

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

Good morning Senator Baldacci, Representative Meyer and esteemed members of the Health and Human Services committee,

My name is Kim Humphrey, from Auburn. I'm from Community Connect Maine and mother of Dan who is an adult with severe autism.

Section 1

This bill impacts the entire adult, I/DD, Home and Community Based Services (HCBS), system of care now and into the future. Every single person within this service sector will be affected. The proposed rule MUST be made major substantive.

Goal 4. Innovation

“Standardized assessment” What will this mean?

Do you know the details of how this assessment will be tied to funding directly and indirectly? It's all in the details. Let the public weigh in on DHHS's proposed rule by making this a major substantive bill after enough details emerge to know what it is you are voting for.

When discussing assessment, the department highlighted that the concept that fairness is important within a system of care.

Section 2- Relationship to existing programs

But what is happening now in the service sector is painfully unfair and inhumane. A subpopulation of higher needs people are quietly shouldering a heavy burden in order to financially benefit the new lifespan waiver program and many related systemic changes by letting current provider programs financially bleed out. People on section 21 who are at risk of neglect and abuse, except for the most dire circumstances, are pegged to remain on the waitlist, at their own peril, until the department finishes its reform work in a few years.

Using the data we currently have on needs and unmet needs to help guide new policy hasn't been a priority in this reform work. The department is using the new codified rate system as an excuse to ignore the pain individuals bear, by not re-evaluating a rate now, that is currently failing these providers, which also makes it difficult to address the waitlist. Collapsing homes while people are in them is a horrible strategy to reform care and so is forcing higher needs people to waste a few years of their life on waitlists for basic daily needs.

Let me be clear, I fully support the innovations such as the tiered shared living concept. I think self-direction is an essential new option. I believe in technology being explored and added to the system of support options, potential great outcomes for behavioral

support and earlier transitional support. But it shouldn't add to the collapse of an important choice for others. How this plays out financially isn't publicly known at this point. This bill shouldn't be passed to give the department a pass on the power of public input that happens with a major substantive bill. Please vote no and put this bill on hold until it is changes to major substantive and more details are known about how it all works. This will allow all the brave hard work the department has done, that includes some great potential changes, to work more successfully. It will protect what is working well now remain a viable choice for those who won't fit the new options. A major substantive bill will also help facilitate much needed trust with users as mentioned by Rachel Dyer in her oral testimony.