October 31, 2023

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

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

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

Re: Opposition to H.1694/S.980, An Act to provide critical community health services

We are a coalition of advocates, people with lived experience, and family members who oppose Involuntary Outpatient Commitment (IOC). We write to express our opposition to H.2694/S.980, An Act to provide critical community health services, heard by your Committee on July 18, 2023 and September 7, 2023.

H.1694/S.980 would allow a range of persons to petition courts to force medication and other treatments and services upon individuals with mental health issues who are living in the community. It further allows courts to sanction those who do not comply with such treatment with treatment orders or curtailment of liberty through involuntary hospitalization.

Members of our coalition have provided your Committee with substantial oral and written testimony in opposition to this legislation and IOC more generally. We write now to <u>summarize oral and written</u> <u>testimony provided to your Committee against IOC</u> and to provide supplemental information regarding certain issues that may be of particular interest to the Committee, including <u>impact of IOC on BIPOC communities</u> and the <u>misuse of the concept of "anosognosia" to advance IOC</u>.

I. Coalition resources previously provided to the Committee

As we have said, this letter summarizes testimony and addresses some specific concerns. It does not provide a comprehensive review of all arguments against IOC. For a <u>broader reflection of our coalition's concerns with IOC</u>, please see this <u>fact sheet</u> and this <u>Policy Paper</u>, both the products of our coalition.

Additionally, we know that the Committee is interested in <u>learning how IOC has been implemented in other U.S. states and locals</u>. For a review of research regarding that implementation, please see this <u>paper which we prepared at the suggestion of Committee staff.</u>

We also take this opportunity to provide a link to a very recent guidance on mental health from the World Health Organization (WHO) and the United Nations Human Rights, Office of the High Commissioner, entitled Mental Health, Human Rights and Legislation: Guidance and Practice (2023).

The guidance unequivocally rejects the use of coercion in mental health care. WHO and the UN Office of the High Commissioner call upon "countries to review their legal frameworks to repeal community treatment orders," noting that "overwhelming evidence indicates that these orders are ineffective, with no reported decrease in hospitalization or benefits for persons using mental health services." Community treatment orders are the same as and are usually called IOC or Assisted Outpatient Treatment (AOT) in the United States.

II. Summary of written and oral testimony in opposition to IOC

Testimony on Behalf of Organizations

Written testimony from the Center for Public Representation (CPR) focused on six concerns with the bills: 1) The bill would impose a substantial programmatic, personnel, and financial burden on the courts and the mental health system; 2) Research shows that courts disproportionally impose involuntary outpatient commitment on people of color; 3) the bill creates a scheme for outpatient commitment, but does not require or fund the development of an array of community treatment options as a less restrictive alternative; 4) the bill would effectively create a legal entitlement for community-based services; 5) the bill would empower courts to compel health care providers to supervise and even fund forced treatment plans that they might not be able to oversee and/or do not believe are appropriate; and 6) the bill infringes on the constitutional right to privacy and property. Steven Schwartz, Esq., CPR Litigation Director, delivered oral testimony for CPR.

Oral testimony from the Committee for Public Counsel Services (CPCS) addressed IOC proponents' claim that this bill does not involve forced treatment. A court order requiring treatment is forced treatment. A non-compliance hearing for failure to adhere to a court order is also forced treatment. CPCS objected to the bill as a violation of the constitutional right to privacy, that is, freedom from nonconsensual invasion of bodily integrity. This right means that we are all presumed competent to decline treatment, even those persons civilly committed after being adjudicated mentally ill and a danger to self or others. First, there are constitutionally sound due process procedures used by courts to enter orders for the administration of extraordinary treatments, such as anti-psychotic medication, ECT treatment, and other extremely invasive treatments. These procedures require a hearing on the competency of the person to make informed medical decisions. Then a substituted judgment determination to ascertain what the treatment would be that would be acceptable to the person determined to be incompetent. By ignoring these requirements, this bill unconstitutionally forces medications on individuals regardless of their competency and their substituted judgment to decline treatment. Second, this bill will overburden district courts. In 2022, there were over 480,000 filings in District Court before 157 District Court judges. This bill would require not only the initial trials, but also non-compliance trials and termination trials appeals and monthly monitored monitoring of the treatment process. CPCS does not have enough mental health attorneys to cover the commitment procedures, proceedings, of which we get about 6000 on a yearly basis, despite tremendous efforts to

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¹ World Health Organization (WHO) and the United Nations Human Rights, Office of the High Commissioner, Mental Health, Human Rights and Legislation: Guidance and Practice (2023) at 13, 66-67. ² *Id.* at 67.

recruit and retain attorneys. CPCS's Deputy Chief Counsel and Director of CPCS's Mental Health Litigation Division Laura Sanford delivered oral testimony for CPCS.

