

Formerly known as the Western Mass Recovery Learning Community

187 High Street, Suite #202 Holyoke Ma 01040 Toll free 866.641.2853 Fax 413.536.5466 Voice/TTY {413} 539-5941 www.wildfloweralliance.org info@wildfloweralliance.org

September 9. 2023

The Honorable Senator James B. Eldridge Joint Committee on the Judiciary 24 Beacon St. Room 511-C Boston, MA 02133

The Honorable Representative Michael S. Day 24 Beacon St. Room 136 Boston, MA 02133

RE: Written Testimony on S.980/H.1694, An Act to provide critical community health services

Dear Chair Eldridge, Chair Day, and members of the Joint Committee on the Judiciary,

Thank you for inviting testimony from the public at the hearing on September 7, 2023, (as a continuation to the paused hearing from July 18, 2023). Three members of the Wildflower Alliance team – myself, Sera Davidow (Director), Liz Momborquette (Bridging Coordinator), and Tasha Pearce (Virtual Peer Support Specialist) – spoke <u>in opposition to H.1694/S.980</u>, 'An Act to Provide Critical Community Health Services.' We very much appreciated the opportunity to be heard.

Having listened to all the testimony on both days, we recognize that you have a difficult but very important job of determining how to move forward with this Bill. Based on what we heard and the points we believe are essential for consideration, we are going to separate our testimony into two parts:

<u>Part I</u>: Key rebuttals to points made by "AOT" proponents <u>Part II</u>: Key additional points for your consideration

#### Part I:

Our disagreement with points made by proponents of "AOT" do not simply amount to differences in perspective. Rather, there are fundamental inaccuracies that must be countered, including:

**1. AOT <u>DOES</u> involve force both in the current Massachusetts proposal and in other states:** Several times, people stated that AOT does not involve force in this state or any other across the nation.



Formerly known as the Western Mass Recovery Learning Community

187 High Street, Suite #202 Holyoke Ma 01040 Toll free 866.641.2853 Fax 413.536.5466 Voice/TTY {413} 539-5941 www.wildfloweralliance.org info@wildfloweralliance.org

This assertion is patently untrue and the denial is very difficult to hear for those of us who've experienced force and coercion (which itself is still a form of force) ourselves. One can only assume that what the people who say this mean is that no one will come into a person's home, tackle and restrain them, and inject them with drugs against their will. That much is true.

However, in many states, refusal to take psychiatric drugs as prescribed when under an AOT order absolutely does result in police being sent to someone's home to forcibly take them into an inpatient psychiatric facility against their will. For example, the 2017 documentary 'Crazy' by Lise Zumwalt (<a href="www.crazythefilm.com">www.crazythefilm.com</a>) follows Eric, a young man trying to live under an AOT order in Wisconsin, and in fact includes a scene where police arrive to take him in when he refuses his psychotropics in spite of in no way appearing to be a "danger to self or others." Wisconsin is certainly not the only state where this can happen.

Given that individuals who testified in favor of AOT gave clearly incorrect information — whether intentionally or not - about such a key point it should draw into question everything else that they've said, too.

Even in Massachusetts, the current Bill suggests that – if someone is refusing to follow their AOT plan – a judge can order them to be evaluated. It is critical to understand that evaluation is not typically a benign event that occurs comfortably in someone's home. It frequently involves a trip to the Emergency room, and if someone resists, it can become a forced event itself which is traumatizing even if it doesn't result in a hospital stay. This is but one example of where force may play a role.

Perhaps more importantly, we heard several people – including those stating that there is no force involved with AOT – reference the "black robe" effect. Essentially, what they are saying is this:

"Where there is no explicit force, many individuals will nonetheless infer force due to fear of and/or reverence for the Judge and court process. Based on the belief that they are required to follow the court order or face consequences, they will then behave exactly as if they were being forced, because they believe that they are."

Using the fact that someone incorrectly believes they are being forced is still force, whether it shows up on paper as such or not. It is also an abuse of power (as knowledge is power), and a violation of informed consent law. It is disingenuous to suggest there is no force involved when someone has been led to believe they have no other choice but to comply.



Formerly known as the Western Mass Recovery Learning Community

187 High Street, Suite #202 Holyoke Ma 01040 Toll free 866.641.2853 Fax 413.536.5466 Voice/TTY {413} 539-5941 www.wildfloweralliance.org info@wildfloweralliance.org

2. Anosognosia is <u>NOT</u> a validated diagnosis for individuals with psychiatric histories. Anosognosia is a real neurological condition. The was coined in 1914 by Joseph Babinski in reference to individuals who had developed a peculiar inability to sense the left side of their body. This neurological condition was typically seen in relationship to people who had strokes or similar medical phenomena.

