

January 27, 2020

Chairman Gratwick, Chairwoman Hymanson,
Honorable members of the Joint Standing Committee on Health and Human
Services:

My name is Dixie Redmond and I am from Hampden, Maine. I am testifying FOR
LD1984.

Waitlists create crisis.

Our beautiful son Alex needs 24-7 eyes-on support. Alex is autistic and has
intellectual disability. Professionals worked hard to help him learn and grow. But
he needed and still needs significant support.

When high school ended, we had **no opportunity to plan for a transition**
because our son was placed on a waitlist.

School supports ended, but his disabilities didn't. Crisis hit.

**Our son, who has intellectual disability, autism and other disabilities, tried
to solve the problem. With limited language, he reviewed his life, and tried
to pinpoint what he had done wrong that his support structure had
disappeared.**

It was very dark time. Our son regressed. He stopped talking. He
communicated his needs through behavior we hadn't seen in many years. In
moments when he finally could speak, he asked, "What happened to my good
life?" My son, who has multiple disabilities, knows this is NOT the way things
should be in Maine.

I had to stop my work to care for my son. Sometimes my husband had to leave
his work because my son needed two people to help him. We took turns sitting
with him day and night during this time for about four months.

Eventually, Alex received Section 29. But because of the time on the waitlist, **my
son's needs had become more intensive, and the 1:1 support he now
requires must be at a higher skill level.** Agencies have a difficult time finding
workers, let alone workers with knowledge about autism and depression and
anxiety.

So for over 6 years, Alex has only been able to access 12 to 15 hours a week of services. He is eligible for 40 hours. There were times services stopped all together.

We KNOW the individuals who will need significant support through school records. But the state has sent disabled people into crisis by not providing support structures when needed.

It is not enough to clear the waitlist for this year only! As a state, we must build a roadway so that our most vulnerable citizens aren't harmed by time spent waiting for supports.

There is so much Alex can accomplish when properly supported – he can participate in society AND contribute TO society. This past week for the first time Alex delivered meals on wheels as a volunteer with the support of staff. Yesterday he proudly told his grandparents, "I have he had a job delivering food."

My son needs Section 21 to help him build his life. Some of the things he needs are not available in present services, such as behavioral support, maintenance speech therapy, maintenance occupational therapy. Yet he remains on the waitlist in the lowest-priority because he lives with his parents and is not at risk for abuse. What kind of standard is that? That isn't the way life should be in Maine.

Transitions require planning. **We want to help our son transition to an independent, good life while we are alive to help support that transition. We have seen what happens when a transition plan is not in place.**

Thank you.