

August 14, 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

**Testimony in opposition to S.980/H1694 An Act to provide critical
community health services**

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

I am writing as a parent of a son with schizophrenia and an independent mental health advocate. I have come to this new career to help families like mine have a better outcome, specifically to avoid the type of estrangement my family has experienced since 2007. My journey into this new career began with a graduate program that provided me the opportunity to be an intern at the State House. At that time, I chose to work for Rep. Kay Khan specifically because she was advancing Assisted Outpatient Treatment (AOT) in Massachusetts.

As a parent, I came to AOT thinking that it would be okay – even better – because while it was forced treatment it was not forced hospitalization. What I learned through doing research on the matter for Rep. Khan and in partnership with Morgan Shields, a research fellow who has since completed her PhD in healthcare research, is that AOT is not the panacea that families are led to believe. In fact, the results, even in 2017, were at best murky. Today there is much more research that shows forced treatment only succeeds for as long as it is being forced. Do we really want an AOT order to be something permanent for those individuals? My wish as a parent, and I suspect it's true for many, is that our loved one will become independent and live a fulfilling life. Not a life controlled by others indefinitely.

In the many years since my son experienced his first psychotic episode, I have met many parents, like me, who have come to realize that attempting to bargain with, force or otherwise decide a treatment course for our loved one has not worked and has generally worsened our relationship to the point of permanent estrangement. George Kaufmann is a NAMI parent ([YouTube video](#)¹) who I met recently. He speaks eloquently about the need to rely on building supporting relationships with loved ones. He also laments the many years wasted trying to convince his son to do it "his" way. Today, they have a loving relationship that is the goal for all of us as

¹ I suggest watching the next 11 minutes

families. My family has not been so lucky. My son is no longer connected to us in any way.

Of course, the problem families face is real. Watching your loved one get more and more ill, abandoned by the system, is not acceptable. But there are alternatives. Born out of the discussions in Rep Khan's office, I attempted to generate interest in a Relentless Outreach PACT program in 2017. Modeled on Roca's approach of relationship and trust building, which typically takes six months, I believed we could connect these family members with wrap around services. I have come to learn that about that same time, a similar program was launched in Westchester County, NY called INSET. This past year, the State of New York allocated additional funding of \$2.8M to start up 4 additional INSET teams in the state (there are 4 counties covered today). I am submitting a fact sheet on INSET with this testimony.

What is most important about INSET is how it is distinct from AOT is its ethos. INSET is grounded in the understanding that the existing system has failed a certain group of people. Approaching that group with the same techniques that haven't worked in the past are only frustrating. INSET is also grounded in trust and relationship building. I attended the NAMI National Conference in late May and the Mental Health America Conference in early June. A recurring theme among attendees is how to shift the conversation from convincing people that XYZ is what they need and instead build trust and talk together about goals and how to achieve them. INSET is the most mature program of this type, but other places are coming to the same realization.

We need to address the problem of folks failed by the system or unwilling to engage with it. Forcing engagement in the same system, does not work. We need to approach this very human problem with a very humane answer. Listen, listen, listen, so we can establish a relationship with hope.

Boston Healthcare for the Homeless approaches their patients by "bringing care to patients where they are, taking the time to build relationships and trust, all with abundant compassion."

Here in the Commonwealth, we can do better than AOT. We can be a leader in adopting the right approach without "passing through" coercion on the way. I urge you to oppose this bill and support an INSET-style pilot in Massachusetts. Our families and loved ones also deserve care with abundant compassion.

Thank you for the opportunity to submit this testimony.

Monica Luke
Mental Health Advocate
mhpolicy.org
Somerville, MA