

David Cowing
Woolwich
LD 1606

DATE: 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 Ingwersen, Representative Meyer, and Distinguished Members of the Joint Standing Committee on Health and Human Services,

My name is David Cowing and I live in Woolwich. My son has an intellectual disability as well as other disabilities, including significant mental health and medical challenges. He lives in a group home in Bath. I am submitting this testimony electronically rather than in person before the committee due to a health emergency we're in the middle of with my son. I appreciate the opportunity to provide testimony in support of LD 1606.

Due to the dependence of my son on his Section 21 waiver services, I have closely followed the development of and planning for the Lifespan waiver. As proposed, the Lifespan waiver will not only impact every Mainer with an intellectual or developmental disability (IDD) leaving special education and entering the adult service system--ultimately it will have significant impact on individuals like my son served under Section 21.

I question how those individuals who require 24/7 support will have their needs met appropriately under Lifespan. It is very questionable whether people with more significant needs will be adequately served outside of overburdened family settings. Scores of group homes have closed in the last year, and many agencies are abandoning their group home services altogether. Affordable housing for those with significant disabilities is thus becoming less available. This is due to the unsustainability of agencies losing thousands of dollars in annual costs in the running of quality group homes for individuals requiring this level of support.

Additional resources will inevitably be necessary to support all individuals identified with IDD and graduating from high school each year. In addition, DHHS/OADS must also eventually serve the many hundreds of individuals currently on the existing waiting list for services. This will inevitably create additional challenges to Maine adequately serving all adult Mainers with IDD. I question whether DHHS/OADS has, first, collected adequate data necessary for Lifespan's rollout (and planned for future data collection to monitor how it is working), and second, can realistically anticipate having both the resources needed and system capacity to fulfill its promise of improving the system as envisioned in the Lifespan proposal. I don't doubt the sincerity and good intentions of the effort. I do doubt whether it is sufficiently grounded in the reality of Maine's current economic situation.

Under current law, only Lifespan's initial rulemaking will be considered major substantive. LD 1606 will require rulemaking for the Lifespan Waiver to be considered major substantive indefinitely. This will allow the Legislature to better monitor how Lifespan is being implemented: where it is working, and where problems and gaps exist. It will also make the implementation of this new waiver more transparent to all stakeholders. Critically, LD 1606 also requires DHHS/OADS to collect specific data related to the unmet needs identified in individuals' Person-Centered Plans.

I believe that the major systemic change OADS is undertaking requires ongoing oversight that includes this committee. Involving HHS members with the monitoring of such a significant change in the structure of services for those with IDD is both reasonable and necessary. The rest of the legislature should also have a voice in the implementation of such a significant system redesign. The Lifespan waiver will not only have significant impact on my son's life, but on the lives of sons and daughters

with IDD across Maine for years to come.

Thank you for this opportunity to submit testimony in support of LD 1606.

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