However, anosognosia as a psychiatric condition is pure conjecture. Yet, individuals pushing AOT reference it as a universally accepted phenomenon and employ it as justification for using psychiatric force. Psychiatrist Larry Davidson published a statement in the Hartford Courant that included the following:

"No such lesions have been found in schizophrenia, despite over 200 years of research looking for them ... Other than justifying outpatient commitment, this theory [of anosognosia as it applies to people with psychiatric conditions] has led to no breakthroughs in treatment."

Larry's full statement is attached.

Psychiatrist Sandy Steingard of Vermont also pushed back on the idea of anosognosia in a 2012 article, noting that the brain research simply doesn't hold up:

As with the notion of "chemical imbalance", the term anosognosia has crept into the psychiatric lexicon. Its use confers a certain sophistication of understanding and knowledge that is not supported by the data.

Sandy's full article is attached.

In reality, there are many legitimate reasons why someone may appear to "lack insight" due to denial of emotional or mental problems. Claiming that the denial is a medical condition often serves as little more than an excuse to justify force. A sampling of reasons for said denial are included here:

- · Risk of loss of liberty is too great.
- · Risk of experiencing discrimination (in housing, employment, child rearing, and more) is too great.
- · Loss of power and control in one's own life is usually scary and/or demoralizing (which can worsen distress).
- · Cultural beliefs and practices related to emotional distress may be incompatible with mainstream perspectives.



Formerly known as the Western Mass Recovery Learning Community

187 High Street, Suite #202 Holyoke Ma 01040 Toll free 866.641.2853 Fax 413.536.5466 Voice/TTY {413} 539-5941 www.wildfloweralliance.org info@wildfloweralliance.org

- Treatments most readily available are often ineffective, and sometimes harmful (and clear harm is often not reason enough for providers to concede that they should be stopped).
- · Even if someone wants help, they may not want it from the person(s) offering help at that time.
- The person being diagnosed often has significantly less power than those diagnosing them, and denial and resistance may seem like the only choice.
- · Past experiences in psychiatric system (or any system) have too often been alienating and traumatic and led to broken trust.
- **3. H.1694/S.980** is <u>NOT</u> especially "limited in application." Several times, proponents of "AOT" stated that the current Bill is "limited in application." However, it is a serious mistake to see any Bill that uses recent psychiatric hospitalizations or similar as criteria as being "narrow" or "limited." There are many reasons why people find themselves in the deep sort of emotional distress that can land them on a psychiatric inpatient unit, including repetitively and/or by force. These reasons include (but are not limited to):
  - $\cdot$   $\;$  The stress of being away from home for the first time in a high-pressure college environment
  - Sexual assault and rape
  - · Grief and unexpected loss of a loved one
  - · Domestic violence situations
  - · End of a relationship and/or child custody issues
  - · Physical illness and chronic pain
  - · Overwhelming debt

Additionally, the fact that the criteria is quite vague guarantees it will be applied in a highly subjective manner. Furthermore, even when psychiatric criteria is better defined, we know that application is rife with subjectivity and the negative effects of power imbalances. For example, in spite of incongruency with legal definitions, over the last decade we have continued to see:

- · Doctors pre-signing Section 12 paperwork so that they can approve Section 12s without seeing a patient
- · Providers misusing vague references to suicidal thoughts as constituting "imminent risk" when there is already an agenda to see the person hospitalized
- · Providers interpreting someone's choice to leave voluntary services as constituting a risk to 'self or others' because they don't agree with where they are going

We also know that – when something is formally instituted as an option for "extreme situations" – that people begin to see more and more situations as meeting those extremes. This is human nature.



Formerly known as the Western Mass Recovery Learning Community

187 High Street, Suite #202 Holyoke Ma 01040 Toll free 866.641.2853 Fax 413.536.5466 Voice/TTY {413} 539-5941 www.wildfloweralliance.org info@wildfloweralliance.org

- 4. AOT is <u>NOT</u> needed to ensure effective discharge planning. During the hearing on September 7, we heard from a woman who spoke about her and her husband's confusion and overwhelm upon his discharge from a psychiatric facility. She described him as willing to engage in help, but having no help available. There is no version of "AOT" that would be applicable to someone who acknowledges they are struggling and wants help. Rather, instituting robust funding for community bridgers would be indicated. Community bridging is a form of peer support designed specifically to train people who've been hospitalized to use the wisdom they gained to support others who are being discharged to navigate community resources. Such roles exist across the state, but are very limited in capacity at this time due to funding.
- 5. Though Massachusetts is one of only three states without an "AOT" law, many states do NOT use the "AOT" laws they have on the books effectively or at all. Several proponents of "AOT" appeared to admonish legislators for the fact that Massachusetts is one of only three US states without an "AOT" law. However, what they always fail to mention is that many states do not use their "AOT" laws often or at all. This is due, at least in part, to the reality that it can be very difficult to properly administer "AOT" across a state, especially given minimal returns and the potential of causing additional harm.
- **6.** The BOAT program is <u>NOT</u> the same as Assisted Outpatient Treatment: Several times between July 18 and September 7, people asserted that the Boston Outpatient Assisted Treatment (BOAT) program is essentially the same as "AOT." This is not the case. Most notably, The BOAT program is a voluntary option offered to court-involved individuals in a particular catchment area.