<u>Written testimony from the Disability Law Center (DLC)</u> focused on four concerns with the bills: 1) IOC lacks prove effectiveness, compared with alternatives; 2) IOC misallocates resources and does so in a manner that reflects social stigma; 3) IOC leads to troubling changes in the roles of judges and treatment providers; and 4) H.1694 raises confusing and problematic drafting issues. *Richard Glassman, Esq., DLC's Director of Advocacy, delivered oral testimony for DLC.*

Written testimony from the Disability Policy Consortium (DPC) opposed the bill on the bases that it forces people to participate in treatment, and often to take medication against their will. DPC sees this as a violation of bodily autonomy. They further notes that the bill's reliance on the vaguely defined term "gravely disabled" opens the door for unnecessary institutionalization, stigma, and bias. The bill may exacerbate trauma for people already likely to have experienced it. It is unclear who would pay for services and may expose people to medical debt. The testimony noted that studies have not found IOC to be effective. DPC supports more care coordination services, but not in the form of IOC. Collin Killick, DPC Executive Director, delivered oral testimony for DPC.

Written testimony from the Massachusetts Association for Mental Health (MAMH) focused on Massachusetts' current and emergent service systems, which it argues afford the opportunity to serve us all while relying on voluntary and evidence-based practices. MAMH explains that our Massachusetts behavioral health system has current services, emerging services, and the capacity to add new evidence-based services that can well serve people facing mental health issues. We should invest available resources in making sure these services are fully and effectively implemented, rather than adding a new and expensive layer of state control required by involuntary outpatient commitment. Danna Mauch, Ph.D., MAMH's President and CEO, delivered oral testimony for MAMH.

Written testimony from the Mental Health Legal Advisors Committee (MHLAC) focused on four main arguments: 1) research shows that involuntary outpatient commitment is ineffective and paradoxically deters participation in treatment; 2) voluntary treatment promotes engagement and is effective; 3) outpatient commitment is costly and draws funding away from treatments proven to be effective; and 4) Massachusetts has a statutory scheme to protect individuals with mental illness from harm and, when necessary and justified, to provide court-ordered treatment.

Written testimony from the Wildflower Alliance made fifteen points: 1) Assisted Outpatient Treatment (AOT), the bills' proponents term for IOC, DOES involve force both in the current Massachusetts proposal and in other states; 2) anosognosia is NOT a validated diagnosis for individuals with psychiatric histories; 3) H.1694/S.980 is NOT especially "limited in [its] application;" 4) AOT is NOT needed to ensure effective discharge planning; 5) though Massachusetts is one of only three states without an IOC law, many states do NOT use their laws effectively or at all; 6) the Boston Municipal Court's BOAT program, promoted by the bills' proponents as an example of effective AOT program, is fundamentally NOT the same as AOT; 7) surveys and polls about AOT to the general community should NOT be seen as relevant guidance for evaluating this bill; 8) NAMI Massachusetts does NOT support this Bill; 9) it is psychiatric drugs – NOT what gets called psychosis – that is most likely to cause brain damage; 10) public testimony in favor of AOT as provided by one individual who has been on an AOT order should NOT be weighted heavily; 11) treatments that AOT would force are NOT consistently effective; 12) force causes harm and increases many of the risks AOT proponents claim to want to minimize; 13) AOT perpetuates inequity; 14) AOT is NOT effective and will interfere with implementation of alternatives; 15) AOT laws may serve to prevent

more people from even trying to seek out help at all. **Sera Davidow, Wildflower Alliance's Executive Director, a person with lived experience, delivered oral testimony for Wildflower.**

Written testimony of NAMI Massachusetts, a grassroots organization with members who are individuals with mental health conditions, as well as their family members, loved ones and caregivers, stressed that we should and must support individuals living with a mental health condition and their families who are struggling and refusing support. NAMI Mass further urged support for programs that meet individuals where they are, including when they do not think they need any help. Rather than focusing on forced treatment, NAMI Mass suggests consideration of a non-coercive relentless outreach, peer-led approach. In Westchester County, NY, such a program has been established as an alternative to AOT, called INSET (Intensive and Sustained Engagement Team). Rather than pass AOT in Massachusetts, NAMI Mass suggests we should build specific capacity for care through a peer-led, peer respite-style program. Families then will have a place to turn and get the help they need to support their loved one's path to recovery. Individuals will be in control of their engagement voluntarily. NAMI Mass reviewed research on the inequitable application of AOT programs on Black and Brown people and concluded

