

Jeanne Gore - National Shattering Silence Coalition
Testimony in support of LD 1993 and LD 1994

Senator Claxton, Representative Meyer, distinguished members of the committee, good morning and thank you for hearing my testimony. I served on the stakeholder workgroup in my capacity as coordinator for the National Shattering Silence Coalition whose mission is to raise awareness and advocate for solutions to the humanitarian crisis faced by people with serious brain disorders commonly referred to as serious mental illnesses. I'm testifying in support of this bill. I'm also the parent of a man who suffers from schizoaffective disorder and anosognosia, a neurological condition that robs him of the ability to recognize his illness and know he needs help. As many as 50% of those with schizophrenia and bipolar disorder suffer from anosognosia. It's the number 1 reason why people refuse treatment. For these people, the PTP Program is what will save their lives and the lives of others.

Prior to finally getting my son enrolled in the PTP Program, I spent 13 years living in fear for my life and my sons. He was hospitalized 43 times, jailed twice, homeless, went missing, was beaten up by 7 police officers in Burlington, VT, and on and on. His illness made him think I needed to be eliminated because I was the one trying the hardest to get help for him he didn't think he needed. In 2013, I was able to get my son into the PTP Program. That's when the revolving door he was caught in stopped. It's what saved his life and mine.

I'm sure all of you have read about the two recent deaths here in Maine - one in Freeport and one in Turner - both murders perpetrated by someone who this system of non-care for our most seriously ill citizens has abandoned. Nurses are being assaulted by patients in the throes of psychosis, also a direct result of our failure to provide treatment, a continuum of care, and housing that heals. We have hotels no longer willing to act as shelters because those they're sheltering, I'm guessing, in the throes of psychosis, drug addiction or both, are destroying their hotels.

We must stop thinking of this as a civil rights issue. There is nothing civil or right about allowing someone with a treatable illness, if only we could get treatment, to die or kill someone else with their rights on. I can't tell you how many times I have been told my son has a "right to be psychotic!" Does someone with dementia have a right to be demented? Do we leave them to die in our prisons, rot in our streets, kill people who, in their right mind, they would never, ever kill? As someone who, by the grace of God, survived being chased around my kitchen table by my son with a knife, I can tell you, no one should have to live in the constant fear I lived with for 13 years before getting my son into the PTP Program. I was one of the lucky ones. 29% of all domestic homicides are perpetrated by someone with an untreated serious brain disorder. You have a constitutional duty to keep your citizens safe. They have the right to treatment and their family members and others in the community have a right to be kept safe. Not to mention the fact that it's inhumane and barbaric to deny them access to treatment.

A PTP monitor will insure that people under the PTP are receiving adequate treatment and enable guardians, law enforcement, ACT Teams, etc... to have assistance with the process of getting someone enrolled in the program. The monitor should also be in charge of seeing to it that judges, providers, law enforcement, guardians, and ED's understand the PTP and green paper process. We heard from providers in the workgroup that they were sending people to the ED under the green paper and they were being discharged because they did not meet the dangerous standard. Under the green paper, one does not need to meet the dangerous standard to be admitted to a hospital. My son was once denied a green paper by a judge who said we had to apply for it in the city where the PTP originated which is simply not true. You can apply for the green paper in the city where the person lives.

We must do everything we can to see to it that every hospital, medical provider, guardian, and law enforcement officer takes advantage of the life-saving PTP Program. Maine is the only state in America that requires these entities and individuals to pay the court fees. This barrier to treatment must be removed. Not only will it save lives, it will save millions of taxpayer dollars by allowing access to treatment instead of abandoning people where they become revolving doors in and out of hospitals, ED's, and homelessness, not to mention the other innocent lives lost when they become dangerous to others.

We should also be taking the opportunity to use the IMD Waiver, something this state has refused to do under the mistaken notion that it's somehow the least restrictive setting to deny a hospital bed when it's needed which we all know leads to a jail cell, homelessness, or death. The IMD waiver wouldn't just allow for more hospital beds. The waiver would allow for increased reimbursement for inpatient care and all facilities at various levels of care, including access centers and longer term #HousingThatHeals. Having higher levels of reimbursement would enhance services in all of these levels of care, including more work with psychologists, and multidisciplinary teams so that the models can move away from just a pill and a bed to more comprehensive care. If we had accepted the waiver applied for under the previous administration, perhaps we wouldn't be arguing over how to fund the PTP Program. Please, please pass these bills and start saving lives!