

Testimony of Laura Cordes

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

Joint Standing Committee on Health and Human Services Hearing April 23, 2025

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

Thank you for the opportunity to provide testimony on 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.*

My name is Laura Cordes, and I serve as the Executive Director of the Maine Association for Community Service Providers (MACSP). MACSP represents nearly 100 agencies that provide person-centered educational, vocational, residential, and community-based supports—as well as specialized care—to children and adults with intellectual disabilities, autism, and brain injuries. These services help individuals live full, meaningful lives in their communities.

This bill requires 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, and then to publish and share the data with this committee and on the Department's website on an annual basis.

The introduction of new and revised services under the forthcoming Lifespan Waiver represents a major restructuring of Maine's Home and Community-Based Services for individuals with intellectual and developmental disabilities. Such a significant redesign rightly merits strong legislative oversight and transparency.

During the 131st Legislature, MACSP testified in support of <u>LD 659</u>, which authorized the Lifespan Waiver. At that time, we advocated for all related rules to follow the major substantive rulemaking process. Following discussions with the Department and this Committee, we were part of a

compromise to classify only the initial rulemaking as major substantive, with future amendments handled through the routine technical process.

At this juncture, we believe it would be inconsistent with the spirit of that agreement for MACSP to revisit the rulemaking designation before the initial rules have first been released. In good faith, we will wait for the publication of the first Lifespan Waiver rules before reassessing our position on whether subsequent rulemaking should be elevated to major substantive.

MACSP supports the other provisions of this bill which would direct the Department to report on the unmet need or "care gap" for individuals with disabilities authorized for services under the forthcoming Lifespan Waiver and would encourage the Department to analyze and report data for individuals who are authorized for services under Section 21 and 29 as well.

In January 2024 MACSP surveyed 25 of our member organizations employing 2,388 full time staff providing support to 1729 unduplicated individuals across MaineCare Sections 18, 20, 21, 29 50 and 97 -F services to develop a snapshot of our sector's *workforce* care gap. Among these 25 agencies, an additional 293 staff were needed to *fully* support 1557 people who receive agency home support community support and quarter hour home support to receive their authorized hours.

We have long known that the gap between *authorization* and *access* results in unmet needs that often impact health, safety, and quality of life. Without measuring the gap, efforts to reform or expand services may miss the mark or fail to prioritize areas of greatest need.

Thank you for your time and consideration.

Respectfully submitted,

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