Testimony for Submittal to the Committee on Health and Human Services public hearing on LD 1866 on May 12, 2025.

Senator Baldacci and Senator Meyers, Chairpersons, and all members of this important committee.

My name is Jennifer Johnson and I am the mother and legal guardian of an adult son who has had a diagnosis of a severe brain disorder, schizophrenia and accompanying anosognosia (a neurological condition in which the patient is completely unaware of their neurological deficit or psychiatric condition. A complete lack of insight into their condition.) He was diagnosed at age 20, and his father, his brother, and I, along with other valued family members, have been on his devastating journey with him every single day, every step of the way. His courage is amazing, and his trust in our love and care for him is unwavering.

I became his guardian in 2007, for the same reasons that this advocacy agency exists; to ensure that my son is treated competently and fairly, that he has the right to access all existing inpatient and outpatient services available for his illness, and most importantly, to be his voice when he is not able to use his. To be by his side, to ensure he is not mistreated or refused services in any way, given advice by individuals not qualified to do so, and to be his liaison in communicating and advocating the frustrating and discouraging task of navigating the our state mental health system, these are roles that I shoulder willingly even after 30 years of this journey.

I do support the necessity of this advocacy agency and the services provided by it, as we do not live in an ideal world, and not every person suffering from a serious brain disorder has family supports. If we as a state had more than a sufficient number of inpatient facilities, psychiatrists, counselors, ACT teams, group homes, a thriving and well supported and funded PTP program, myriad effective and diverse outpatient support programs, then perhaps this agency would not be necessary. Sadly, this is far from reality. But here is the caveat, and a very important one. On more than one occasion when my son was admitted to a state psychiatric hospital in the throes of profound and severe psychosis, I had to intervene in the one-sided conversation between an inhouse advocate from Disability Rights Maine and my son, who was experiencing psychosis and was unable to sit down, let alone distinguish between his internal stimuli and the distracting and exacerbating voice of a stranger. My son was being told, and I was a witness to it, that he had rights. Rights to refuse care, rights to not take the medications prescribed to him, rights to refuse longer term admission if warranted by his psychiatrist. He certainly has rights, but he also has the right to not be told that he has these choices when he is in crisis and has anosognosia by a person who has no right as a non-medical professional to convey this information. If I were not his legal guardian and had not been there, and if he was able to process any of the rights she was explaining, he very well could have reacted in a very negative and detrimental way, to himself and possibly to staff if he understood that he didn't need to take meds or to remain in the hospital. I had to ask the advocate to please leave, and to please not talk to him without my permission. I have gained much trust, respect and gratefulness over the years for the expertise and knowledge of medical staff who are trained to provide and administer psychiatric care for the most severe and debilitating brain disorders. I appreciate that DHHS and this agency realize that supporting and advocating for those with serious mental illnesses is important, but there is a distinct difference between supporting and advocating and networking for those who need them, and informing those with anosognosia that they have completely free will and complete rights to refuse treatments that they aren't cognizant that they need. We do not tell Alzheimer's patients that they have the right to refuse effective treatment when they clearly have no insight into their illness, and no agency or representative thereof has the right to cross the line between advocacy and imparting medical advice, ever.

My son will not die with his rights on, and many lives could have and should have been saved if we only realize that true advocacy means sometimes deferring rights if it means saving lives and restoring the ability to make sound decisions.

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