

April 23, 2025

Chair Ingwersen, Chair Meyer, Distinguished Members of the Joint Standing Committee on Health and Human Services:

My name is Alan Cobo-Lewis. I live in Orono. I am testifying FOR LD 1606, “An Act to Require Data Collection and Major Substantive Rulemaking for the Lifespan Waiver Providing Home and Community-based Services for Individuals with Intellectual and Developmental Disabilities, Autism Spectrum Disorder or Other Related Conditions”.

I have two young adult sons, one of whom has autism, who needs significant services and supports, and who is supported by the Section 21 Home and Community Based Services (HCBS) waiver.

The lifespan waiver is a good idea, and I thank the Department and this Committee for their support of the lifespan waiver to date.

This bill would make two significant improvements to the lifespan waiver, which I hope you'll support.

1 Data

First, the bill would require data collection on the extent to which people supported by the waiver actually get the services they need. In the face of the workforce crisis, people on HCBS waivers don't always get what they need, even when they're not on a wait list.

For example, my own son went a full **SEVEN MONTHS ON THE SECTION 21 WAIVER BEFORE HE RECEIVED ANY WAIVER-SUPPORTED DIRECT SUPPORT**. If this Committee had not this information from me directly then you never would have known, because existing law requires the Department to post information about wait lists but not about people on the waiver not having their needs met. LD 1606 would fix that. And it would also require collection and reporting of other information that you as the policymaking body need to make sound policy decisions.

2 Major Substantive

Second, the bill would make the lifespan waiver rules major substantive. Already, the initial lifespan waiver rules are required to be major substantive, for which I thank this Committee and the Legislature, as the rules are far too important in the lives of people to be routine technical. But potential future revisions to the rule should be major substantive as well, for the same reason that the initial rule should be major substantive.

Although I anticipate that the Department will be able to submit initial major substantive rules for legislative review in time to secure approval of the lifespan waiver by the end of the current Executive's term, I remind you that, in the event that becomes challenging, you can always authorize the Department to adopt emergency major substantive rules as contemplated in [5 MRS §8073](#).