

Date: April 22, 2025

Subject: 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: Testimony and LD 1634, An Act Regarding MaineCare Waiting Lists

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

We reside in Portland and are testifying in support of LD 1606 and LD 1634.

We are the parents of a 16-year-old with highly complex medical, communication, and sensory needs. He requires assistance with all aspects of daily living and will continue to need significant, around-the-clock support as an adult.

Our son is a wonderful, vibrant individual who brings joy to those around him. He deserves to be cared for responsibly and with kindness when he inevitably transitions to care outside our home. Our biggest source of anxiety and sleepless nights is looking at our son's future and worrying about what kind of supports will be available.

Managing his care requires proper and consistent support paired with clear, ongoing oversight and communication. Without this transparency, he will not be able to live a safe or healthy life — and that is true for all individuals with special needs.

LD 1606 would help Maine avoid unintended harm as we transition to the Lifespan Waiver. When our son begins receiving services on the Lifespan Waiver, it is vital that these services be adequate and consistent. LD 1606 requires unmet needs to be reported annually, and this additional feedback can help policymakers make more informed decisions about how to best address any gaps in the system.

Further, it is crucial for the state to have a clear plan to address waitlists for services and set a maximum wait time of no more than six months, as outlined in LD 1634. People with complex needs cannot — and should not have to — wait for the vital services they need.

For these reasons, we urge you to support LD 1606 and LD 1634 to ensure that people like our son are not left behind as the system changes.

Thank you for your time, consideration, and commitment.

Sincerely,

Amy and Peter Bucklin
Portland, ME