

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

My name is Debbie Dionne, and I live in Topsham. I am the mother and sole guardian of my daughter Kate, who lives with cerebral palsy, an intellectual disability, and a seizure disorder.

I am here today in **strong support of LD 1606.**

Forty-five years ago, I became a **disability advocate not by choice** but because I **HAD** to. Since then, I've worked with parents - mostly mothers- to help shape a system of disability services that is accessible, appropriate, inclusive, and visible.

LD 1606 is essential because it secures legislative scrutiny of the Lifespan Waiver—Maine's most significant overhaul of home and community-based care services in a generation, ensuring data collection and major rulemaking receive full oversight.

With 17 different programs many brand new and untested, the Lifespan Waiver will directly affect the lives of thousands of Mainers with disabilities.

LD 1606 ensures we don't enter this transformation blindly. It will provide the transparency, data, and accountability needed to prevent harm, reduce long-term costs, and most importantly protect people with disabilities by ensuring they receive the support necessary to live full, inclusive, and independent lives.

My daughter Kate has lived in the same group home in Brunswick for 23 years sharing her home with five other individuals and a dedicated team of Direct Support Professionals (DSPs). Her extended family understands her communication style, her complex medical and physical needs and how to support her to thrive. Despite persistent understaffing and long overtime hours Kate is growing. Since the pandemic she's gained confidence and is seeking more independence.

That dream is threatened.

Like so many homes across Maine Kate's group home cannot meet the required 92.5 percent staffing ratio and does not receive full reimbursement. **Over 90 group homes have closed statewide. We don't know where many of those residents have gone.** Have they moved back in with aging parents like me? With relatives unprepared to care for them? Or have they been placed in unfamiliar group homes hours away from their communities?

We have no system-wide data available to track the impact. And options like shared living aren't appropriate for individuals with high, complex needs like Kate.

Now I face my own mortality I was recently diagnosed with cancer and a week earlier my husband and Kate's step dad was diagnosed with Parkinson's. I lie awake asking **Who will care for Kate when I am gone?** I have no family to step in. I'm not alone in this fear- many parents of group home residents are aging, ill, and agonizing over what will happen to their children.

We need LD 1606 because oversight and data tracking are necessities not luxuries. This bill will protect vulnerable people, guide critical decisions, and help us build a system that truly supports individuals across their lifespan.

Please vote YES on LD 1606 Our children our families and our future depend on it.

Thank you.