We cannot, in good faith, continue to promote and enact legislation that disparately impacts Black and Brown communities. While the idea of AOT working at its best isn't racially motivated, the systems in which AOT will live are still rooted with inherent racism. We need to evaluate alternatives, as suggested above, that do not place more restrictions on Black and Brown communities, but instead serve as a model to support all individuals living with a mental health condition. We also need to consider what policies we are enacting and how they may adversely impact our Black and Brown community partners.

Individuals providing written and/or oral testimony

Oral testimony of Ruthanne Becker, M.A., the parent of a son with mental health issues since childhood and Senior Vice-President of Adult Rehabilitation and Recovery Services, Mental Health Association of Westchester County, NY, spoke about her New York program, Intensive and Sustained Engagement Team (INSET). She noted that INSET was designed specifically for the people who are the targets of the IOC bills, as an alternative to IOC. She testified that she has overseen this program for five years. INSET provides an innovative approach to working with and engaging with individuals who are currently under IOC or at-risk of being placed under IOC. The goal is a peer-initiated and peer-facilitated approach. INSET relies on intensive engagement, shared decision-making, self-determination and increased personal agency. Recovery is not only possible but probable. She testified that ss a parent, she, even as an expert, often felt powerless to help her child. She has sought help from outside services and often laid in bed hoping that someone could force him to accept hospitalization, treatment, mediation. But, she said, the truth was that when compelled he would only participate as long as he was required to. Only when he felt he was creating his own path, did recovery begin to happen. Being mandated to treatment does not help people to trust that people have their best interests at heart (even when we actually do), she testified. Instead, it makes them angry, defensive, or reluctant to let anyone know they are struggling. INSET started with the belief that if the focus was on engagement and the program was persistent in that engagement, they could make a difference. Team members with their own lived experience of recovery meet participants in the community, hospitals, shelters, homes, correctional facilities to begin engagement and provide ongoing support. They have provided INSET services to 235 individuals, and 86 of these individuals have been engaged. (Remember, she said, that this is a population viewed as not engaging in supports.) 95% of the people meet AOT criteria and during their tenure with INSET, not one

person has required a referral to AOT. She testified that people are provided with supports and services, through INSET, Peer Bridger, peer respites, or another type of program, if they are helped to engage, they will not require AOT. While the sample size is small, the results are significant. INSET has reduced hospitalization frequency and length of stay, sometimes eliminating admissions, reduced engagement in services, and eliminated the need for involuntary services.

Oral testimony of Thomas Brown, M.Ed., a person with lived experience, an advocate, a peer supporter, and cofounder of Massachusetts Advocating for Change Together (MassACT), a group of over 500 individuals with lived experience of trauma and other conditions and who oppose this bill, covered several topics. He spoke of the misuse of the concept of anosognosia, which is not a psychiatric term, but a medical one for a condition affecting stroke victims. He discussed his own lived experience to provide a sense of what people who are given medications or given forced treatment go through. He was experiencing terror and terrifying voices directly related to nearly two decades of sexual and physical assault. His psychiatrist put him on antipsychotics. And for three months, he experienced the worst period of his life, a sense of being entirely dead inside. His entire life fell apart by the third month of being on the medication and all he was doing was thinking of ways to end his life. He stayed on the medication because his psychiatrist said it was the only thing that would help him. When he finally had the courage to come off the medication, he experienced the same terror again, but it was an incredible relief, compared to being on the anti-psychotic medications. What is often missing in these conversations about what is good for people are the people's voices themselves. This concept of anosognosia is used without really looking at other possible interpretations for why some people need to resist treatment. There are alternatives to using coercive treatment: the EOHHS Behavioral Health Roadmap, a plethora of services specifically geared toward people in crisis, and the peer respite bill, which would put a peer respite in every county. Let's give these alternatives – let's give these alternatives a chance.

