



Senator Baldacci
Representative Meyer
Members of the Committee of Health and Human Services

RE: LD 464 An Act to Eliminate Waiting Lists for Community-based Services for People with Autism Spectrum Disorder, Intellectual Disability, Brain Injury or Other Related Conditions and LD 659 An Act to Promote Seamless and Flexible Home and Community Supports Across the Lifespan for Individuals with Intellectual and Developmental Disabilities or Autism.

Senator Baldacci Representative Meyer and members of the Health and Human Services Committee. My name is Carrie Woodcock I am the parent of two children with special needs and the Executive Director for Maine Parent Federation (MPF), the federally funded Parent Training and Information Center (PTI), Family to Family Health Information Center (F2F) and Statewide Family Network. We assist families of children with disabilities and special healthcare needs to navigate all systems of care. I am submitting this testimony neither for nor against LD 464 An Act to Eliminate Waiting Lists for Community-based Services for People with Autism Spectrum Disorder, Intellectual Disability, Brain Injury or Other Related Conditions and LD 659 An Act to Promote Seamless and Flexible Home and Community Supports Across the Lifespan for Individuals with Intellectual and Developmental Disabilities or Autism.

Maine Parent Federation fully supports eliminating all waitlists for individuals with disabilities and special health care needs as well as seamless and flexible supports across the lifespan. One concern we have is eliminating waitlists does not prevent against them returning in the future. I believe back in July of 2016 we eliminated Section 29 waitlists. While the waitlist was cleared it was not long before it was again created as the need far outweighed the supply. The Lifespan waiver programming is a start but as was presented at the public hearing there are a lot of missing details that still need to be answered, including decentralization.

It is of the utmost importance that Maine does the work to create a system that provides the right services at the right time for each person. This work is not just contained to adult services but also services received Birth through the age of 18 – something I like to refer to as the real Early Intervention. Our transition planning across all systems of care needs to greatly improve. We need to include these individuals into school and community life with their typically developing peers. We need to stop the placement of students in self-contained classrooms. We need increased opportunities for post-secondary academic college experiences, which currently do not exist in our state.

In short we need our schools, Vocational Rehabilitation Services, Office of Children and Family Services, Office of Aging and Disability Services, and University and Private College systems to work together to create a comprehensive transition plan. This plan should be individualized and should include

employment, voluntary work, adult services, adult education, college, and independent living. One system should not shoulder the responsibility. We need to leverage all systems to meet the need. Some of this work was done under LD 924 out of the Educational and Cultural Affairs Committee and is currently being considered for legislative action.

I will conclude with sharing a conversation I recently had with my 15-year-old daughter with Down Syndrome. As she entered her freshman year in High School, she shared with me her expectations. She was going to do her freshman, sophomore, and senior year (I reminded her about junior year 😊) and graduate with her friends. She is then going to go to college and with her friends. She wants to graduate from college and become a police officer and live in an apartment with her friends. If I was presenting this idea to you about a typically developing 15-year-old you would have no hesitation about their ability to reach those goals. Because I told you Sami has Down Syndrome, I challenge you to be honest with yourself about what you thought about Sami's ability to reach these goals. With the right supports, accommodations, modifications, and preparation Sami can come pretty darn close to realizing her aspirations just like her peers.

Thank you for your consideration.

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