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Greetings, honorable members of the Joint Standing Committee on Health and Human Services. My name is Janet Hamel. I live in Orono and I'm testifying in favor of LD 1490.

My 38-year-old daughter Marty has intellectual and developmental disabilities, or IDD. She will always need help. MaineCare Home and Community Based waiver services exist to provide the help that individuals like Marty need—to learn the skills that enable them to live, work, and contribute to their communities. When Marty has the support services that waiver funds provide, her workers help her continue progressing toward greater independence. Marty is on a waiting list for waiver Section 21 services. Section 21 funding would provide Marty with sufficient support staffing to live in her own apartment.

Mainers with disabilities who complete high school don't automatically receive adult support services. If eligible, they go on a waiting list. While waiting, they may go into crisis from losing their school supports and social connections. Skills they worked hard to learn in school often disappear. In some families, a parent quits work to care for their child, but many cannot. A waiting list leaves the whole family isolated and struggling.

Some adults with disabilities are ready to leave their family homes. They may receive some funded assistance, but not enough to live away from home. Yet parents age, become ill or infirm, and eventually die. These adults with disabilities – eligible for comprehensive funding – wait on a list for enough funding to live away from home. Some wait years. Sometimes it takes a death or other crisis before someone receives sufficient funding for a different residential situation. Having to move during a crisis creates additional trauma for vulnerable individuals.

Each person on these waiting lists has unique strengths and challenges. The common denominator? Everyone is awaiting the help they need to live safely, develop independence, and participate in their community. Instead of continuing to learn and grow, their lives are on hold.

Parents of adults with disabilities agonize about our children's futures after we are gone. Waiting list parents share an additional, immediate concern: When can our children build their adult lives separate from the family, with the assistance they need to succeed?

In order to eliminate the current wait lists for waiver services—and prevent their return—DHHS and the Legislature must together address the needs of tomorrow's high school graduates with the necessary forward thinking, funding, and budgeting. LD 1490 is a bill that will establish regular and ongoing reporting by DHHS to the Legislature and to the public of information regarding individuals with developmental disabilities who are eligible for waiver funding.

This bill would require DHHS to post data about wait lists numbers and time on wait lists, to make projections about wait list growth, and to tell the Legislature what kind of appropriations would be required to prevent such wait lists in the future.

LD 1490 would also establish the principle that reimbursement rates to service providers should be high enough that they don't stand in the way of actually delivering services, and would broaden the stakeholder input requirements for DHHS to meet in carrying out waiver service system redesign.

Adult Mainers with developmental disabilities do not want to languish at home, losing the skills they worked hard to learn in school, and missing out on opportunities to work, to live away from their families if they choose to, and to contribute to their communities. Please enact LD 1490 and take a proactive approach to ensure these individuals do not spend years sitting at home, waiting for their adult lives to begin.