Written testimony of Lisa Cosgrove, Ph.D., professor at the University of Massachusetts Boston and a Faculty Fellow at UMB's Applied Ethics Center, describes her experience as a professor who teaches master's and doctoral level clinicians in training. In her experience, involuntary commitment does not achieve the desired effect that proponents hope it will. She highlights that numerous studies have shown that involuntary outpatient commitment is not effective at meeting its proponents' goals of treatment compliance and reduced rates of hospitalization. She explains that a growing number of both health care professionals and people with lived experience argue that involuntary commitment undermines the therapeutic alliance, is not evidence-based, violates fundamental human rights, and disproportionally impacts BIPOC communities. Both communities have coalesced around the message that voluntary treatment is more effective than involuntary treatment and that supported decision-making should supplant substitute decision-making.

Written testimony of Daniel Fisher, M.D., President of the National Empowerment Center, a board-certified community psychiatrist with 45 years of experience, a policy expert, and a person with lived experience of schizophrenia, focused on his own recovery, his policy work, and his clinical practice. He noted that the most important factors in his recovery were gaining a voice, self-determination, and empowerment through peer support and voluntary services and that his three involuntary hospitalizations were traumatic because they interfered with his self-determination. As a Commissioner on the White House Commission for Mental Health, he established a national mission supporting recovery through voluntary services. In his practice he has found that voluntary trauma informed services delivered in a compassionate, respectful manner enable people to engage and build the trust that is vital to people coming back. "We have to talk about the relationships that are formed and that this bill and most coercive treatment interferes with the relationship between the person receiving

services and the provider," he testified. Surveys have shown that over 50% of people would not want to return to services in the future. *Dr. Fisher also delivered oral testimony.*

Written testimony of Kathleen Flaherty, Esq. described her experiences being civilly committed in Massachusetts and the lasting impact forced treatment has had on her. Now the head of mental health legal advocacy program in Connecticut, she testified that IOC has been repeatedly rejected by the Connecticut Legislature and described why. She made these additional points: 1) expansion of involuntary medication to the community is a step backward in the advancement of rights of people with psychiatric issues; 2) while psychotropic medications help some people, there are others for whom they are not helpful; 3) the bill discriminates against people with psychiatric disabilities, who suffer loss of self-determination with no proven benefits to them or to the public; 4) international law from the United Nations has found that forced psychiatric treatment may amount to torture. Attorney Flaherty also delivered oral testimony.

Written testimony of Robert Fleischner, J.D. made and explained five points: 1) the research shows that involuntary outpatient commitment does not work; 2) involuntary outpatient commitment will likely be used disproportionately against persons of color; 3) the fiscal and policy costs of administering a new system of coercion will undermine the goals of Massachusetts' mental health system; 4) Massachusetts has a de facto system of outpatient commitment; 5) the bills are contrary to well established fundamental legal rights.

Written testimony of Jordan Goldstein, a person with lived experience and a Disability Rights Advocate at DLC, categorizes IOC as a "distraction that attempts to gain appeal by playing on the public's fear of persons with disabilities, stigmatized stereotypes of dangerousness, and the efficient logic of force." IOC criminalizes mental health by making care correctional, turning clinicians into parole officers and patients into crimeless parolees, all while compelling an understaffed mental health system to function as law enforcement too. He explains that force and coercion are traumatic and counterproductive. His own hospitalization, which involved forced and coerced medication, was not only unhelpful but harmful. It profoundly impacted his level of trust and interest in working with mental health professionals. He urges investment into the existing Behavioral Health Roadmap and accessible, community-based services, such as those proposed by the Peer Respite Bill (S1238/H3602) and its statewide network of voluntary non-hospital alternatives. *Mr. Goldstein also delivered oral testimony.*

Written testimony of Alex Green, Fellow, Harvard Law School Project on Disability & Visiting Scholar, Brandeis Heller School Lurie Institute for Disability Policy, discusses his work examining the history of Massachusetts legislation that impacts rights of people with disabilities. He has concluded that these bills repeat historic mistakes in ways that are widely known and understood. As with similar laws passed in Massachusetts over the last 200 years, these bills name, identify, and target a specific subset of disabled people—in this instance, the "gravely disabled"—through a combination of medical, legal, and social criteria that are not similarly used to identify any legally recognized class of disability. Such laws tend to be used in arbitrary and capricious ways. They almost never withstand the most basis court challenges because they use a person's past and present behavior to justify a state's predictive restraint of an individual at the expense of that person's individual rights and liberties.

