

March 20, 2023

To: Senator Baldacci, Representative Meyers and distinguished members of the Joint Standing Committee on Health and Human Services. Thank you for the opportunity to testify today.

RE: ***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***

My name is Debbie Dionne and I am the mother of a 43 year old woman living with a diagnosis of cerebral palsy, and an intellectual disability. My daughter's complex support needs continue to increase as she ages. For the past 22 years she has lived in a licensed group home with 5 lifelong friends. The Section 21 Waiver has provided those with higher, more complex needs, like my daughter, the supports and oversights needed to allow them to safely live an independent, purposeful life with friends in their community.

Despite being reassured by DHHS, that in the Lifespan Waiver, group homes will continue on for those Mainers currently living in a licensed home, the number of group home closures continues to grow. As of today, 75 group homes have closed with an additional 20 more homes predicted to close in the next six months. There is no shared data from DHHS as to where these displaced Mainers with ID/DD have moved to. These group homes have closed because the group home rate does not support the program's cost and the competitive wage needed to maintain the service. And there are over 1900 adults languishing on the wait list for section 21 services, many who have high support needs and live with elderly parents. "Keeping families together" is another DHHS objective with the Lifespan Waiver. A question I would ask DHHS : What is the time expectation for families who have been caregivers for their adult children with severe medical, physical, or behavioral disabilities since birth : "til death do us part"?

In theory, the Lifespan Waiver appears to be a seamless, flexible solution to the existing waivers Maine currently operates under. As they say, it is all about the timing and the details. The Lifespan Waiver will eventually become the sole funding source and all other waivers will become obsolete. The rate study for section 21 is not due to take place until 2025, one year after the Lifespan Waiver is scheduled to begin to be phased in. It feels as though this delay is deliberate and will cause the eventual death of all group homes and their service providers through attrition. I have never been so fearful for the future for all Mainers with ID/DD and higher support needs, like my daughter. She is counting on me to make sure her home and her independent life is not taken away from her.

There is nothing routine technical about the enormous changes and funding mechanisms proposed to take place with the Lifespan Waiver. In order to prevent the collapse of services for the ID/DD population with the highest needs this bill demands to be amended from routine technical to major substantive.