federal Legislation" published in the *Oregon Law Review*.[36] Families of the seriously ill and officials who want to improve care for the seriously ill, simply cannot compete with PAIMI and SAMHSA funded groups because they get federal funds to lobby against treatment.

In spite of the fact that it is courts, not PAIMI that determines what does and doesn't violate rights, PAIMI uses the charge of "violating rights" to justify supporting whatever policy conforms with its ideology and opposing those that don't. For example, it claims AOT violates rights, but according to courts, "It is now well settled that Kendra's Law is in all respects a constitutional exercise of the states police power, and its parens patriae power."[37] Recently PAIMI has marshaled the 'violates rights' claim to oppose allowing persons with mental illness to use hospitals and nursing homes.

Returning PAIMI to its original function of protecting the ill from abuse and neglect is smart public policy.

Signatories misinformed about role of police and criminal justice.

The signatories argue against AOT by expressing concern about "the involvement of the court system and law enforcement treatment' of people with mental illness. As previously described, AOT decreases arrest and incarceration. It is the lack of AOT, and the support of PAIMI and SAMHSA that has led to ten times as many persons with serious mental illness being incarcerated as hospitalized.

Signatories misinformed about SAMSHA.

The signatories claim SAMHSA is needed to help the seriously ill. But SAMHSA has directed states to use mental health block grants for people without serious mental illness, refuses to certify programs that help the seriously ill like Mental Health Courts, funds antipsychiatry and pseudoscience, and wastes money.[38]

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[1] The letter expressing concerns signed by 18 Democrat representatives is available at http://matsui.house.gov/uploads/Mental%20Health%20Letter%20to%20Upton%20and%20Pallone%2010.23.15.pdf

[2] The study found that those with first episode psychosis who had their medication regimen supplemented with talk therapy and family support made greater strides in recovery over the first two years of treatment than patients who did

not. This was a large, important multi-site project of NIMH. Source: John M. Kane, M.D., Delbert G. Robinson, M.D., Nina R. Schooler, et. al. “Comprehensive Versus Usual Community Care for First-Episode Psychosis: 2-Year Outcomes From the NIMH RAISE Early Treatment Program” American Journal of Psychiatry. October 2015 It is available at http://ajp.psychiatryonline.org/doi/abs/10.1176/appi.ajp.2015.15050632 Note that reporting in the NY Times on this study was misleading and corrected by the NY Times.

[3] Substance Abuse and Mental Health Services Administration (SAMHSA). "*NSDUH 2013* Report: Substance Use and Mental Health Estimates from the 2013 National Survey on Drug Use and Health*:* Overview of Findings." Rockville, MD, September 2014. Available at http://store.samhsa.gov/shin/content//NSDUH14-0904/NSDUH14-0904.pdf (Accessed 3/14/15)

[4] Research on AOT also available at http://mentalillnesspolicy.org/national-studies/aotworks.pdf

[5] See Summary of AOT Research at http://mentalillnesspolicy.org/national-studies/aotworks.pdf

[6] SAMHSA National Registry of Evidence based Practices and Programs (NREPP) 2015

[7] Department of Justice. "Crime solutions: assisted outpatient treatment." Crime Solutions.gov. 2012.

[8] Agency for Healthcare Research and Quality U.S. Department of Health and Human Services Management Strategies To Reduce Psychiatric Readmissions May 2015

[9] NAMI Policy on Involuntary and Court Ordered Treatment (1995)

[10] National Sheriff’s Association endorsement at http://mentalillnesspolicy.org/crimjust/National-Sheriffs-Association.html

[11] IACP 2014 endorsement at http://mentalillnesspolicy.org/crimjust/iacpadoptsaot.pdf

[12] Virginia Hiday, and Teresa Scheid-Cook. "The North Carolina experience with outpatient commitment: a critical appraisal." International Journal of Law and Psychiatry 10, no. 3 (1987): 215–232.

[13] Mark Munetz, Thomas Grande, Jeffrey Kleist, Gregory Peterson. "The effectiveness of outpatient civil commitment." Psychiatric Services 47, no. 11 (1996): 1251–1253.

[14] Robert Van Putten, Jose Santiago, Michael Berren. "Involuntary outpatient commitment in Arizona: a retrospective study." Hospital and Community Psychiatry 39, no. 9 (1988): 953–958.

[15] Barbara Rohland. "The role of outpatient commitment in the management of persons with schizophrenia." Iowa Consortium for Mental Health Services, Training and Research, 1998.

[16] Report on the Study Commission on Violence, October 2015. The legislatively mandated report is at http://mentalillnesspolicy.org/states/newjersey/commission-on-violence-endorses-AOT.pdf

[17] Michael Heggarty, Behavioral Health Director, Nevada County. “The Nevada County Experience,” Nov. 15, 2011).