<u>Written testimony of Monica Luke</u>, parent of a son with schizophrenia and an independent mental health advocate, describes her journey towards embracing voluntary treatment and rejecting coercive measures. While she came to AOT thinking it would be okay, after doing research for Representative Kay Khan, she concluded that AOT is not the panacea that families are led to believe. Ms. Luke then presents

alternatives to AOT, particularly alternatives which reject coercion for a form of outreach known as "relentless outreach." She found such a program in New York State: Intensive and Sustained Engagement Team (INSET). For her, what is most important about INSET is how it is distinct from AOT in its ethos: INSET is grounded in trust and relationship building. Rather than trying to convince people of what they need, INSET staff spend time building trust and talking 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. *Ms. Luke also delivered oral testimony*.

Written testimony of Kim Mueser, Ph.D., clinical psychologist and professor in the Departments of Occupational Therapy and Psychological and Brain Sciences at Boston University and former Executive Director of the Center for Psychiatric Rehabilitation at Boston University, built upon his extensive research on the development and evaluation of psychosocial interventions for people with schizophrenia and other serious mental illnesses (SMI), and on evidence-based practices for the treatment of SMI more generally. He has co-authored over 400 peer reviewed journal articles, over 20 books, and over 100 book chapters and had family members with SMI. He explains that he opposes the IOC bill because the research indicates that it does not work and the broad consensus in the field is that AOT is not an evidence-based practice for improving the outcome of SMI. He goes on to cite four evidence-based psychosocial interventions that are effective: 1) training in illness management and recovery by teaching individuals with SMI about the nature of their disorder and how to manage it while helping them set and pursue their own recovery goals; 2) family psychoeducation, an intervention in which a member of the client's treatment team works with the family (including the client) to teach them about the psychiatric illness and the principles of its management, as well as strategies for reducing stress and solving problems together; 3) supported employment, an approach to helping individuals with SMI quickly get and then, by providing supports, keep competitive jobs in areas that are of interest to them; 4) Coordinated Specialty Care programs (CSC) for people who have recently developed a first episode of psychosis, which is often the beginning of a schizophrenia spectrum disorder. Dr. Mueser also delivered oral testimony.

Oral testimony of Ruthie Poole, a person with lived experience of trauma and a mental health diagnosis, who has been active in the mental health peer movement in Massachusetts for many years. Ms. Poole is also a Certified Peer Specialist and currently works as the Assistant Director of Recovery at Bay Cove Human Services. She described IOC as a threat to our dignity, autonomy, and civil liberties and a "slap in the face" to the principles of disability rights and recovery movement. She described how voluntary treatment had been helpful to her recovery, while forced treatment had been detrimental.

Commitments to a psychiatric hospital were "horrendous experiences," leaving her hopeless and suicidal upon discharge. She worries that fear of forced treatment can keep people from seeking voluntary health services. She also highlighted non-clinical alternatives to traditional mental health services, for which we need to increase funding, including peer respites, the state's five recovery learning communities, and the peer support network within the Metro Boston Recovery Learning Community.

Oral testimony of Harvey Rosenthal, Executive Director of the New York Association of Psychiatric Rehabilitation Services (NYAPRS), a peer-provider partnership that has been a state and national change agent for the past 3 decades, focused on his own experience as a person in long-term recovery and his work as a mental health practitioner and advocate. What helped him recover from mental illness was not medication, but food, rest, and being around people (all available in a peer respite). He spent 18 years as a mental health practitioner in a state hospital clinic to help people reenter the community and then worked in a community-based clubhouse program. He has been an advocate for 30 years in a grassroots program. The program was part of the creation of the INSET program and the

Peer Bridger model. His program has a lot of experience finding programs for people who are not finding help. He reminded us that Massachusetts has been the birthplace of peer support and psychiatric rehabilitation and we should be proud to have rejected IOC. He notes that anosognosia is a condition that applies to stroke victims and does not apply in this context. He was part of research into NY's IOC law and found that people subject IOC fared no better than those not under IOC; any benefits were due to more and better services rather than the coercion. The NY Legislature has never made Kendra's Law permanent so they can continue to review it. He said he shares the frustration of families, but it does not make sense to continue to impose the same services that have failed them in the past. He testified that he and his colleagues have figured out programs that work. They created a program that helped people on the streets of NY and reduced admissions by 50%. "Our love affair with hospitals is misguided; it doesn't work," he said, noting that some . people return 40 and 50 times. "What works is peer bridging as people leave the hospital, people to work with you, a place to live, and a place to go."