In reviewing the "Information Sheet" available on the BOAT webpage, it is worth noting that step #1 for attorneys representing individuals who might be a fit for the BOAT program is:

Discuss the BOAT program with the client to <u>ensure they are aware of & interested in the referral.</u>

While options offered as an alternative to punitive action may not be entirely voluntary in that individuals who wish to avoid the punitive action may feel they don't have too many other choices, it is nonetheless substantively different and at least creates some space for weighing of options and retention of some degree of personal agency.

7. Surveys on "AOT" to the general community should <u>NOT</u> be seen as relevant guidance for evaluating this Bill. A pollster working with "AOT NOW" testified that he had completed a poll with the citizens of the Commonwealth that indicated that the majority wanted an "AOT" law. In order for this to be seen as a meaningful result:



Formerly known as the Western Mass Recovery Learning Community

187 High Street, Suite #202 Holyoke Ma 01040 Toll free 866.641.2853 Fax 413.536.5466 Voice/TTY {413} 539-5941 www.wildfloweralliance.org info@wildfloweralliance.org

- a. We would need to see exactly what people were asked, including the phrasing of the questions. Questions would need to be evaluated for clarity, and whether or not they were leading or similarly flawed.
- b. We would need to see what educational information was provided to individuals surveyed to help them understand the issue at hand, whether or not it offered accurate and balanced information, and similar. Educational information would need to be adequate both in terms of understanding of what "AOT" laws would require of someone, expected rates of efficacy, and potential for harm caused.

To date, "AOT NOW" administrators have not responded to requests to see the details of this survey.

Furthermore and beyond the need to evaluate the quality of the survey and data collected, it is important to be aware that the average citizen has little to no pre-existing understanding of this issue. What they have heard is often distorted by negative and biased stereotypes in the media, as well as profit-driven advertising by pharmaceutical companies (one of the many reasons why direct-to-consumer pharmaceutical marketing is illegal in all countries other than the US and New Zealand).

Even scientific research has been found to carry substantial racial bias (Roberts et al, Perspectives on Psychological Sciences, 2020), and to leave many more critical papers filed away and out of the public eye (Button et al, BMC Psychology, 2016). As such, even with information given prior to being surveyed, members of the general public would be highly unlikely to have what they need to fairly evaluate the situation and provide an informed recommendation.

For all of these reasons balanced against the extreme restrictions on liberty that AOT laws present, a survey of the general public's opinion should not be seen as a relevant measure.

- **8. NAMI Massachusetts does <u>NOT</u> support this Bill:** Proponents of "AOT" testified that NAMI National supports AOT overall, and instructed us to look at their webpage. While this is true, there are two issues with this generalization:
  - a. It glosses over the fact that NAMI Massachusetts has explicitly come out <u>against</u> H.1694/S.980. This testimony has been provided in writing by senior NAMI leadership, and verbally on September 7 by a member of NAMI, as well.
  - **b.** While NAMI National may support the overall idea of "AOT," a search on "Massachusetts," "1694" and "980" brings no results relevant to the current legislation.



Formerly known as the Western Mass Recovery Learning Community

187 High Street, Suite #202 Holyoke Ma 01040 Toll free 866.641.2853 Fax 413.536.5466 Voice/TTY {413} 539-5941 www.wildfloweralliance.org info@wildfloweralliance.org

As such, to say that NAMI National supports this Bill is conjecture, as the only clear message we have from NAMI as it applies to H.1694/S.980 is from NAMI Massachusetts, and that is to **NOT** support this Bill.

9. It is psychiatric drugs – NOT what gets called psychosis – that is most likely to cause brain damage: One AOT proponent stated that untreated "psychosis" causes brain damage over time. However, it is now fairly widely understood that psychiatric drugs cause brain damage, including much of the damage previously attributed to a disease process. In fact, Nancy Andreasen (former Editor in Chief of the American Journal of Psychiatry) has been deeply involved in research that ultimately found that psychotropics lead to brain "shrinkage." (Arch General Psychiatry, 2011).

