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Testimony of Betsy Mahoney, Esq., Community Outreach Liaison, Autism Society of ME, in Support of LD 1984, An Act To Eliminate Waiting Lists for Home and Community-based Services for Adults with Intellectual Disabilities, Autism, Brain Injury and Other Related Conditions

Senator Gratwick, Rep. Hymanson, and Members of the Joint Standing Committee on Health and Human Services, my name is Betsy Mahoney and I am the community outreach liaison for The Autism Society of Maine. I am also the parent of an adult son with autism and intellectual disabilities who receives supported housing and other services under MaineCare Sec. 21.

The Autism Society is very much in favor of LD 1984. In order for people with disabilities to be included in their community and enable their family members to work, the State must provide services and programs, and provide adequate reimbursement payments to ensure a workforce to work with this population.

Over the past few years the Legislature has approved funding for the elimination of the Section 21, Priority 1 waiting list, as well as the Section 29 waitlist. This is huge and should be applauded. However, more work remains. As of October 1, 2019, there were:

- 1,918 people on the Sections 18, 20, 21, and 29 waitlists – with 1639 of those people waiting for Section 21, some of whom have been waiting years for services
- Therefore there are close to 2,000 people waiting for services lacking adequate support and care.
- Enacting LD 1984 would remedy this, so long as agencies have adequate staffing capacity, the crux of which is having the ability to pay direct support staff suitable wages.

The most important reason that ASM supports this bill is that it acknowledges and addresses the fact that people with autism and intellectual disabilities should be able to live the fullest lives possible AFTER they finish school. Right now, the federal Individuals with Disabilities Education Act (IDEA) requires that school districts provide a free appropriate public education to eligible children with disabilities and ensures special education and related services from age 3 until a child reaches adulthood. Regular, structured instruction is key to the development of children with autism and intellectual disabilities. For those students, this means a variety of extra supports and services throughout the year for up to 30 hours a week.

Once these students graduate, however, there is no guarantee that they will receive any services at all. Without further community-based activities and supports, these individuals will almost certainly regress in their social, functioning and intellectual skills and will have no way to be independent or to productively occupy their time.

When an individual goes without services for an extended period of time other negative habits will come into play and reversing them often proves difficult. This happens even when the student has a school break. Coming back to school without losing ground can be very difficult because parents are unable to offer the same structure as the child receives at school.

Community-based services and supports through adulthood are important to the whole family. Without structured activities for their children with autism, parents often have to give up their jobs to be home with their adult child. This causes significant emotional and financial stress and takes people out of the workforce at a time when unemployment is low.

The Autism Society also endorses other provisions of the bill, including the system of care it provides for, as well as its emphasis on adequate reimbursement rates, workforce availability, the importance of allowing people with disabilities to lead an independent life, the requirement that information about the waitlist be posted on the Department's website, and the roles of various state departments and agencies.

Providing sufficient funds to ensure a workforce large enough to provide direct services to people with autism and intellectual disabilities is absolutely critical, but so is ensuring that that workforce is trained to work with individuals with ASD. Training requirements need to be built into the statute as the plan is developed.

We look forward to working with members of Legislature as well as the Departments of Health and Human Services and Education to promote the well being of people with autism and their families.