Written testimony of Rae Simpson, the mother of a son with significant mental health challenges, offers the perspective of someone who is a parent and someone who has worked for years, through NAMI, supporting families seeking resources for loved ones. Simpson states that the claims for AOT simply do not hold up to the scrutiny of unbiased research. Part of the reason AOT fails, according to Simpson, is that 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. Rae further notes that if AOT were effective, the 47 states that have implemented versions of it would be doing better than Massachusetts in their delivery of mental health services, and they most certainly are not. A key reason for their failure is that people change through trusting relationships, and AOT does terrible damage to relationships. There are many programs that do work including 1) CAHOOTS which keeps most people in crisis out of emergency rooms to begin with; 2) EMPATH which send 75% or more of ER mental health patients home instead of to hospitals; 3) Open Dialogue; and 4) INSET. Rae Simpson has also prepared a fact sheet summarizing research regarding IOC. It describes why AOT is not effective, reasons AOT fails, and what does work. It is appended to her written testimony. Ms. Simpson also delivered oral testimony.

Written testimony of Susan Stefan, Esq. explains that she has studied and written about IOC for 37 years, with publications beginning in 1987. Her research includes studies of IOC implementation in North Carolina, New York, Tennessee, and Arizona. She explains why IOC has not been used extensively in most places where it exists: 1) one of the factors that states adopting outpatient commitment have in common is a shortage of mental health treatment professionals, making implementation difficult and unlikely, and—most importantly—rendering the need for coercive methods unknowable; 2) most good mental health professionals do not like coercing unwilling patients into treatment, and many are unwilling to do so. Stefan suggests that it is counterproductive for the Legislature to authorize coerced community treatment when people who want mental health treatment in Massachusetts for themselves and their children cannot get voluntary mental health treatment. She concludes:

Instead of pursuing IOC, a substantial increase in support to initiatives such as the Massachusetts Department of Mental Health's Massachusetts Behavioral Health Helpline, along with expansion of peer support options such as the Wildflower Alliance in Holyoke, which runs a crisis house,

drop-in center, and groups for people who are suicidal, www.wildfloweralliance.org, and the Center for Psychiatric Rehabilitation at Boston University, www.cpr.bu.edu, along with more robust in-home crisis services, might go some distance in alleviating current shortages in access to community mental health services without imposing an expensive and time consuming overlay of coercion, paperwork, and court hearings.

<u>Written testimony of Howard Trachtman</u>, a person with lived experience, centered on three arguments: These include, but are not limited to, the facts that the Commonwealth does not need outpatient commitment as existing commitment and forced medication laws suffice, that the bill would create an unfunded mandate, and that the bill will violate the civil rights of people with behavioral health issues. He urged the expansion of peer-operated services, such as the state's six Recovery Learning Communities. *Mr. Trachtman also delivered oral testimony.*

Written testimony of Rob Wipond, an investigative journalist and author of Your Consent Is Not Required, which in part examines how scientific evidence does not show forced treatment helps, focused on distortions of science by promoters of AOT. He recounts his review of a recent Treatment Advocacy Center (TAC) report of a survey they conducted, which they use to support AOT. TAC promoted their survey findings with claims that AOT participants reported high levels of satisfaction and feelings of empowerment" and "More than three-quarters of participants agreed that they were satisfied." (This is similar to a claim made by psychiatrist witnesses who testified in favor of the bills.) Mr. Wipond explained that none of TAC's survey questions even asked if participants felt empowered. And when AOT clients merely answered that they'd met with court staff and treatment teams enough times and felt "somewhat" comfortable asking questions, TAC described that as participants feeling "satisfied and empowered" by courts and treatment teams. Most of TAC's questions were multiple choice and asked about the AOT program as a whole and blocked participants from commenting separately on the voluntary supports versus coercion. TAC also selectively dismissed some answers as showing lack of insight and avoided asking about adverse drug effects. TAC's highlights omitted key findings regarding respondents including that: 1) only 20% said AOT helped their well-being, health, or mental health; 2) half felt "angry" and "disrespected;" 3) 61% disliked the forced drugging, coercive meetings, and threats of incarceration if they didn't comply; and 4) 65% said they disliked AOT so much that, even if in future they felt they "needed" help, they still did not want to be in an AOT program ever again. Finally, he noted that these responses came from a survey group that wasn't random—the AOT treatment teams chose the participants and mainly chose those who self-reported as highly medication compliant. So, TAC's own data actually showed that, even among highly medication-compliant people, a large majority disliked the coercion so much that they'd never again want AOT. Mr. Wipond's written testimony also included his full analysis of the TAC report. Mr. Wipond also delivered oral testimony.

