February 26th, 2024

Chairwoman Margaret Rotundo,
Chairwoman Melanie Sachs,
Chairman Joe Baldacci
Chairwoman Michele Meyer
To Other Members of Appropriations Committee
and Health and Human Services

RE: LD2214

Thank you so much for this opportunity to be able to speak to you today. My name is Mary Barker and I am here to talk about LD2214. I am a mother and legal guardian of an adult child with a severe brain disorder. The fact that the mental health portion may not be funded this year, is in my view, a tragic mistake. Although I personally believe that having policies that include an expansion of mental health clinics fills a certain need, there is a gaping hole where funding should be for those suffering from severe brain disorders. My son, who suffers from schizoaffective disorder, is not going to voluntarily walk into a clinic to get mental health help. To believe so is both naive and dangerous. When you live with a psychotically distressed person you potentially put your life on the line trying to get them help.

The only way that my son in the throes of psychosis ever got to the hospital was a police welfare check initiated by me. I have had dozens and dozens of interactions with police in the various places my son lived over the years because of dangerous situations we found ourselves in and he is now only 26. The police that I spoke to were extremely frustrated that they had limited ability to help. They had no idea, because they have not been properly trained, that they can themselves initiate a green paper from a Progressive Treatment Plan (PTP) to get people with acute psychosis help. Hospitals have no idea what their rights and responsibilities under the law are. Maine people and their families fall through the cracks.

I witnessed this first hand where I work, in a hospital emergency department, where obviously unmedicated psychotic people are let go to the street to fend for themselves because of misinterpretation of the law or the desire to find loopholes. Many people with psychosis are discharged to the street regardless of the reason they were brought in short of physically hurting themselves or others (as a blue paper policy would ascribe to). Many are unaware that they are ill, some are aware and want treatment but are discharged anyway because they are not in the position to advocate for themselves. According to the National Institutes of Health (May-June 2014), between 57% to 98% of people suffering from schizophrenia have no insight into their disease. That sets up a dangerous situation for them and others. Families in Maine are dealing with it alone.This is a fact. This puts all of us at risk. Hospitals have a revolving door of admission and discharge if not for the lucky few that get into a Progressive Treatment Plan. Because of the lack of funding, the lack of education and leadership for hospitals, police and the

State of Maine, people are getting hurt, hurting others and dying. The Progressive Treatment Plan ("PTP") has been in place since 2010 to help with this population, yet I have found very little evidence that it has been implemented as needed, both from my own personal experience or through my work at the hospital.

No one wants to see their child go through a catastrophic illness and no one wants to see that illness spill over tragically into the lives of others. Throughout this thirteen year struggle with my son's untreated, unrelenting psychosis, I have come to believe the only viable way to resolve this is to have in place a team of mental health professionals (ACT team) to create a comprehensive wrap around program to help people and their families with severe brain disorders like schizophrenia, schizoaffective and bipolar disorder to progress towards a health. Other States successfully do this. I have found no other avenue that works. My son suffers with schizoaffective disorder, having both the psychosis of schizophrenia and the mania of bipolar. He has lived with the torturous elements of his disease for many years because of gaps in the system and lack of appropriate care. He is now getting the treatment he needs through the Progressive Treat Program.

Like others here today my son has seen the inside of jails, hospital ED's, interactions on a first name basis with multitudes of police around the various counties he has lived, homeless or otherwise and the horrendous cost of his actions on his own personal life and the lives of those around him because he has no insight into his illness. I have had to rescue him several times hypothermic from homelessness, I've filed missing person reports and fielded multitudes of police calls because of horrendous situations he got into because he was acutely psychotic. The costs incurred by the State have been tremendous for the ultimate lack of treatment my son has received.

Since September my son has been on a PTP and is stable in a group home. He is doing the best he ever has in the last thirteen years. It didn't have to be this way. People had to get hurt before this happened. I had to find out about the PTP through a news article and pursue it myself, when even my son's psychiatrist, Assistant District Attorney, District Court clerks, police, social workers, therapists that knew nothing about the PTP and this was last year. When I went to Maine.gov to research this new information, one that was supposed to inform me of a specific DHHS department that manages the PTP and called them at the listed phone number, no one in that office had ever heard of PTP. One has to wonder if whoever is in charge of this flow of information is purposely doing this to undermine the effectiveness of the PTP program. The Progressive Treatment Plan has been law since 2010, but you would never know it.

And I have to ask why for all those years did my son not get the same consideration as someone with other illnesses? It is medical malpractice when people with severe brain disorders are dumped on the street as my son has been, literally and metaphorically by the very institutions we rely on and pay taxes for. We don't typically dump Alzheimer's patients on the street (my hospital system doesn't anyway), so why do we dump people that have no ability to take care of themselves because of their psychosis and have no insight into their illness. Yet we as a community stand by as the lives of others are lost and the accumulation of the costs of police involvement, property damage, destruction of families and the millions of dollars incurred by the State of Maine for court costs, incarceration, hospital costs and the like are occuring. It really doesn't have to get to this point. What we need to accomplish this task is commitment from the State in the terms of a real partnership, adequate funding and to keep the lines of communication open. The lives of Maine families are at stake. Make no mistake. I am a family member of a person with a brain disorder that you haven't heard about in the news only by luck. Under these circumstances, compassionate care is a court order.