

My name is Lisa Wesel and I live in Bowdoinham, and I support LD 1606.

My 28-year-old daughter, Lidia, has a rare genetic disorder that causes intellectual disabilities and uncontrolled seizures. She is on the Sec. 21 waitlist, and unless my husband and I get hit by the same bus at the same time, she is never coming off that waitlist.

I support this entire bill, but I want to specifically address the data point about shared living. Shared living, which is adult foster care, isn't new, but until recently, people caring for a family member were not allowed to be compensated as shared living providers. That created a financial hardship, because caring for an adult with a disability often prevents someone from holding a job. (I gave up a high-paying union job decades ago to care for my daughter.) To its credit, Maine acknowledged that hardship and now allows family members to be shared living providers. That change was intended to address the specific issue of financial hardship. It was not meant to have parents replace other forms of community-based support. But OADS has stated that, under the Lifespan Waiver, shared living will play a much larger role in the system of care. Where will these caregivers come from? We need data to answer that question.

My concern is that the OADS plan is magical thinking. You know how difficult it is to find qualified foster families for children – imagine how hard it is to find community members willing to care for an adult with disabilities. If they use a wheelchair, it's nearly impossible, because so few homes are accessible, and the homeowner, not the state, is responsible for paying for the ramp and the chairlift. If the person has a mental health diagnosis or struggles with behavior issues, it's that much harder.

I called a few agencies and learned that well over half their shared living providers are family members. We need real data, because if most of those providers are in fact their parents, then we are not creating a system of care – we are simply postponing the crisis that will occur when those parents become too old or die, and there is no alternative in place to care for their child.

OADS may argue that this bill duplicates LD 977, or that they are already collecting data under the new CMS ACCESS Rule. There is some overlap with Rep. Cluchey's bill, but LD 977 does not address shared living. And can we count on the federal government anymore? 25% of the DHHS workforce is set to be eliminated, along with the programs they staff. Do we know if the ACCESS Rule is even moving forward?

That is why the Lifespan Waiver must remain major substantive indefinitely. All of the federal guardrails that were in place when it was initially approved – the ones we count on to regulate and support these MaineCare-funded services – are disappearing. The state of Maine – you, specifically – are all we have left. Considering how expansive the Lifespan Waiver is, I would think you'd want to retain oversight, and would welcome the input of the users to feel confident that the program is working as intended.

The state needs to collect all of the data requested in this bill, and the process must remain transparent and collaborative, to determine if the system of care is sustainable. Otherwise, you cannot answer the one question that keeps me awake at night: "What happens to Lidia when her father and I can no longer care for her?"