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April 1, 2025

Re: LD 977, Resolve, Requiring the Maine Health Data Organization to Develop a Plan for Measuring Gaps in Home and Community-based Services

Senator Ingwersen, 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 28-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 of the Maine Developmental Services Oversight and Advisory Board (MDSOAB).

I am testifying in strong support of LD 977, Resolve, Requiring the Maine Health Data Organization to Develop a Plan for Measuring Gaps in Home and Community-based Services. *This resolve requires the Maine Health Data Organization to develop a plan for annual measurements of the gap between authorized care and the services actually provided for home and community-based services under the MaineCare program, state-funded programs and the forthcoming lifespan program using existing data. The Department of Health and Human Services is required to provide data to the Maine Health Data Organization upon request. The Maine Health Data Organization must submit a report to the Joint Standing Committee on Health and Human Services no later than January 15, 2026.*

I can tell you that the biggest concern parents have, including myself, is what happens when we die.

We know that we are going to die before our children who, by the very nature of their disabilities, will still require support to allow them to flourish in the community, and to keep them from danger. Children without special needs can launch into independence and success. But what will happen to our loved ones who in many ways can't care for themselves? Who will take care of them?

As a society, we long ago decided: Care for this vulnerable population should be a state obligation. As citizens, we empowered and entrusted DHHS to step in and ensure that our most vulnerable citizens received proper care and support for success in their lives.

I would like to thank the Department, specifically leadership and staff within the Office of Aging and Disability Service (OADS). OADS has been working diligently to improve and streamline the ID/DD service system, seeking stakeholder feedback on how best to do so, and incorporating this feedback into its short- and long-term planning efforts – including the Lifespan Initiative. However, more work remains.

As of September 20, 2024, there were 2,135 people on the Section 21 waitlist, and 50 people on the Section 29 waitlist. And as of the quarter ending December 2024, the average wait times for the people on the Section 21 Priority 2 and Priority 3 waitlists were 7.6 and 6.4 years respectively. This means there are almost 2,200 people waiting for services lacking adequate support and care – with most waiting multiple years for services. Though 1,745 of the people on the Section 21 and 29 waitlists are receiving “other coverage”, it is not commensurate with their need.

There is an obvious gap in Home and Community-Based Services (HCBS) for populations with intellectual/developmental disabilities (ID/DD) in Maine, the calculation of which this bill would address. LD 977 would develop a plan for annual measurements of that gap for HCBS and the forthcoming Lifespan program.

Importantly, people on the Section 21 waitlist, though they have waived their rights to it, have been determined to be eligible for a nursing level of care – usually in an Intermediate Care Facility (ICF). The Department ought to, at the very least, be reviewing, analyzing, and reporting on the gaps and needs of the system and the status of these individuals on the waitlists as a result.



Working towards a system in which waitlists are sufficiently short (or non-existent) to provide the same level of care as received by the general population is a wise solution, and an effective and efficient investment. In order to do so, we must understand the current gaps and needs of the system of care. People and their families thrive when they are supported in reaching their potential. Leaving people with no or insufficient support steers them away from their potential and throws individuals and families into expensive and often redundant crises. Maine would be wise to examine gaps in services so we all can help people with ID/DD in Maine reach their full potential.

I hope that you will help Maine create a measure of accountability for its system of care for people with ID/DD by supporting LD 977.

Thank you for the opportunity to comment.