In a 2013 article that cited Andreasen and co-researchers findings that "the higher the anti-psychotic medication doses, the greater the loss of brain tissue," Nancy was quoted as saying:

"This was a very upsetting finding ... We spent a couple of years analyzing the data more or less hoping we had made a mistake. But in the end, it was a solid finding that wasn't going to go away, so we decided to go ahead and publish it."

Rather than being an argument in favor of forced treatment, findings related to brain damage are actually one of the strongest pieces of evidence that any form of force or coercion related to psychiatric drugs poses a high degree of risk, and likely shouldn't be considered as an acceptable intervention to force.

10. Public testimony in favor of AOT as provided by individuals who've been on an AOT order should **NOT** be weighted heavily. While all voices deserve to be heard, we hope that the testimony of Bradley Tarr will be considered with several caveats in mind as follows.

First, as a Google search reveals, Bradley Tarr has been highly utilized by the Treatment Advocacy Center as a speaker on the matter of AOT on many occasions. Bradley's own writing also reveals that he's been hired as a trainer based on his experience. While this does not automatically negate his perspective, it is possible that the fact that he is personally benefiting from giving pro-AOT talks may influence what he says and his motivation in continuing to say it. In fact, it is not uncommon for individuals who've previously experienced oppression and/or voicelessness to gravitate toward whatever brings them power and voice, even if it means shifting what they say in order to retain that position.



Formerly known as the Western Mass Recovery Learning Community

187 High Street, Suite #202 Holyoke Ma 01040 Toll free 866.641.2853 Fax 413.536.5466 Voice/TTY {413} 539-5941 www.wildfloweralliance.org info@wildfloweralliance.org

Secondly, we ask that you bear in mind that many people in treatment lie to providers. Specifically, research has suggested that the matter about which they lie most commonly is how well the treatment is working, generally exaggerating positive effects (American Psychological Association, Shaffer, 2019). This may happen for any number of reasons including not wanting to hurt the provider's feelings, that certain other benefits (housing, SSI/SSDI income, etc.) are or are perceived to be dependent upon the continuation of the relationship, fear of what might be tried next if something is acknowledged as not working, and power imbalances and fear of negative consequences.

Finally, we ask that you factor into your considerations how difficult it is to find individuals who've been subjected to AOT orders who are willing to speak out against AOT, and to balance out pro-AOT perspectives. These individuals are hard to find for multiple reasons including:

- · Many individuals on AOT or other forced drugging orders struggle with sedation and clarity of thought that make it difficult to speak out
- · Many individuals currently or previously on AOT orders are afraid to speak out against AOT for fear of facing retaliation or other negative consequences

Between us – we have met hundreds of people with psychiatric histories and while opinions on what does help varies to some extent - we've only very rarely heard anyone argue in favor of force, coercion and loss of liberty.

#### Part II:

In addition to the above rebuttals, we would like to offer the following for your consideration:

#### 1. Treatments that "AOT" would force are <u>NOT</u> consistently effective:

We now have a variety of studies showing the limited efficacy and high risk of negative effects related to the treatments "AOT" would require.

In a 2013 TED Talk (<a href="https://tinyurl.com/DAndTED">https://tinyurl.com/DAndTED</a>), neurobiologist David Andersen said the following:

"These drugs have so many side effects because using them to treat a complex psychiatric disorder is a bit like trying to change your engine oil by opening a can and pouring it all over the engine block. Some of it will dribble into the right place, but a lot of it will do more harm than good."



Formerly known as the Western Mass Recovery Learning Community

187 High Street, Suite #202 Holyoke Ma 01040 Toll free 866.641.2853 Fax 413.536.5466 Voice/TTY {413} 539-5941 www.wildfloweralliance.org info@wildfloweralliance.org

Additionally, we have a study by Martin Harrow (World Psychiatry, 2018) on the outcomes of long-term use of neuroleptics (aka "Antipsychotics") that shows that many people who stay on these medications for an extended period actually tend to do worse in all areas of life (including those related to risky or potentially dangerous behavior).

We are also struck by a decision in Norway that forcing use of the class of drugs called antipsychotics is not legal according to their Psychiatric Act expressly because the likelihood of positive outcomes is too low (Gøtzsche, Mad in America, 2019). It must also be noted that individuals taking these drugs risk serious health consequences including metabolic disorders, kidney failure, and tardive dyskinesia all playing a role in the fact that individuals treated in the psychiatric system are dying on average over 20 years younger than the general population (Frontiers in Psychiatry, Mooij et al, 2019). Additionally, there does not appear to have been improvements in outcomes for mental health treatments in several decades. In actuality, increased use of psychotropics appears to strongly correlate with an increase in disability rates (Whitaker, Mad in America, 2016).

