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March 20, 2023

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.

Senator Baldacci, Representative Meyer, and members of the Health and Human Services Committee, my name is Cullen Ryan, and I am the Executive Director of Community Housing of Maine or CHOM. I am also the parent of a 26-year-old son with Intellectual/Developmental Disabilities (ID/DD). I serve as Chair of the Maine Coalition for Housing and Quality Services, a coalition of some 4000 people, consisting primarily of parents, that focuses on housing and quality services for people with ID/DD. I also serve as chair the Maine Developmental Services Oversight and Advisory Board (MDSOAB).

I am testifying neither for nor against 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

If LD 659 were as simple as creating a lifespan waiver, making it be the case that a person is served from early childhood to the end of their life with continuity of care through the existing array of services, there is no question that I would be in strong support. But as I am watching this design roll out, it is growing apparent that it is not so simple. There are many proposed changes rolled into this one initiative.

One of the root strategies unveiled this week involves decentralizing services and moving to what is being called a hub and spoke model. Hub and spoke models have their place, but in this incarnation, it appears to be a recipe for dismantling what has been proven effective in favor of a replacement model that appears to be very labor intensive and potentially isolating to consumers.

Whereas now, my son has been able to participate with a consistent group of peers in a community-based day program that involves independent skill building, socialization skill building, activities for enhanced skill building, and community involvement and engagement, the new model appears likely to shutter that in favor of someone coming to pick my son up and taking him into the "community" by himself. I am filled with questions and concerns.

My son would love to be employed but so far has had no luck securing paid employment. Although his thought processes are akin to that of a 4-year-old, he is energetic, enthusiastic, and widely loved. But he has not been able to turn that into something sellable to a paying employer. He has, however, been a very successful volunteer. This new waiver puts even more focus on employment and again, my son (and many others like him) would be left out of that equation.

What my son lives for – is his day program – a place where he is surrounded by peers. He learns a broad array of skills, feels connected, and has fun with actual friends. It is the centerpiece of his life. Eliminating centralized services, which is exactly what my son participates in, would be devastating to him. Insisting instead he be led into the community by a support staff mostly exclusively, is akin to replacing actual relationships with peers – with something more like a paid escort service. The relationship is simply not the same.



When I think of my son and where he is developmentally, I'm reminded that no kid (or adult) is thrilled about chaperones; they want to be free as much as possible with their friends. We need to celebrate group learning. I have concerns we may move away from peer-based models to something more isolative. I would expect centralized services would disappear much like group homes which are disappearing due to lack of staffing, referrals, and staff pay rates that no longer work. Once group homes are gone, they are not going to be replaced; once centralized services are gone, these won't be replaced either. Years of expertise and best practices will be lost.

There are good ideas here, but the devil is in the details. This must be looked at very carefully. Please ensure this is major substantive so that all concerns can be addressed, and unintended consequences can be avoided. We can't afford to jump into something that could upend our continuum of care on a hope it will be better. Yes, let's create a lifespan waiver. But let's not create a win-lose proposition or throw out the old for the new. Let's take the time to get this right and celebrate what works and preserve that at the same time. My son's and thousands of other lives are worth the extra care to get this right.

Thank you for the opportunity to comment.