vermont psychiatric survivors

Equal Rights, Protection and Participation

September 27, 2018

Re: *Vermont Psychiatric Survivors Position on ONH Statutes*

Dear fellow members of the ONH legislative study committee,

The mission of Vermont Psychiatric Survivors is to provide advocacy and mutual support that seeks to end psychiatric coercion, oppression and discrimination. Involuntary outpatient commitment is on its face coercive, and the arguments for its use further oppression and discrimination against those marginalized by having received psychiatric labels.

The Vermont legislature has codified its intention "to work toward a mental health system that does not require coercion or the use of involuntary medication."[1] VPS, therefore, calls on the state to strike from the books legislation that allows for court-ordered outpatient treatment, or orders of nonhospitalization, and join Connecticut, Maryland, Massachusetts, and Tennessee in resisting the punitive and paternalistic model put forth by the Treatment Advocacy Center and other proponents of force.

Our position is based on:

- Research indicating that involuntary outpatient commitment does not improve outcomes compared with voluntary services;
- The harmful effects of long-term neuroleptic use common among outpatient court orders;
- The disruption of the therapeutic alliance with providers and further institutionalization of service users and survivors; and
- The threat to privacy, liberty, and independence, which has been condemned by human rights organizations including the United Nations.

We recommend that the state refocus on providing more and better voluntary supports including housing subsidies, peer-operated crisis respites, support for psychiatric drug withdrawal, and stronger protections for psychiatric advance directives.

[1] 18 V.S.A. § 7629.

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Overview

It is agreed in clinical practices that the only effective treatment is engaged in voluntarily with informed consent. Anything else should be referred to not as "treatment" but rather as social control. In this committee, we have heard arguments for engaging in this type of social control based on assumptions of the criminality and dangerousness of those labeled with a mental illness.

For example, the state's attorney's office suggests that people found not competent to stand trial or not guilty because of psychiatric disability should be subject to supervision that is at least as onerous as the criminal supervision they would have been under if found guilty. Civil commitment orders are no less punitive than criminal court orders. The vast majority of ONHs represent "treatment" imposed to curtail behaviors that do not break any laws.

Last year, the Vermont legislature found in S.3 (Act 51) that "the overwhelming majority of people diagnosed with mental illness are not more likely to be violent than any other person; the majority of interpersonal violence in the United States is committed by people with no diagnosable mental illness."

Nevertheless, unlike any other class of person, people with psychiatric labels may be detained, drugged, and/or monitored based on what we *might* do, whereas in the criminal justice system we must be convicted of a crime in order to be punished. A person convicted of a crime may serve a finite sentence based on that conviction, whereas our peers serve indefinite sentences locked in institutions or forced into outpatient psychiatric intervention and surveillance, based on a mere prediction of dangerousness.

Clinicians cannot predict dangerousness, as several studies have shown. One recent study found that standardized risk assessments could not predict violence among discharged forensic patients.[2] Its authors assert that, even with the development of new risk assessment instruments, there is little evidence they are any better than their predecessors.

When someone chooses not to follow a given treatment plan, it's most often because that plan is not working for them. Rather than force compliance with treatment that is not perceived as helpful, the standard of care should be to improve services so as to make them desirable. Resorting to coercion means that the system has failed to provide adequate services to begin with.

A few years ago, when the Murphy bill was making its way through Congress, Vermont Congressman Peter Welch joined 19 other House Democrats in a letter opposing provisions of the bill that restricted civil rights, particularly what the TAC calls "assisted outpatient treatment." They wrote, "The use of the court system and law enforcement to force individuals into care is a dramatic departure from how individuals, particularly those who pose no imminent threat to themselves or others, obtain health care services in this country."

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[2] Coid JW, Kallis C, Doyle M, Shaw J, Ullrich S (2015) Identifying Causal Risk Factors for Violence among Discharged Patients. PLoS ONE 10(11): e0142493. https://doi.org/10.1371/journal.pone.0142493

In a letter dated Jan 18, 2000, then-DMH Commissioner Rod Copeland wrote about why Vermont's mental health system was not more successful at reducing coercion and its negative impacts: "I believe a major part of the answer lies in the overemphasis, even dependency, in our treatment and rehabilitative practices on power, control, paternalism and, ultimately, coercion." Here we are, almost two decades later.

ONH Benefits and Harms

Studying the current ONH system in terms of "strengths and weaknesses" is a misguided effort. A "strong" ONH system can be a harmful one with few benefits, and a "weak" one does not necessarily require strengthening as much as questioning why it even exists. Instead, we ask whether the current system is beneficial or harmful to those who are subject to it, and in what measures.

