

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 Ingwerson, Representative Meyer and distinguished members of the Joint Standing Committee on Health and Human Services

My name is Diane Boas and I live in Cape Elizabeth. I am the mother and guardian of my 33-year old son who has an intellectual disability.

Ben has lived in a group home in South Portland for over 11 years. Today, he is thriving. He is supported by staff who help him manage daily life at home and in the community. Because of the location of his home and the consistency of his supports, he can walk to a grocery store, get his haircut, and visit local businesses where people know him. He also attends his temple twice a week and has formed lasting friendships through that community.

This level of stability didn't happen overnight—it took years of dedicated support and hard-won progress. But under the Lifespan Waiver, Ben's services may be reduced. He may even be required to leave his current home—the only home he's known since turning 22. A change in services would seriously affect his well-being. A change in both services and setting could be devastating.

We need to monitor what happens to people like Ben. That's what LD 1606 is about. Oversight and data collection are not bureaucratic exercises—they are essential safeguards.

Without legislative oversight, decisions about who gets what level of service—and how services are being delivered —can happen behind closed doors, without transparency or public accountability.

There is a belief that individuals in group homes are “overserved,” and that savings are best achieved by consolidating or closing homes. More than 90 group homes have already closed. But people like Ben should not be moved like pieces on a budget spreadsheet. For someone with complex needs, stability isn't just nice to have—it's a crucial form of care.

LD 1606 would require DHHS to track residential disruptions and changes in services. It would require the department to examine the impact of relying on aging parents as caregivers and ensure that the waiver's implementation is guided by real-world data, not just policy intentions.

The state must retain the ability to adjust course—promptly—when the waiver causes harm. That's not just good governance. It's a moral obligation.

I urge you to support LD 1606. Thank you.