Cheryl Stalilonis-Francis
MDDC
LD 2009

Respectful acknowledgement of the 131st Maine State Legislature and esteemed members of the Health and Human Services Committee. My name is Cheryl Stalilonis-Francis and I represent families of adults with developmental disability in my seat on the Maine Developmental Disabilities Council. I completed a graduate level Leadership Education in Developmental Disabilities course through UME and UNH and have provided family support through the Wraparound ME program and as an Autism Information Specialist with the Autism Society of Maine. I strongly oppose LD 2009 out of fear of harm to Maine's disabled citizens who are already under guardianship, which implies more of a significant disability, and are now in a crisis situation in the ER. To take a supportive guardianship away from an individual in this situation when they most need informed, ethical and wise decision making by those who truly know their needs, is unfathomable to me. The hospital has the responsibility to provide a safe and reasonable outcome for the individual who was admitted to the ER for valid safety, health, or medical concerns. If there is no safe and currently available support situation, whether within Maine's system of supports, or within the family's home, due to the parents/guardian being physically or otherwise unable to meet the needs, and now new needs, behavior, etc.. related to the current crisis, and the guardian refuses to discharge back home, they will lose their guardianship? I was a Licensed Social Worker in Massachusetts and Maine, and worked mostly with the geriatric population until my family received a devastating diagnosis of Childhood Disintegrative Disorder, a rare and severe form of Autism, for our 4 year old. Our interactive, highly verbal son who previously helped others at his day care with a toy or his company, had lost all of his speech, most milestones, and became impulsive, anxious, and had no safety awareness. All efforts centered on early intervention and safety. He is now 25 years old, lives in a residential setting, and has high support needs to maintain his health, safety and medical stability. His father, brother and I are his legal guardians. I take this awarding of guardianship, this responsibility, this obligation and this opportunity to support my son to the best of my ability very seriously. I have invested much of my life this past 21 years in supporting him, gaining knowledge, and making connections with others in the field. I have contributed greatly to my son's quality of life as his guardian, and know that if our guardianship had been taken from us for refusing an unsafe placement to discharge him from Spring Harbor Hospital, his life would have been at risk The hospital asked Adult Protective Services to take our guardianship, as he had a very lengthy hospitalization, and they were very anxious that he be placed anywhere that would take him. APS declined the request. And due to his bolting, and other high support needs and behaviors, there were no places that would provide for him, until this particular placement opened up on a major travel route with high traffic, between 45-50 mph. The house was close to the road and the entire situation was highly unsafe for someone who runs impulsively with his speed and lack of safety awareness. I will never forget the look on his father's face when he walked the property of the proposed placement, (which the hospital social worker had only viewed on-line), and he said, "Cheryl, I will not sign his death warrant". We were in complete agreement. Because of our son's high safety needs, we were no longer able to keep him safely at home, and in fact, had struggled to keep him home as long as we possibly could; advocating with the state of Maine for double staffing at home, and me working with the staff as well. It had been the entire team's concensus, including all professionals, that he could not be maintained safely at home. With our battle with the hospital, and within several more months, a more suitable setting became available. He later also had an ER stay, and I stayed with him to support him during the waking hours as much as I could. This stay was due to multiple medication errors made over a 3 day span at the residential placement. Had they not been able to take him back, i don't know what his options would have been. I ask you to consider the scenario of what if, in fact, the refusal to take a child/adult back home is due to extensive guardian knowledge of the disability and risks, and a real fear of imminent danger to the individual? Did not that guardian just make a very informed and good decision? Is this not what the state of Maine awarded to the guardian to do just that? This would allow APS or Child Protective to supercede this legal authority based on an ER physician's limited knowledge of developmental disability in general, and a very limited knowledge of the individual presenting with an extreme need for care. I was educated on the importance of a working knowledge of developmental disability in general for all providers, but that it is far more important to have knowledge and understanding and insight into a person's particular presentation, needs, relevant history and best ways to support that individual. This is especially true for an individual with developmental disability, which can present in many different ways. This is a guardian's responsibility, and often their strength. It is mine, and it can't be allowed to be replaced by a public guardian. If I can provide any additional information, or clarification, please contact me at stalilonisc@gmail.com. Respectfully submitted, Cheryl Stalilonis-Francis