Research into the outcomes of coercive treatment is sorely underfunded given that the pharmaceutical industry subsidizes the majority of studies related to psychiatric interventions. Studies showing a benefit to involuntary outpatient treatment have been determined by researchers to have faulty research designs such that the conclusions drawn are not supported by the studies.

A systematic review by the Cochrane Schizophrenia Group published in 2017 of all relevant randomized controlled clinical trials included only three small trials comparing involuntary outpatient commitment with voluntary treatment in the community. Cochrane reports: "Results from the trials showed overall CCT [compulsory community treatment] was no more likely to result in better service use, social functioning, mental state or quality of life compared with standard 'voluntary' care."[3] A 2014 review of 18 randomized and non-randomized studies found a "lack of evidence ... that CTOs [community treatment orders] are associated with or affected by admission rates, number of inpatient days or community service use."[4]

So with no added benefit, we need to ask whether involuntary outpatient commitment causes any harm.

Outpatient commitment frequently involves medication with neuroleptics (major tranquilizers also called antipsychotics). For decades now, we have known about the large percentage of patients treated with these drugs that develop tardive dyskinesia, a chronic, often permanent neurologic disorder characterized by loss of voluntary muscle control. There is also ample evidence of damage to the highest centers of the brain, causing dementia and psychosis. They have been shown to cause brain atrophy, Parkinsonian symptoms, akathisia, cognitive impairment, and metabolic disorders, contributing to the reduced average life expectancy of those labeled with mental illness.

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[3] Kisely SR, Campbell LA, O'Reilly R. Compulsory community and involuntary outpatient treatment for people with severe mental disorders. Cochrane Database of Systematic Reviews 2017, Issue 3. Art. No.: CD004408. DOI: 10.1002/14651858.CD004408.pub5

[4] Maughan D, Molodynski A, Rugkasa J, Burns T. A systematic review of the effect of community treatment orders on service use. *Social Psychiatry and Psychiatric Epidemiology* 2014; 49(4): 651-663.

Citing a recent Cochrane review on antipsychotic maintenance treatment and a randomized clinical trial by Wunderink and colleagues, Shawn S. Barnes, M.D., and Nicolas Badre, M.D., write in *Psychiatric Services*, "if a clinician is considering compulsory long-term use of these side effect–laden medications against a patient's will, with the threat of involuntary psychiatric hold if the patient is noncompliant, then it is our opinion that the evidence for the long-term use of these medications should be far stronger than that provided in the current literature."[5]

Forced outpatient interventions alienate service recipients from care providers and disrupt any possibility of therapeutic alliance. The threat of force deters others from seeking treatment voluntarily.

Very little data have been collected on the experiences of those directly impacted by outpatient commitment orders. A recent study in Norway found that patients subject to these orders felt like their lives were "on hold." Their compulsory "treatment" got in the way of taking control of their own lives, and the conditions imposed by mental health providers actually reduced their quality of life.[6] In our own experience working with our peers on ONHs, the court orders contribute to feelings of hopelessness, loss of autonomy, an increase in suicidal thoughts, and for some, increased trips to the ER because of these intensified feelings of powerlessness.

From a budget perspective, any forced or coercive interventions—whether inpatient or outpatient—divert resources from those who would access them willingly.

Human Rights Violations

Beyond the question of whether ONHs are effective is whether they constitute a severe threat to the privacy, liberty, and independence of the people subjected to them. Achieving a desired outcome is not a standard by which we measure the ethicality of an intervention.

Globally, involuntary treatment is coming under increasing scrutiny. The United Nations Convention on the Rights of Persons with Disabilities has concluded that "forced treatment by psychiatric and other health and medical professionals is a violation of the right to equal recognition before the law" protected by Article 12; therefore, signatories "must abolish policies and legislative provisions that allow or perpetrate forced treatment."[7] The UN Special Rapporteur on Torture called on all states to "impose an absolute ban on all forced and non-consensual medical interventions against persons with disabilities, including the non-consensual administration of psychosurgery, electroshock and mind-altering drugs such as

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[5] Barnes, Shawn S. and Badre, Nicolas. Is the Evidence Strong Enough to Warrant Long-Term Antipsychotic Use in Compulsory Outpatient Treatment? *Psychiatric Services* 2016 67:7, 784-786

[6] Stensrud, Bjørn et al. "'Life on Hold': A Qualitative Study of Patient Experiences with Outpatient Commitment in Two Norwegian Counties." *Issues in Mental Health Nursing* 36.3 (2015): 209–216. PMC. Web. 18 Sept. 2018.

