

Janet Hamel
Orono

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 962.

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.

What do “needs help” and “support services” mean for my daughter? She needs help solving everyday problems – lost key, plugged toilet. Kitchen hazards are plentiful, yet she wants to cook. Learning basic life skills? An ongoing process. At work she needs help learning and organizing tasks. She needs help building friendships. She can learn, with help, and she is determined to do things herself. With assistance from trained support staff, her independence grows, and she thrives.

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?

Enabling Mainers with disabilities to thrive in their communities is not a partisan issue – it is an issue of heart. The Dalai Lama notes, “It is not enough to be compassionate. You must act.”

Marty and I count on the Legislature and the Governor to act. Through no fault of their own, these Mainers need help to live their adult lives. Please eliminate the waiting lists for adults with disabilities. That's the way life should be.