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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; and LD 1634 An Act Regarding MaineCare Waiting Lists

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 on behalf of CHOM in strong support of the following bills:

-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: *This bill requires the rulemaking for the lifespan waiver to be major substantive. Current law requires only the initial rulemaking to be major substantive. The bill also requires the Department of Health and Human Services to collect data related to unmet needs identified in individuals' personal plans and related to residential transitions between group homes, shared living and self-directed residential arrangements. The department is required to publish an annual report with the data on its publicly accessible website and submit the report to the joint standing committee of the Legislature having jurisdiction over health and human services matters.*

-LD 1634 An Act Regarding MaineCare Waiting Lists: *This bill directs the Department of Health and Human Services to require that for any service covered under the MaineCare program, an individual enrolled in the MaineCare program may not be required to wait for services longer than 6 months from the time the services are requested. If at any time a provider's waiting list exceeds the 6-month waiting limit for those individuals, the department must submit to the joint standing committee of the Legislature having jurisdiction over health and human services matters a corrective action plan to reduce waiting times within 3 months from the time the department becomes aware of this occurrence.*

The Department of Health and Human Services (DHHS) Office of Aging and Disability Services (OADS) developed the Lifespan Waiver to support people with ID/DD to meet their evolving needs throughout various stages of their lives. This initiative is the most substantial overhaul of the system of care since the closure of Pineland and the inception of HCBS.

The Lifespan Waiver seeks to improve the current system of care through greater flexibility and choice, by eliminating waitlists and by serving students starting at age 14. This is exactly what the Developmental Services Lifelong Continuum of Care envisioned for the system of care for people with ID/DD in Maine.

Information on the Developmental Services Lifelong Continuum of Care: In late 2009 and 2010 the Maine Coalition for Housing and Quality Services initiated a parent-led project to redesign, from the ground up, a system of care for persons with developmental or intellectual disabilities. This began with a visual and conceptual diagram, evolved to a narrative, a structural design for implementation, goals and action steps to achieve them, and notes about what parents specifically don't want to repeat from the current system of care. The Coalition completed the White Paper in September 2011. In 2012 the Maine Legislature created the LD 1816 Developmental Services Workgroup which was charged with studying ways to create a more efficient and effective service delivery system. This Legislatively appointed workgroup soon decided that the Coalition's White Paper proposed a service delivery model that addressed nearly all of the concerns the Workgroup was tasked to solve. Focusing on the first four pages of the five-page White Paper, the Workgroup made modest language changes to the document while maintaining the content. The Workgroup version was finalized after receiving input from the Coalition in January 2013. On February 1, 2013, the Developmental Services Workgroup adopted the following interim report to be sent to the Legislature through the DHHS Commissioner. This is now a document that is endorsed by the LD1816 Developmental Services Workgroup and the Maine Coalition for Housing and Quality Services.

The Lifespan Waiver could be a game-changer for our system of care for people with ID/DD if implemented and funded properly. Lifespan could ensure a seamless transition from children's to adult services – which everyone agrees needs improvement. Too often people fall off the “cliff of no



services” once they leave the children’s world. Lifespan could solve this if implemented well. The Department has thoughtfully sought feedback from stakeholders in the creation of the waiver which is commendable. However, the devil is in the details. Details must be looked at very carefully prior to implementation, especially considering the current lack of capacity within our system and the ever-increasing unmet needs. Uncertainty around Medicaid funding at the state and federal levels adds urgency to the need for thoughtful deliberation and Legislative oversight when the Lifespan Waiver is implemented.

Please ensure this is Major Substantive so that **all** concerns can be addressed as they arise, and unintended consequences can be avoided. Let’s ensure Maine gets this right. My son’s and thousands of other lives are worth the extra time and care to do so.

And Maine needs to get this right. The biggest concern parents have, including myself, is what happens when we die. 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 receive proper care and support for their success.

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 and incorporating feedback on how best to do so into its short- and long-term planning efforts – including Lifespan. However, more work remains.

In the third quarter of SFY 25 ending in March, there were 2,222 people on the Section 21 waitlist and a combined total of 2353 on the priority 2 and 3 waitlists for Section 21. There were also 59 people on the Section 29 waitlist. And as of the quarter ending December 2024, the average wait times for people on Section 21 Priority 2 and Priority 3 waitlists were 7.6 and 6.4 years respectively. This means there were 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 receive “other coverage”, it is not always commensurate with their need.

SFY25 Count of Individuals on Waiver Service Waitlists*

Count of Individuals Waiting by Waiver	Q1	Q2
Brain Injury (18)	189	200
Other related Conditions (20)	27	31
All Comprehensive Services for IDD/ASD (21)	2135	2,222
Priority 2 IDD/ASD (21)	716	728
Priority 3 IDD/ASD (21)	1569	1625
Support Services for IDD/ASD (29)	50	59
Total Unduplicated Individuals	2381	2487

**Additional information regarding waitlist data is located here:*<https://www.maine.gov/dhhs/oads/about-us/data-reports/participation-and-waitlist-data>

There is an obvious gap in HCBS for people with ID/DD in Maine. LDs 1606 and 1634 would address this. LD 1606 would develop a plan for measurements of that gap for HCBS and LD 1634 would work to ensure that if people wait longer than six (6) months for HCBS, the Department will report to the Legislature on a corrective action plan. This is essential. We cannot ignore our system’s current shortcomings while we wait to implement a new one through Lifespan. Lifespan can’t address the needs if the current unmet needs continue to go unreported. In order for Lifespan to work well, Maine needs to enact LD 1606 and 1634.

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. This population requires services commensurate with need for their safety and well-being.

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. However, to accomplish these important goals, we must understand the current gaps and needs of the system and have a mechanism in place to remedy the waitlist times.

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 improve its system of care for people with ID/DD by supporting these bills.

Thank you for the opportunity to comment.