RENELLE RAY Cape Elizabeth LD 1606

Hello - My name is Renelle Ray and I am the mother & guardian of a 36-yr old who has Cerebral Palsy, is on the Autistic Spectrum and has an Intellectual Disability.

The last 15-years have been a long and arduous journey. After living in various group homes where staff turnover was a constant and his roommates were sometimes violent, my son is finally in a place that is a good fit.

Now that he has consistent and better trained staff, he has become more independent, and his behavior has improved significantly. Due to mobility limitations, he still needs help with dressing, personal hygiene, and cooking. Fortunately, under Section 21 he has the 24/7 support that he requires – not only with his adaptive living skills but in case of a fire or other emergency, he has staff who are there to transport him. The Lifespan waiver promises to serve students with disabilities in high school and to eliminate the waitlists. I applaud those goals but am concerned about whether DHHS has the capacity to serve almost double the number of individuals that it serves now. In the face of an ongoing workforce shortage and budget cuts at the state and federal level, I'd like to have a better understanding about how the Lifespan waiver is going to be rolled out without harming my son and others like him with more complex needs. As an aging parent, I am especially concerned about his future.

As the Lifespan waiver will completely overhaul services for our most vulnerable population, the need for continuous legislative oversight is essential. A requirement to collect more data about waiver recipients and to identify the gaps in services can only be a good thing. Why wouldn't DHHS want more information to inform and help improve the system?

I urge you to support LD 1606 and to make rule making for the Lifespan waiver major substantive indefinitely.

Thank you to Senator Anne Carney and Representative Michelle Boyer for sponsoring this bill in response to families' concerns about the Lifespan Waiver.