III. Adoption of IOC will exacerbate already existing inequities facing communities of color

As several witnesses testified, research strongly suggests that since IOC targets persons who have not accessed-mental health services, it will likely be used disproportionately on Black, Indigenous, and people of color (BIPOC) community members.

When compared to other groups, racial and ethnic minorities have less access to mental health services than whites.³ Cultural misunderstandings between patient and clinician, clinician bias, and a fragmented mental health system are some of the reasons for this disparity.⁴ In addition, it takes longer for members of BIPOC communities to be referred by a primary care provider to specialty psychiatric care.⁵

When BIPOC community members do receive care, it is likely to be of poorer quality than that provided to whites. Research shows that, in clinical practice settings, minorities are less likely than whites to receive treatment that adheres to treatment guidelines. Additionally, for African Americans, mental health services most often occur in emergency rooms and psychiatric hospitals because of the barriers to community mental health services.

Disparities in accessing voluntary, quality, community-based care raise concerns that BIPOC community members would be more likely to be placed under involuntary outpatient commitment than other groups. The research demonstrates that this is precisely what happens. A New York study found that, statewide, outpatient commitment is imposed on African Americans five times more frequently than white people. Black and Hispanic people make up 17.6% and 19.3% of New York's population, but comprise 38% and 27% of those under outpatient commitment, respectively. Involuntary outpatient commitment reinforces and aggravates already existing disparities; effectively establishing a separate mental health system in communities of color that costs people their agency and causes them to experience the stigma of coerced treatment.

Moreover, multiple studies have confirmed that racial and cultural bias contributes to misdiagnosis of mental health conditions for certain populations, particularly African Americans. ¹¹ In particular, research has established the presence of significant racial disparities in the diagnosis of schizophrenia. ¹² Considering that the vast majority of those under outpatient commitment are likely to have a

³ Thomas G. McGuire *et al., New Evidence Regarding Racial And Ethnic Disparities In Mental Health: Policy Implications*, 27 HEALTH AFFAIRS 393, 396 (Mar./Apr. 2008).

⁴ U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, MENTAL HEALTH: CULTURE, RACE, AND ETHNICITY—A SUPPLEMENT TO MENTAL HEALTH; A REPORT OF THE SURGEON GENERAL (2001), at Chapter 2, Introduction.

⁵ Patricia A. Galon *et al.*, *Influence of Race on Outpatient Commitment and Assertive Community Treatment for Persons with Severe and Persistent Mental Illness*, 26 Science Direct 202, 204 (June 2012). ⁶ Thomas G. McGuire *et al.*, *supra* note 11, at 396.

⁷ U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, *supra* note 12, at Chapter 2, Evidence-Based Treatment and Minorities.

⁸ See, e.g., National Disability Rights Network, Bazelon Center on Mental Health Law - Murphy Bill Impact Based On Race - 2013 (2013), https://www.ndrn.org/images/PAIMI/Bazelon Murphy bill - impact based on race - 2013.pdf.

⁹ Jeffrey Swanson *et al.*, *Racial Disparities In Involuntary Outpatient Commitment: Are They Real?*, 28 HEALTH AFFAIRS 816 (May/June 2009).

¹⁰ Victoria M. Rodríguez-Roldán, *The Racially Disparate Impacts of Coercive Outpatient Mental Health Treatment: The Case of Assisted Outpatient Treatment in New York State,* DREXEL L. REV. 945 (2020).

¹¹ U.S. Department of Health and Human Services, *supra*, at Chapter 2, Clinician Bias and Stereotyping.

¹² C. M. Olbert, A. Nagendra, & B. Buck, *Meta-Analysis of Black vs. White Racial Disparity in Schizophrenia Diagnosis in the United States: Do Structured Assessments Attenuate Racial Disparities?* 127 J. OF ABNORMAL PSYCHOLOGY 104 (2018).

schizophrenia diagnosis – e.g., 72% of participants in New York 13 – diagnostic bias foreshadows the potential for an alarming overrepresentation of BIPOC individuals in any Massachusetts program.