Where serious infringements on the liberty of an individual is concerned, at a bare minimum, there should be reasonable amount of assuredness that treatments will work and will not cause additional harm in the process.

#### 2. Force causes <u>HARM</u> and <u>INCREASES</u> many of the risks AOT proponents claim to want to minimize:

It is also essential to note that the loss of power and agency that comes with force has repeatedly been identified as a risk factor in increasing suicide and decreasing trust in (and thus, willingness to engage with) providers and their services.

In a 2017 meta analysis from the Journal of the American Medical Association (JAMA) psychiatry (Chung et al), it was found that people committed to a psychiatric facility could experience increased suicidal risk for up to two years following discharge. Another study (Suicide Life Threatening Behavior, 2019, Jordan & McNeil) found that even the perception of coercion at the point of admission to a psychiatric facility led to an increase of suicidal risk upon discharge. And a 2008 study (BMC Health Services, Gilbert et al) found a direct correlation between lack of coercion and positive relationships with providers, as well as related increased likelihood of engaging in treatments.

The risk of loss of power is not isolated to holds on inpatient units. In 2021, the Wildflower Alliance itself conducted research about the impact of COVID quarantines on people who experienced them as loss of power. They found that – particularly for people who had previously experienced involuntary psychiatric treatment – the loss of power associated with quarantines led to substantial increases in problems with



Formerly known as the Western Mass Recovery Learning Community

187 High Street, Suite #202 Holyoke Ma 01040 Toll free 866.641.2853 Fax 413.536.5466 Voice/TTY {413} 539-5941 www.wildfloweralliance.org info@wildfloweralliance.org

suicidal thoughts, substance use and so on. These sorts of impacts of quarantines have also been documented in previous meta-analyses (Lancet, Brooks et al, 2020)

Also of note, in 2017, the United Nations Special Rappoteur, Danius Puras said the following:

"I see the global state of mental health not as a crisis of chemical imbalances but a crisis of power imbalances, requiring urgent policy responses to address the social determinants of mental health as well as the reflection of powerful stakeholders on their role in perpetuating an abusive status quo."

The bottom line is that loss of power has real impact on people. This can include both increased risk of suicide and violence toward others. AOT leads to precisely this type of loss of power, whether perceived, implied, or actual, and thus also leads to increased risk of the outcomes it seeks to mitigate.

- **3. AOT perpetuates inequity:** Not only does "AOT" perpetuate discriminatory attitudes toward individuals with psychiatric histories, but it is also highly likely to disproportionately impact Black and Brown communities. Black and Brown individuals are already over represented in the public sector mental health system, and are frequently subjected to harsher diagnoses, and more frequent and harsher use of force (forced drugging, incarceration, restraint, etc.) Along those lines, other states have found that "AOT" is also applied with the same sort of bias (NYARPS, Martinez et al, 2016).
- **4. AOT** is <u>NOT</u> effective and will INTERFERE with implementation of alternatives. A great deal of the data collected on "AOT" is highly flawed, particularly research samples professing to have found that people subjected to "AOT" tend to appreciate it over the long-run. This just doesn't bear out in practice, though some individuals may at times support "AOT" because they're afraid of consequences if they don't.

Furthermore, research on "AOT" has often been conducted in a highly flawed and biased manner, and has led to outcomes that are impossible to interpret for their inability to be separated out from the impact of an influx of voluntary services and supports.

Also of concern, diverting substantial resources into "AOT" plans means less resources for alternatives such as peer respites which – if they're ever to reach their full potential – must be supported much more robustly than in the past.

Ultimately, more of the same (especially by force) simply isn't any kind of solution at all.



Formerly known as the Western Mass Recovery Learning Community

187 High Street, Suite #202 Holyoke Ma 01040 Toll free 866.641.2853 Fax 413.536.5466 Voice/TTY {413} 539-5941 www.wildfloweralliance.org info@wildfloweralliance.org

5. AOT laws may serve to PREVENT more people from even trying to seek out help at all. The Wildflower Alliance has approximately 50 team members between those who hold permanent and per diem hours. Almost all of us have met people who refuse to interface with the conventional mental health system for fear of a mix of poor options and force. They engage with us specifically because we won't use force, and function largely outside of the clinical system.

What we have learned from hundreds of thousands of conversations is that:

- $\cdot$   $\,$  Many people would rather seek no help than experience force and loss of control as a result of reaching out
- · This greatly increases the frequency by which people seek no help until things have reached a full crisis and reaching out can no longer be avoided (or someone else reaches out on their behalf)

In order to improve access to effective supports and positive outcomes, we must focus on building a system that individuals can trust. Among other things, this requires limiting use of force as much as possible. Introducing AOT would have the opposite effect.

