Betsy Mahoney Cumberland Foreside LD 1606

Good afternoon Senator Ingwerson, Representative Meyer and distinguished members of Joint Standing Committee on Health and Human Services. My name is Betsy Mahoney and I'm the mother and guardian of an adult son with autism and intellectual disability. I live in Cumberland Foreside. I'm here in support of LD 1606.

Adopting the lifespan waiver was a good idea, and the current bill will only strengthen it for two reasons. LD 1606 will require major substantive rulemaking for the Lifespan Waiver indefinitely as opposed to the current one year requirement. Potential future revisions should be major substantive, whereas a routine technical requirement which will not give the Committee and the Legislature enough information to make sound decisions. With the major substantive requirement, the Legislature will have some oversight into how the Lifespan waiver is implemented.

The Lifespan Waiver promises to improve the current system of care through greater flexibility but I am concerned about whether the state will have the capacity to fulfill its promise to improve the system. The uncertainty around Medicaid funding at both the national and state level adds urgency to the need for caution and additional oversight when the Lifespan Waiver is implemented.

LD 1606 also requires data collection on whether people supported by the waiver are in fact receiving the services they need. These services are identified in an individual's Person-Centered Plan. Unmet needs must be reported every year. Given the limits on Medicaid reimbursement rates and resulting workforce shortage, some people on HCBS waivers are not receiving the services they need.

Three years ago, for example, the agency that operates my son's group home was forced to close it due to lack of staff. The workforce shortage was probably due to the low wages offered by the agency, which were in part related to the Medicaid reimbursement rate. My son was lucky in that the agency was able to transfer him to another home. A couple of years after that, the agency pushed to transfer my son to a home that his father and I did not believe would meets his needs. We strongly objected and my son did not move, but I am concerned about what will happen after my husband and I are gone.

This bill is important because it builds in accountability before problems arise. I urge you to support it to ensure people like my son are not left behind as the system changes.