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

The Honorable Michael S. Day
Chair, Joint Committee on the Judiciary
24 Beacon Street, Room 136
Boston, MA 02133

Re: Testimony in opposition to S.980, H.1694, An Act to provide critical community health services

Chair Eldridge, Chair Day, and Honorable Members of the Committee on the Judiciary:

Thank you for the opportunity to provide testimony in opposition to S.980 and H.1694, An Act to provide critical community health services.

My name is Rae Simpson, and I have a son with significant mental health challenges. Also, although I am not writing to represent my local NAMI affiliate, I answer our phone line, run family support groups, and respond to emails, so I hear from many families searching for resources for their loved ones. As you can imagine, I would like nothing more than for AOT to be a solution to the serious problems with services.

But I have also done my homework. As a specialist with 40 years of experience in science communication and research analysis, now retired from MIT, I've looked at the studies—Does AOT really work as promised? And the answer is unequivocally no. The claims for AOT simply do not hold up to the scrutiny of unbiased research. We need to pay attention to the impartial experts, because families like mine are being misled.

Families are being lured with false promises about AOT. Mine used to be one of those families, waiting for my son to get better with long periods of involuntary treatment and medication. But he got worse and worse, in a heartbreaking spiral, until he landed in a voluntary community program of safe housing and supportive relationships. Now, finally, he is getting better.

I learned the hard way. And I don't want to see more families go through what ours did.

I have created a short Fact Sheet summarizing the research, which is an addendum to this testimony. Bottom line, a number of controlled, unbiased studies have been done on AOT in other states, and they do not show effectiveness of AOT beyond that of comparable voluntary services.

This is in part because the medications that are imposed in AOT are, by the pharmaceutical industry's own studies and researchers' meta-analyses, helpful only to a minority of patients. And those medications—again by the industry's own acknowledgement—often have debilitating effects, especially brain fog, inability to focus, Parkinson's-like movement disorders, agitation, and metabolic disorders. The odds of significant recovery have been found to be dramatically lower for those who take antipsychotics long term than for those who stop or never start, in part because they are chronically disabled, less able to work or live the independent life that families have in mind.

What is sometimes dubbed "anosognosia" is often an effort by the individual to weigh the complex equation of costs and benefits of risky medications. According to the NIH, 55% of people prescribed ANY medication, for any health condition, do not take the medication according to directions, but their concerns are not attributed to a biological lack of insight.

Even intuitively, it makes sense that AOT isn't working. If AOT were effective, the 47 states that have implemented versions of it would be doing better than Massachusetts, and they most certainly are not. They simply haven't moved the needle.

A key reason for their failure is that people change through trusting relationships, and AOT does terrible damage to relationships. According to the eminent psychiatrist Thomas Insel MD, former head of the National Institute for Mental Health, our standard approach to psychiatric care has failed. *Patients need "people, place, and purpose"* –relationships that build trust, safe housing, and meaningful work. As Dr. Insel and many have testified in other venues, there are many programs that provide that—voluntarily and successfully.

We can learn from their experience and use our resources for programs that really do work, of which there is an impressive array. There are programs like CAHOOTS that keep most people in crisis out of emergency rooms to begin with, and there are programs like EMPATH that send 75% or more of ER mental health patients home instead of to hospitals, and there are programs like Open Dialogue and like INSET, about which you heard testimony at the hearing on September 7th, that bring recovery permanently, not just as long as people are under a mandate.

Programs like these are expanding rapidly around the country, because they work—and they save money. We already have local versions of many of these and other excellent programs in Massachusetts, some nationally recognized, ready to expand. I would be happy to provide a list.

These programs are the wave of the future in mental health care; **AOT is part of the failure of the past.** The World Health Organization now advocates phasing out involuntary programs altogether.

I urge the Legislature to support and expand the services that have a track record of success, and that will in fact help the many families like mine. I urge the Committee report on S.980/H.1694 as "ought not to pass." Thank you.

Respectfully submitted,

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ASSISTED OUTPATIENT TREATMENT (AOT)
What the Research Tells us

AOT Is Not Effective

- Unbiased research studies do not find significant differences in outcomes between patients in AOT and in voluntary community services. See for example the Bellevue study[i], the North Carolina study[ii], the UK study[iii], the Oxford study[iv], the Cochrane Collaboration review[v], and the summaries of studies here[vi], here[vii], and here[viii]. *The Oxford study concluded, "In the absence of further trials, moves should be made to restrict or stop their use."*

    - As a result, the World Health Organization now advocates[ix] a transition from coercive to voluntary community services worldwide.

- Studies and data that appear to show success from AOT use methodology that is flawed[x], and more rigorous analysis[xi] calls the results into question. The small percentage of success stories does not change this fundamental reality.

- Common sense alone, from a simple reading of the national news, tells us that AOT is not working. If AOT were effective, we would see it working in the 47 states that have adopted versions of it. Instead, some of the most extensive users of AOT, such as New York and California, have worsening problems with senseless tragedies, homelessness, and violence.

Reasons Why AOT Fails

- Generally, the goal of AOT is to require people to accept treatment, and that treatment specifically means medication, on the assumption that their problems stem from being "off their meds." However, antipsychotics[xii] and antidepressants[xiii], by the pharmaceutical industry's own studies and researchers' meta-analyses[xiv], are *helpful only to a minority of patients*. Technically, their benefit is "statistically significant," so they are described as effective. However, this only means that the drugs help *a fraction of* patients, even after multiple trials. And even these results come from the kind of industry studies whose methodological flaws[xv], publication bias[xvi], and misreporting[xvii], have been the subject of major scholarly concern, just as they have in other branches of medicine.

- There is also ~~important evidence of racial bias in the implementation of AOT~~ [xviii] ~~and in~~ drug marketing[xix].

- Psychiatric medications—again by the industry's own acknowledgement—carry life-threatening consequences. For some, medication can mitigate symptoms in ways that are needed and welcome, at least until something better comes along. But odds of full recovery have been found to be dramatically lower[xx] for those who take antipsychotics long term than for those who stop or never start, in part because they are less able to work[xxi] or live independently—they become more chronically disabled.

- Psychiatric medication carries substantial risks with uncertain benefits. What is often dubbed "anosognosia" by AOT proponents, in many cases, may well be a struggle to determine whether and to what extent the risks of these flawed medications outweigh the benefits. This is a complex calculus, one that happens with supportive care, not coercion.

- These reasons for AOT's failure are fundamental, and won't be solved by tinkering with the details of legislation. At heart, AOT depends on strategies that simply don't work.

What does work

- What work are approaches that build trusting relationships, offering persistent but voluntary help that allows people with mental health conditions to maintain their humanity and balance the odds of receiving benefits from treatments against the realities of their harmful effects, and, with support, to find what is uniquely right for them.

- As widely respected psychiatrist Thomas Insel MD, former head of the National Institute for Mental Health, ~~puts it~~[xxii]~~, we~~ now know that our standard approach to psychiatric care has failed. *Patients need "people, place, and purpose"* –relationships that build trust, safe housing, and meaningful work. As Dr. Insel and many have testified, there are many programs that provide that—voluntarily and successfully.

- Other countries[xxiii] are having much more success in reducing problems associated with mental health than the U.S., based on widespread use of these voluntary approaches.

Conclusion

Bottom line, rigorous studies have not substantiated proponents' claims for AOT, for reasons that make common sense and fit the widespread experience of experts. There are treatments that are not only more humane but also less costly and more effective.

--Prepared by Rae Simpson, PhD, mental health advocate and consultant, raesimpson.com, raesimpson1@gmail.com. Current version is a work in progress: Please contact Rae for updated information.

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