In conclusion, we implore you to reject H.1694/S.980, and to instead, focus on Bills that increase voluntary supports and alternative crisis responses. These include:

- · H.3602/S.1238, An Act to Establish Peer-Run Respite Centers Throughout the Commonwealth
- · H.2264/S.1407, An Act to Create Equitable Approaches to Public Health
- · H.1980, An Act to Ending Unnecessary Hospitalizations and Reducing Emergency Department Boarding

I have also attached a copy of my Masslive OpEd, 'What's Missing from Talk of 'Assisted Outpatient' Care published in June, 2023.

Thank you for your time and consideration.

On behalf of the Wildflower Alliance,

Sera Davidow

Director

**Attachment 1:** Letter to the Editor re: Anosognosia by psychiatrist Larry Davidson, Hartford Courant

Attachment 2: Article re:Anosognosia by psychiatrist Sandy Steingard, Mad in America

Attachment 3: OpEd re: AOT by Sera Davidow, Masslive



Formerly known as the Western Mass Recovery Learning Community

187 High Street, Suite #202 Holyoke Ma 01040 Toll free 866.641.2853 Fax 413.536.5466 Voice/TTY {413} 539-5941 www.wildfloweralliance.org info@wildfloweralliance.org



Formerly known as the Western Mass Recovery Learning Community

187 High Street, Suite #202 Holyoke Ma 01040 Toll free 866.641.2853 Fax 413.536.5466 Voice/TTY {413} 539-5941 www.wildfloweralliance.org info@wildfloweralliance.org

#### **Denial of Mental Illness Not Neurological**

Letter to the Editor, Hartford Courant, by Larry Davidson, May 3, 2013

I can reassure Drs. E. Fuller Torrey and Xavier Amador that I know of their theory linking anosognosia to schizophrenia [May 1, letter, "Neurological Basis For Denying Illness"; and May 3, letter, "Condition Obscures Mental Illness"]. Anosognosia is a neurological condition in patients with nondominant parietal lobe lesions, who deny their partial paralysis.

I can understand wanting to apply this notion to mentally ill persons who refuse treatment, but there are at least five reasons not to:

 No such lesions have been found in schizophrenia, despite over 200 years of research looking for them. What Drs. Amador and Torrey have is a theory, not a fact. Other than justifying outpatient commitment, this theory has led to no breakthroughs in treatment.

Not only are such theories dangerous, but they 2) do not explain how so many people with schizophrenia gain insight and recover over time; 3) do not take into account the power of stigma, which persons with mental illnesses identify as the major barrier to accessing care; 4) do not take into account the limited effectiveness and responsiveness of much mental health care; and 5) do not support outpatient commitment because schizophrenia is the least likely condition among the mental illnesses to be implicated in the extremely rare acts of violence that occur.



Formerly known as the Western Mass Recovery Learning Community

187 High Street, Suite #202 Holyoke Ma 01040 Toll free 866.641.2853 Fax 413.536.5466 Voice/TTY {413} 539-5941 www.wildfloweralliance.org info@wildfloweralliance.org

# Anosognosia: How Conjecture Becomes Medical "Fact"

How ideas become mainstream without any research basis.

Posted August 30, 2012, Psychology Today

#### By Sandy Steingard

Neurologists use the term anosognosia to describe a peculiar syndrome in which a person has a profound lack of awareness of an obvious deficit. For instance, a person who has a stroke on the right side of his brain and is paralyzed of the left side of his body has no awareness of the problem. He might not recognize his left arm as his own. When given a page to read, he might only read the words on the right side of the page. He would only put his shirt on his right arm but when asked if he was adequately dressed, he would answer, yes. This phenomena is regularly associated with damage to the right side of the brain in the section called the parietal lobe.

In the 1990's, a psychologist, Xavier Amador, began to use this term in the context of describing a person who was experiencing psychotic symptoms and did not believe that his problems were due to an illness. For instance, if a



Formerly known as the Western Mass Recovery Learning Community

187 High Street, Suite #202 Holyoke Ma 01040 Toll free 866.641.2853 Fax 413.536.5466 Voice/TTY {413} 539-5941 www.wildfloweralliance.org info@wildfloweralliance.org

person heard voices that no one else heard, he might conclude that he was communicating with dead relatives. When his doctors or family told him that he was sick, he would disagree. Doctors would call this "lack of insight" and Amador was one of the first to appropriate the neurological term anosognosia to describe this.

There is a history in neuroscience of trying to apply what has been learned from studying the cognition and behavior of people who have had strokes to develop a more general understanding of the connection between brain function and behavior. In that spirit, there have been multiple studies to address whether there were changes in the brains of people who were psychotic and were described as having a "lack of insight" that were similar to the changes found in people who had right hemisphere strokes.