Additionally, involuntary outpatient commitment is particularly problematic for BIPOC communities because members of those communities are already overrepresented in restrictive settings such as mandated psychiatric services, jails, and prisons. BIPOC community members are more often treated as inpatients and are four times more likely to be legally mandated to treatment than their white counterparts. ¹⁴ There is also a greater likelihood that the police are involved in the hospital admissions of BIPOC community members for psychiatric care than for other community members. ¹⁵ Imposing involuntary outpatient commitment on BIPOC communities contributes to the narrative that these populations need more governmental policing – here, in the mental health realm – while shifting needed resources from addressing the root problem, which is discrimination in the provision of access to inclusive community mental health care resources.

IV. <u>Since many valid reasons exist for refusing psychotropic medication, there is no legitimate basis for a diagnosis of anosognosia</u>

As several witness testified, there are many reasons why some people refuse powerful psychiatric medications. These reasons include past experience, concern regarding side effects, the questionable efficacy of some medications, long-term risks, and withdrawal responses. Side effects from these medications are serious and sometimes dangerous. Medications may have withdrawal effects and/or may be difficult to discontinue. Moreover, psychiatric medications are often ineffective. There are also individuals for whom earlier traumatic experiences make submission to forced medication administration, particularly injectable medication, a frightening and retraumatizing scenario. ¹⁶

There also are reasons why a person with mental health issues may decline to engage with the psychiatric system more generally. Past experiences in psychiatric system (or any system) have too often been alienating and traumatic and led to broken trust. The person may want help but may not want it from the person offering help at that time.

Additionally, there are legitimate reasons why someone may simply deny having emotional or mental problems. They may be rightly concerned about the risk of loss of liberty, experiencing discrimination (in housing, employment, child rearing, and more), or loss of power and control in one's own life. They may hold cultural beliefs and practices related to emotional distress that are incompatible with mainstream perspectives. Or the person being diagnosed may feel disempowered in relation to the person diagnosing them, and denial seems like the only available recourse.

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¹³ Rodríguez-Roldán, supra note 18.

¹⁴ Galon, *supra* note 13.

¹⁵ *Id.* at 205.

¹⁶ It is helpful to keep in mind that, according to the National Institute of Health, 55% of people prescribed <u>any</u> medication, for any health condition, do not take the medication according to directions. A decision to decline to take medication should not be seen as evidence of illness.

Attributing refusal simply to "anosognosia" is misleading and pseudo-scientific. Anosognosia is a term some neurologists use to describe a syndrome in which a person, typically one who has suffered a stroke, has an inability to sense the left side of their body. As Dr. Fisher testified, most neurologists who acknowledge anosognosia at all, believe it is a transient phenomenon. Until recently, the term has not been used in psychiatry. Supporters of forced treatment have tried to apply the concept to people who refuse mental health treatment, without scientific evidence.

Proponents' attempts to label resistance to medication (or even something as basic as disagreement with a doctor about a diagnosis) as being a symptom of illness is troubling. This approach allows proponents to ignore the range of reasons people may have for declining to accept treatment. Or, more broadly, as Sue E. Estroff has written in an essay on the use of anosognosia to deny the value of individual perception, "[b]y considering lack of insight as a sign of neurological impairment, we excuse ourselves from taking the time for and encouraging the emergence of an individual's formulations of him- or herself."

Anosognosia as a psychiatric condition is pure conjecture. Yet, individuals pushing IOC reference it as a universally accepted phenomenon. It is not. They suggest that one could find neurological evidence in people with SMI like that found in people who had suffered strokes. As witness Sera Davidow testified, this tactic has not gone unchallenged. 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." Psychiatrist Sandy Steingard of Vermont also pushed back on the idea of anosognosia in a 2012 article, noting that the brain research simply does not hold up. She explains that, as with the notion that people with mental health conditions have a "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. 18

For all of the above reasons, as well as those available in the additional resources we have referenced, our coalition opposes H.1694/S.980. We appreciate your interest in our views and would welcome any requests for information.

Thank you for your consideration.

Sincerely,

Arise for Social Justice, Springfield

A Tribe Called Black

Center for Public Representation

Committee for Public Counsel Services

¹⁷ Larry Davidson's full statement is attached to Wildflower Alliance's testimony.

¹⁸ Sandy Steingard's full article is attached to Wildflower Alliance's testimony.

Disability Law Center

Disability Policy Consortium

Kiva Centers

Massachusetts Advocating for Change Together (MassACT)

Massachusetts Association for Mental Health

Massachusetts Psychiatric Rehabilitation Collaborative

Mental Health Legal Advisors Committee

Metro Boston Recovery Learning Community

Northeast Recovery Learning Community

Southeast Recovery Learning Community

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