

Joint Testimony in Opposition to SB 453 — Disapprove

"We all have our lists of casualties"

Judy Grahn, *A Woman is Talking to Death*

After reading testimony submitted to the House Health and Government Operations Committee in support of the companion to this bill, e.g.:

"Medications can allow people to be their true selves, and even more importantly it can allow people to live the lives they want to live and avoid the horrific repercussions of untreated mental illness."

"It will restore their competency, and their independence."

"It was not from innate stubbornness, but one of the most diabolical symptoms of the brain disorder. Some can be persuaded, and enough trust established to participate in treatment, but others would not accept treatment if it came with a cash prize and was provided at a 5-star resort... The sad irony is that we have treatments that work."

I feel compelled to submit my own, and to endorse that of Disability Rights Maryland. Without dismissing the experience — or suffering — behind the testimonies, I believe they present only a partial truth, and that what the bills offer is a false and destructive solution. I know I and others have sustained irreparable physical and psychological harm from forced psychiatric intervention.

Background: I've worked as a paralegal at a law clinic that served as a regional Protection and Advocacy office. As a minor I was detained in a psychiatric facility, given major psychiatric diagnoses (paranoid schizophrenia and manic depression) and forcibly drugged with neuroleptics until a court enjoined it and denied the hospital's petition for retention. Later I was active in Project Release, one of the earliest mutual support and advocacy organizations run for and by people with "lived experience" of the mental health system.

I moved from New York over 30 years ago and Project Release is long defunct, but I've maintained contact with some of the people I met through it. It's given me a long perspective on the impact of psychiatric intervention — including community commitment orders — on their lives. So when I read proponents' arguments, especially the many speculations about how compelled community treatment would have saved or salvaged particular lives, I think of them.

One has been under an "Assisted Outpatient Treatment" [AOT] order for years. It's required her to take psychiatric drugs. When I've been in NYC I've visited her in an assortment of locked hospital units — because drugging has not prevented her severe episodes from recurring, or kept her from being repeatedly, involuntarily hospitalized. She lives in what's technically the community — in actuality, a unit in a high rise building at one of the state hospitals in NYC. Chronic administration of neuroleptics gave her tardive dyskinesia (and obesity, and cardiac issues) so it's difficult for her to walk, and she's further isolated from the community by the layers of security protocols just to get in or out of the building. Before years of institutionalization and drugs she had an executive level job in the health care system, was athletic, hadn't lost most of her hair and teeth. I remember her criticism of the mental health system, describing her encounters with hospitals as "incarceration and brutalization." Lately she seems to have

given up on regaining a life outside the institution.

Another was on an AOT for years and technically living in the "community" — a congregate residence on the grounds of another state hospital in NYC. Thanks to her extended commitment to the state hospital she'd lost her subsidized apartment; another possible placement at a shared apartment with a supportive acquaintance was vetoed by the treatment team over concerns about overseeing her compelled drug regimen. She refused placement in an SRO. She recently suicided in her room at the residence. The day before she left me a voicemail saying "I'm in a modern day snake pit... it's the most horrible place on earth."

The primary focus of these AOT orders appeared to be containment and control. They did not prevent hospitalizations, trauma, homelessness or suicide. They were not remotely person-centered or supportive and they did not provide a less restrictive alternative. If anything, they foreclosed alternatives outside of congregate facilities and maintenance drugging. Nor was competency a basis for discontinuing an order. They were, in effect, open ended, despite the option of challenging them.

Another woman who occasionally attended Project Release meetings was chronically homeless, with a long history of testing — and failing — people's limits of tolerance. She'd experienced involuntary hospitalizations and electroconvulsive shock treatment [ECT] and was highly critical of the mental health system. She got locked up in a psychiatric unit in a Manhattan hospital, where she died in surgery for fecal impaction — an adverse effect of the psychiatric drugs that were being forced on her.

Refusal can, and often is, based on knowledge and direct experience. The blanket characterizations of refusal as a symptom is inaccurate, profoundly discriminatory and offensive. It also begs the question of the dubious track record of many psychiatric treatments and the inadequate or indifferent response to adverse effects.

Testimony in support of the companion bill has repeatedly emphasized that AOT orders will only be applied to a small number of people. But the impact of this "tool" would be far wider than those directly subject to orders. The vague, attenuated and predictive nature of required dangerousness and the relative ease of targeting a person make it a possibility — or threat — to anyone with a significant psychiatric history.

Concerning advance directives, which would merely be considered rather than control: a 1998 Vermont enactment limited advance directives of people who were civilly committed to forty-five days after which they could be set aside. It was challenged, and the Second Circuit affirmed the District Court's finding that the provision violated the ADA and Section 504 of the Rehabilitation Act. See *Hargrave v Vermont*, 340 F.3d 27 (2d Cir. 2003) [<https://casetext.com/case/hargrave-v-vermont>].

Concerning electroconvulsive shock treatment [ECT], the bills are silent. Forced outpatient maintenance electroshock has been a practice elsewhere. There are apparently no protections or further due process to prevent this highly intrusive intervention from occurring under an AOT order. I hope this was an omission and that the committee will expressly exclude this modality.

Thank you for considering my testimony. Please see the accompanying/joint testimony of Judith Shalitt, below.

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I am 85 years old and 25 years ago I was one of the early peer workers in New York State. As a participant in Project Release I advocated—and I continue to advocate—against any kind of forced treatment. I know the people described in Ms Ziegler's testimony, which is accurate, and I add my name to her testimony.

I myself have irreversible tardive dyskinesia, first detected by my dentist, from taking a prescribed antipsychotic drug for over 15 years. Neither the prescribing doctor nor the psychologist counseled me about the difficult, painful process of tapering off, which I did on my own over a period of two years, and I have taken no psych drugs for over 40 years, although doctors had told me I would have to take them for the rest of my life.

I have observed among friends, former clients and family members that long-term use of psychiatric drugs often leads to early diabetes, heart, lung, kidney, or digestive diseases, obesity, as well as dangerous, painful, and/or disfiguring neurological problems, and the warnings on these very medicines bear this out. No one should be forced to take these medicines against their will.

IS THERE A BETTER WAY? Look at what Promise Resource Network in North Carolina has accomplished with fully voluntary services. (promiseresourcenetwork.org) Promise Resource Network has created a community of peers who now provide a 24/7 warm line, a respite residence without locked doors, classes, support groups, including harm reduction groups, and continuing peer worker training. The decision on whether to take psych medicine, which, and for how long is left to the individual, based on their own experience.

Build a better mental health system and you won't have to force people to use it.

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