[7] Convention on the Rights of Persons with Disabilities: General Comment No 1. Article 12: Equal Recognition Before the Law (2014). New York, United Nations, Committee on the Rights of Persons with Disabilities, 2014.

neuroleptics, the use of restraint and solitary confinement, for both long- and short-term application."[8]

On the Ground in Vermont

In the absence of formal studies showing ONH outcomes for Vermonters, VPS can offer what we have observed and the first-hand testimonies of those we serve. As the survivor-led, membership-based advocacy organization in the state, we come into regular contact with people subject to ONHs, whether on inpatient units or in the community, and have a unique perspective on how they are impacted by the process.

What we regularly hear is that people involved in this process lack even the most basic information about the ONHs they are placed on. Several individuals have described a bewildering process. When stipulating to an ONH, they don't feel as if they have a choice. They describe decisions made for them without their input or knowledge, decisions that are barely explained. Once discharged from the hospital, they seek guidance from case workers or psychiatrists to explain the conditions. Rumors among service users abound: that you can never get off an ONH, that you cannot leave the state, etc.

Those who manage to become informed realize that it exists primarily as a threat—something providers can hold over their heads if they don't "comply." One individual stated, "I think my life would've been the same without it [the ONH]. I think if they would've just sat down and talked to me, I would've listened. … The idea of someone telling me what to do doesn't sit well with me."

The current issue of *Counterpoint* has a telephone poll asking readers whether ONHs are of value to psychiatric survivors. One person responding to the poll via phone commented, "They're useless, and we should just get rid of them." As of this writing, the Facebook poll asking this same question has 41 votes, 98% responding "no."

Recommended Strategies

The practice of involuntary outpatient commitment doesn't need to be replaced by anything. Under the Hippocratic oath, "first do no harm" is a directive to begin by not engaging in any harmful practice. However, many of us on this committee would presumably like to go beyond simply not doing harm and would like to provide the needed support for people in our communities who are struggling. We have several evidence-based recommendations that the state can implement to help Vermonters achieve their goals of wellness and autonomy.

- VPS has identified lack of affordable housing as a primary driver of distress and instability among our peers. Subsidized housing and basic income have been shown to result in fewer ER visits, inpatient stays, health problems overall, and interactions with law enforcement. One peer we spoke with recently said that his ONH helps ensure that he will be housed, that

[8] UN Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, 5 March 2015, A/HRC/28/68.

without it he would likely be without housing. How much better would it be for everyone if he could get the supports he needs without an unnecessary and punitive court order?

- For those for whom psychiatric interventions have been helpful and who want to adhere to a treatment plan, psychiatric advance directives are a way to formalize their wishes for treatment when deemed to lack capacity to make healthcare decisions. In the event that legal capacity is not absent, everyone should retain the right to opt in or out of care and services. Holding regular statewide advance directive clinics could make this practice more widespread, relieving the state from the responsibility for making healthcare decisions on our behalf.
- Data show that most people who take neuroleptics will attempt to stop taking them at some point. Withdrawal can be accompanied by a range of physical, cognitive, and emotional symptoms. Without information and support for coming off psychiatric drugs, many people become caught in a disruptive cycle of stopping their use of drugs they find harmful or unhelpful, experiencing withdrawal, and then being hospitalized and court-ordered to resume taking them. We need community-based supports, from both our peers and providers, for coming off psychiatric drugs in the safest, best informed way possible. Many psychiatrists, including Vermont's own Dr. Sandra Steingard, are looking into the practice of patient-centered deprescribing as a harm-reduction measure.
- Peer-operated crisis respites provide better outcomes than hospital stays, can be developed rapidly using existing peer-run networks, and cost far less than inpatient care. Vermont currently has only one peer-based crisis respite with two beds, serving 50 individuals per year and turning away more than half that many because those beds are occupied.[9] Others have not been able to access this resource because they lack transportation to its remote, low-population location. VPS is proposing to the Agency of Human Services the creation of six additional respites throughout the state where they are needed most and can be accessed most easily.

In the event that the legislature does not immediately retire the ONH statutes, we would like to recommend two measures that would help reduce the harm to those subjected to them.

- Provide for a sunset clause that would allow ONHs to be terminated upon completion. Do not allow them to be renewed indefinitely on the meager grounds that "the patient doesn't believe he or she is ill," as is the current practice.
- Conduct annual surveys of Vermonters subject to ONHs in order to monitor the process and get input from those directly affected. This is best done by contracting with an independent organization conducting interviews using peer advocates.

Thank you all for your ongoing work on this issue.

Sincerely,

Calvin Moen, Director of Training

[9] VERMONT 2017 Reforming Vermont's Mental Health System Report to the Legislature on the Implementation of Act 79, Department of Mental Health, Waterbury VT. January 15, 2017.