Readers on this site have wondered how the notion of a "chemical imbalance" could have been accepted by so many when the research did not actually support the concept. A recent paper from the Treatment Advocacy Center that summarizes studies of anosognosia in psychosis gives some clue as to how this type of thinking becomes entrenched and accepted.



Formerly known as the Western Mass Recovery Learning Community

187 High Street, Suite #202 Holyoke Ma 01040 Toll free 866.641.2853 Fax 413.536.5466 Voice/TTY {413} 539-5941 www.wildfloweralliance.org info@wildfloweralliance.org

The paper reviewed 18 studies of brain imaging of people who were identified as having this syndrome. This is from the conclusion to that study:

"Regarding localization, it is now clear that anosognosia is not caused by damage to one specific area. Rather a person's awareness of illness involves a brain network that includes the prefrontal cortex, cingulate, superior and inferior parietal areas, and temporal cortex and the connections between these areas. Damage to any combination of these areas can produce anosognosia, but damage to the prefrontal and parietal areas together make anosognosia especially likely.

Anosognosia, or lack of awareness of illness, thus has an anatomical basis and is caused by damage to the brain by the disease process. It thus should not be confused with denial, a psychological mechanism we all use."

This conclusion, which will now likely be repeated in TAC publications and elsewhere as a definitive statement of scientific "fact", involves some slight of words. What the paper reports is that 15 of 18 studies found group differences between the study subjects and the controls but the findings were highly variable between studies. In the summary above, they mention that differences were found in multiple brain regions but the findings did not



Formerly known as the Western Mass Recovery Learning Community

187 High Street, Suite #202 Holyoke Ma 01040 Toll free 866.641.2853 Fax 413.536.5466 Voice/TTY {413} 539-5941 www.wildfloweralliance.org info@wildfloweralliance.org

overlap much between the studies, i.e., although 15 studies had "positive" findings, they were often different findings in each study. My assumption from reading this review is that, despite this research, if one were to show a scan to a doctor, he would not be able to make a diagnosis from the scan. In other words, the differences are subtle and do not clearly distinguish a person with "lack of awareness" of psychotic symptoms from any one else.

If one were to do a similar study of patients who had strokes and subsequently had the classic form of anosognosia, the findings would be strikingly different. In every study, there would be profound abnormalities in the brain and they would all be found in the right parietal lobe of the brain. If you showed me a series of scans of people with left sided neglect due to strokes and those of people who did not have this syndrome, I believe I could easily pick out those with left neglect. In this case the brain damage would be obvious and the resulting deficit would be easy to predict.

In the TAC summary, the use of the word "damage" is misleading.

Abnormalities – or in this case group differences – do not equal damage. I am left handed. I imagine that with some types of brain imaging, my brain would look different from my right handed friend but that does not mean my brain is damaged; it only means my brain is different.



Formerly known as the Western Mass Recovery Learning Community

187 High Street, Suite #202 Holyoke Ma 01040 Toll free 866.641.2853 Fax 413.536.5466 Voice/TTY {413} 539-5941 www.wildfloweralliance.org info@wildfloweralliance.org

The final statement in this conclusion, that anosognosia "should not be confused with denial, a psychological mechanism we all use," makes no sense to me. Why do they believe that there are no brain changes underlying the so-called psychological condition of denial? In most of the studies reviewed, they would ask people questions while they were in the scan. A sample question was "If someone said I had a mental illness they would be right." The type of "psychological denial" that the authors want to distinguish between this so-called anosognosia would presumably be something along the lines of someone who has lost a loved one but does not report being sad. The only way one could conclude that the findings in the psychosis studies were different and somehow distinct would be to scan the brains of people who were found to have "psychological denial" and compare those to brain scans from individuals who had "good insight" and as well as those who are identified as having lack of insight of psychosis.

As with the notion of "chemical imbalance", the term anosognosia has crept into the psychiatric lexicon. Its use confers a certain sophistication of understanding and knowledge that is not supported by the data.

Sandra Steingard, M.D. is the Medical Director of HowardCenter and Clinical Associate Professor of Psychiatry at the University of Vermont College of



Formerly known as the Western Mass Recovery Learning Community

187 High Street, Suite #202 Holyoke Ma 01040 Toll free 866.641.2853 Fax 413.536.5466 Voice/TTY {413} 539-5941 www.wildfloweralliance.org info@wildfloweralliance.org

Medicine in Burlington. She was educated and trained at Harvard and Tufts Universities in Boston and received her specialty certification in psychiatry from the American Board of Psychiatry and Neurology in 1986.

Her areas of interest include community mental health and the diagnosis and management of psychotic illnesses. She was named an Exemplary Psychiatrist by the National Alliance for the Mentally III of Vermont in 1996, and has been listed in the *Best Doctors in America* since 2003.



