

April 23, 2025

Re: 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

Senator Ingwersen, Representative Meyer and esteemed members of the Health and Human Services Committee:

My name is Lisa Marin and I live in Jonesport. I am speaking for my daughter and grandson who live in Cape Elizabeth. My daughter is the mother and guardian of my 19-yr old grandson who has autism. He currently lives at home with my daughter who is a single mom. I am testifying in favor of LD 1606.

Evan is a happy 19-yr old who enjoys body surfing, hiking, visiting waterfalls and spending time with friends. Unfortunately, he also frequently becomes agitated and aggressive, lashing out, hitting, punching, slapping, kicking and screaming at his mother. She is constantly on edge worrying over when Evan is going to lose it. Physically she can barely deal with Evan when he is upset. Once he threw a chair through a window at home. Another time he broke a windshield while riding with his mother in the car. She has had to call the police to come and calm Evan on more than one occasion. Marie works approximately 4 hours a day as a hairdresser in the business she owns. She'd like to work more hours but she is limited to the time Evan is in school.

It's hard to think of a time when Evan got the proper services he needed. Mostly he's had to wait endlessly for one level of approval only to have to get on another list for the next stage of approval. Marie is constantly kept making appointments to get Evan the services he deserves only to be put on another waitlist, all the

while Evan languishes. I'd like to hope that future changes to services will make a positive, significant difference for kids and adults like Evan but this won't happen unless there is the will to create proper oversight and accountability. It's way past time that Maine ensures that families are being supported when advocating for loved ones. I want to be optimistic but there have been too many times when our family has built up our hopes for Evan only to be let down. Families and caregivers need help before it's too late. I'm asking for your support to keep the Lifespan Waiver a major substantive rule by insisting on the inclusion of oversight, and accountability.

LD 1606 ensures that the Lifespan Waiver will be implemented thoughtfully, through real-world data collection not just through blanket policy intentions and would have the ability to adjust course quickly when needed. We are all in this together. Please do the right thing and support LD 1606. Thank you.