[18] “Laura’s Law has provided life-saving services to individuals suffering from mental illness and kept many from the trauma and brain damage associated with involuntary commitments to mental health facilities under W & I Code, Section 5150, and the jail commits and tragedies associated with untreated mental health crisis.” Source: Thomas M. Anderson, Presiding Judge of the Superior Court California, County of Nevada, Letter to Bill Campbell, Chair of Orange County Board of Supervisors, September 28, 1911

[19] County of Los Angeles. “Outpatient Treatment Program Outcomes Report" April 1, 2010 – December 31, 2010. And Michael D. Antonovich, Los Angeles County Fifth District Supervisor, Los Angeles Daily News, December 12, 2011.

[20] Summary of Kendra’s Law research available at http://mentalillnesspolicy.org/kendras-law/research/kendras-law-studies.html

[21] Marvin Swartz, Christine Wilder, Jeffrey Swanson, Richard Van Dorn, Pamela Clark Robbins, Henry Steadman, Lorna Moser, Allison Gilbert, John Monahan. "Assessing outcomes for consumers in New York's assisted outpatient treatment program." Psychiatric Services 61, no. 10 (2010): 976–981.

[22] Bruce G. Link, et al. Ph.D. Arrest Outcomes Associated With Outpatient Commitment in New York State Psychiatric Services May 2011

[23] New York State Office of Mental Health. Kendra's Law: Final Report on the Status of Assisted Outpatient Treatment. Report to Legislature, Albany: New York State, 2005, 60.

[24] "Effectiveness and outcomes of assisted outpatient treatment in New York State." Jo Phelan, Marilyn Sinkewicz, Dorothy Castille, Steven Huz, Bruce Link. *Psychiatric Services* 61, no. 2 (2010): 137–143.

[25] "The cost of assisted outpatient treatment: can it save states money?" Jeffrey Swanson, Richard Van Dorn, Marvin Swartz, Pamela Clark Robbins, Henry Steadman, Thomas McGuire, John Monahan. American Journal of Psychiatry 170 (2013): 1423–1432.

[26] Robbing Peter to Pay Paul: Did New York State's Outpatient Commitment Program Crowd Out Voluntary Service Recipients? Jeffrey Swanson, et al. Psychiatric Services, October 2010

[27] "Effectiveness and outcomes of assisted outpatient treatment in New York State." Jo Phelan, Marilyn Sinkewicz, Dorothy Castille, Steven Huz, Bruce Link. Psychiatric Services 61, no. 2 (2010): 137–143.

[28] "The cost of assisted outpatient treatment: can it save states money?" Jeffrey Swanson, Richard Van Dorn, Marvin Swartz, Pamela Clark Robbins, Henry Steadman, Thomas McGuire, John Monahan. American Journal of Psychiatry 170 (2013): 1423–1432.

[29] Robbing Peter to Pay Paul: Did New York State's Outpatient Commitment Program Crowd Out Voluntary Service Recipients? Jeffrey Swanson, et al. Psychiatric Services, October 2010

[30] A recounting of the efforts is described at http://mentalillnesspolicy.org/kendras-law/research/no-racial-disparities-kendras-law.html

[31] "Racial Disparities In Involuntary Outpatient Commitment: Are They Real?" Jeffrey Swanson, Marvin Swartz, Richard A. Van Dorn, John Monahan, Thomas G. McGuire, Henry J. Steadman, and Pamela Clark Robbins. Published in Health Affairs, Vol 28. Issue 3. Page 816. Available at http://mentalillnesspolicy.org/kendras-law/research/no-racial-disparities-kendras-law.pdf

[32] See letter from Democrat members of Congress to Chair and Ranking Member of House and Energy and Commerce Committee, 10/23/15 based on information provided by PAIMI and SAMHSA funded groups. Available at http://matsui.house.gov/uploads/Mental%20Health%20Letter%20to%20Upton%20and%20Pallone%2010.23.15.pdf

[33] The NYS Office of Mental Health data on success of AOT includes data on racial background of participants. It is available at http://bi.omh.ny.gov/aot/characteristics?p=demographics-race

[34] NAMI Harlem Letter of Endorsement available at http://murphy.house.gov/uploads/HarlemAMIEndorse2-1%20%282%29.pdf

[35] SAMHSA found problems at PAIMI which it oversees, but refuses to correct them. http://mentalillnesspolicy.org/myths/paimifails2011samhsaevaluation.html

[36] *Oregon Law Review* article available at http://mentalillnesspolicy.org/myths/mental-health-bar.pdf

[37] Brennan, K. J. (2009). Kendra's Law: Assisted Outpatient Treatment in New York. Unpublished revision of Brennan, K. J. (2005). Kendra's Law: Final Report on the Status of Assisted Outpatient Treatment Appendix 2)

[38] See http://mentalillnesspolicy.org/samhsa/samhsa-failures-summary.pdf for summary of problems at SAMHSA. See http://mentalillnesspolicy.org/samhsa.html for extensive information on SAMHSA's refusal to help the most seriously ill.