Formerly known as the Western Mass Recovery Learning Community

187 High Street, Suite #202 Holyoke Ma 01040 Toll free 866.641.2853 Fax 413.536.5466 Voice/TTY {413} 539-5941 www.wildfloweralliance.org info@wildfloweralliance.org

## What's missing from talk of 'assisted outpatient' care (Commentary)

Updated: Jun. 06, 2023, 2:17 p.m.| Published: Jun. 06, 2023, 2:06 p.m.

By Sera Davidow

The public is familiar with "involuntary commitment." If they haven't seen it personally, they've watched it play out on TV. Involuntary commitment usually begins with an ambulance ride to an Emergency Room to assess "risk to self or others," followed by an inpatient hold for further evaluation and treatment.

However, what most people don't know is that a fight – invisible to most – is being waged over something proponents call "assisted outpatient treatment."

Massachusetts is one of only three states still trying to block this form of treatment – and with good reason.

"AOT" may best be understood as "probation" for someone convicted of no crime. Instead, they are deemed "at risk" (due to inpatient hospitalizations, suicidal thoughts, etc.), and are ordered to take medications, attend therapy, and meet other requirements under threat of being brought back to the hospital if they don't.

The argument over this mental health treatment commonly devolves into what I see as a false binary: Does the use of force violate people's right to liberty, or does lack of treatment itself deprive them of their right to health?

Most acknowledge that personal rights are lost through such mandates, but supporters of assisted outpatient treatment refer to the alternative as "dying with your rights on." This debate is not without merit. However, it dances around crucial points, including the impact that use of force has on a person and its potential to worsen things, as well as whether treatments that are being forced even work.



Formerly known as the Western Mass Recovery Learning Community

187 High Street, Suite #202 Holyoke Ma 01040 Toll free 866.641.2853 Fax 413.536.5466 Voice/TTY {413} 539-5941 www.wildfloweralliance.org info@wildfloweralliance.org

People in favor of assisted outpatient treatment provide horror stories about family tragedies that could have been prevented. Some news stories cite such cases, even when the person written about wouldn't have qualified for an "AOT" order). This manipulates an audience's emotions whether or not the facts add up.

In some ways, "AOT" makes sense. It's human nature to seek easy answers, especially after something bad happens. Communities want – perhaps need – to believe that preventive measures have been taken. Unfortunately, these measures amount to little more than illusion, and can make things worse even as they claim to be the "fix."

n 2020, the group I direct, the Wildflower Alliance, conducted preliminary research into the impact of the pandemic on suicidal thoughts.

People were asked if they experienced the pandemic as loss of power, if they had experienced prior losses through forced treatment and whether suicidal thoughts increased during this period.

The results were consistent with an earlier study regarding adverse childhood experiences.

The impact of losses of power is cumulative. Sixty percent of people identifying prior experience with force saw an increase in suicidal thoughts, compared to 25% of people without that history.

This aligns with a 2019 study suggesting that even the perception of coercion when admitted to a psychiatric facility led to increased risk of suicide upon discharge. Several other studies have correlated forced treatment with people wanting to die.

The problem is bigger than that. Journalist Rob Wipond dedicates a chapter in his book, "Your Consent is Not Required," to the science examining the efficacy of force. He cites a "remarkable lack of experimental studies" on the utility of force, and the research that exists doesn't favor it.

Research on "AOT" is even weaker. It points to a history of racially biased implementation and suggests significant potential alienation when thrust upon people who most need aid. Additionally, fear of force contributes heavily to people not seeking help from the start.



Formerly known as the Western Mass Recovery Learning Community

187 High Street, Suite #202 Holyoke Ma 01040 Toll free 866.641.2853 Fax 413.536.5466 Voice/TTY {413} 539-5941 www.wildfloweralliance.org info@wildfloweralliance.org

And, what of the trauma and cost of an unfunded mandate on police to bring in individuals who do not comply? This remains largely unexplored.

The assisted outpatient treatment interventions themselves lack evidence of efficacy. In 2018, Norwegian officials determined that compelling use of "antipsychotic" drugs was inconsistent with their laws because the probability of positive outcomes was too low. Other research indicates that long-term use of these strategies tends to lead to worse outcomes in every possible area.

If force increases alienation and all kinds of risks, and forced treatments are failing the majority, why would we spend valuable resources on more of the same?

In the words of Pat Deegan, leader in the field of mental health recovery, "Help is not help if it doesn't help." And, it certainly is not help if it hurts.

Sera Davidow is a mother, advocate, author, filmmaker, and director of the Wildflower Alliance, a peer support and international training organization in Western Massachusetts.