

Testimony in Support of LD 1606: An Act to Require Data Collection and Major Substantive Rulemaking for the Lifespan Waiver

Submitted by Kim Humphrey, MPH
Mother of an adult son with profound autism
Founder & President, Community Connect Maine

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

Hello. My name is Kim Humphrey, from Auburn. I am the mother of an adult son with profound autism, Founder and President of Community Connect Maine. I'm here to fully support all aspects support of LD 1606. I am testifying both personally and for Community Connect Maine.

This bill matters because the Lifespan Waiver, an extremely ambitious undertaking of OADS, is the most significant overhaul to Maine's disability system in a generation. It **promises flexibility, earlier services, and the end of waitlists**—goals we support. But success can't rest on promises alone. With 17 new programs, four capped tiers, and the erosion of existing waivers, **we need guardrails. LD 1606 provides them.**

This bill is needed because of lack of trust and accountability

- **"Grandfathering" was promised for section 21 and 29.** Last week I learned that the state changed group home rate funding formula from hours based on the person's need to a 3-person:1-staffing ratio under Section 21. Now access to necessary care for a high needs individual is tied to a Supports Intensity Scale (SIS) assessment, with no guarantee of sufficient funding support to follow- previously I was assured at the Department of Health and Human Services Office of Aging and Disability Services (the DHHS OADS) listening session that section 21 members were exempt from that assessment. And that funding would not decrease in section 21 group homes because of the implementation of the Lifespan waiver. **This is not grandfathering- There's no turning back. It's a gamble on our children's lives and it's violation of trust.**
- **My son requires 1-person: 2-staffing, especially in his community.** The new funding model doesn't meet his needs. If the SIS doesn't make up the gap, is the state going to send him out of Maine again?
- **Higher-needs individuals in group homes are being squeezed.** Rate changes appear to cut support for those with the greatest needs, the same people who don't fit in a family care model, who've been stuck in ERs because providers don't have the capacity to serve them.
- **Trust is weak.** The Lifespan Waiver is being promoted to be able to absorb all of the people from the waitlist in 5 year. At the same time the state changed the codified rate system and 125% of minimum wage recently guarantee by law, to now may be limited based on existing resources. Funds are always available if you make it a priority.

This bill provides oversight instead of hindsight

- **Ensure legislative oversight** by keeping the Lifespan Waiver a *major substantive* rule.
- **Require annual reporting** on access, and unmet need, capacity and stability— Timely data could have prevented hardship and saved millions from blind spending, excessive consultants that may not have been needed if data were used.
- **Keep Maine voices heard.** A new Federal Access Rule requires reporting, and that's good. At the same time Mainer's in the system that highlight important data points that may be different from the access rule, shouldn't be shoved aside because of it. The Mainer's are the ones that will be living with good or bad outcomes.
- **Create a structured feedback loop** between DHHS, legislators, individuals ,families, and providers. Trust depends on shared information.

This bill is urgent:

- **Unmet needs are only finally now being analyzed** through the Evergreen database— years late. Make tracking unmet needs number one priority.-It saves money, and improve lives.
- **Currently, Federal disability advocacy systems are being dramatically dismantled.** Families like mine are counting on you for transparency and accountability.

Maine people can solve Maine problems—if we have the information and trust to do it.

What Makes a Rule “Major Substantive”?

Under Maine law, a rule is *major substantive* if it:

- Involves significant agency discretion; or
- Reduces services, increases costs, or burdens the public.

The Lifespan Waiver clearly meets this standard. It redefines services, funding, and the future of our system. If we get it wrong, people suffer. If we get it right, they will live full lives.

It is inextricably linked to section 21 and 29 and the data points are intended to apply to these waivers as well.

Final Thought

Please vote LD 1606 ought to pass: Live up to the promise of the Lifespan Waiver
Thank you,

Kim Fulmer Humphrey