

Supporting LD 659: An Act to Promote Seamless and Flexible Home and Community Supports Across the Lifespan for Individuals with Intellectual and Developmental Disabilities or Autism

Dear Senator Baldacci, Representative Meyer, and Distinguished members of the Health and Human Services Committee

I have lived in Belfast Maine for over ten years and am testifying today in support of LD 659. Among the goals of this proposed Lifespan waiver is the creation of a,

“Seamless transition between children’s services and adult services.”

As the mother, sole surviving parent, and guardian of a 24-year-old with the diagnosis of autism, I truly wish that this lifespan waiver had been an option for my son during his high school years.

When my son had to move from children’s services to adult services, this was not a smooth transition because in the process my son lost the man who had been his Behavioral Health Professional (BHP) consistently for four years while he was in middle and high school. Since my son when he was twelve had lost his father at 50 to Lou Gehrig’s disease, this BHP played a critical role in his life. My son as a person with limited communication and social skills had spent most of his life trapped in his own world. Initially he found it very difficult to be with his BHP, but he did adapt and showed signs of growth in many areas including tolerance for new people and new situations.

He also started to learn many critical life-skills including how to be safe in parking lots, how to use public restrooms, how to relate socially, how to shop and pay for items, etc. Given that my son has multiple sensory issues which trigger behaviors including bolting, the role of his BHP was not an easy one, yet they were together successfully for four years until my son had to drop children’s services.

For a person like my son who is very averse to change, consistency is critically important, he deeply sensed the loss of his BHP. In adult services in almost four years, he has not had a replacement to take him into the community. This issue was further compounded when my son aged out of high school and was home full time with me. He fell off the proverbial cliff and suddenly found himself without any place to go on a daily basis, he lost friends and the positive input he had been receiving from teachers, educational techs, etc. As a result, he regressed severely and many of his old

“behaviors” reemerged. As a mother it is heartbreaking to watch my son lose previously hard-gained skills and instead to see him often lost in isolation and profound sadness.

Through telling the story of my son, I hope that you will all see how important it is for the transition from children’s to adult services to be as seamless as possible. Situations like what happened with my son can be averted, and much heartache can be spared.

I urge you to please support LD 659. By doing so you can help achieve the stated goal:

“Early planning for independence with emphasis on independent living skills and employment services for youth to prepare them for as much independence as possible in adulthood.”

My hope is that DOE, OADS, and DOL/ VR, will collaborate during high school towards achieving this laudable goal.

Thank you for your time,

Respectfully

Linda Lee,

Belfast, Maine.