

To: Senator Baldacci, Representative Meyer, and distinguished members of the Joint Committee for Health and Human Services

From: Debbie Dionne, mother of Kate, founding board member of Community Connect Maine, and Independence Association Board member

RE: In strong support of:

LD 744 An Act to Ensure Access to Services for Adults with Intellectual and Developmental Disabilities by Requiring Rate Studies for Home and Community-based Services

LD 1037 An Act to Fund Competitive Wages for Direct Support Professionals for Persons with Disabilities

LD 1250 An Act Regarding Paying Providers Sufficiently, Maintaining Short Waiting Lists and Creating a Cause of Actions for Aggrieved Persons in the System of Care for Clients with Intellectual Disabilities or Autism

My daughter, Kate, is a vibrant, tenacious, 43 year old woman who has Cerebral Palsy and an intellectual disability. Kate also has limited speech and the fine motor skills that would enable her to advocate on her own. Out of necessity, I have had to step up in my role as her mom to make sure Kate has had equal opportunities to live a full and inclusive life, beginning with pre-school, and now, as an adult living in a group home. Kate's dream when she graduated from Brunswick High School, was to live independent from me. Kate is one of the lucky ones and did not languish at home with mom, on a waitlist for years waiting for services. For the past 22 years, Kate has lived a full and active life with her lifelong friends and in the same community where she was born. However, I have never been more worried than I am now about the future for Kate and all Mainers with disability living with more complex needs.

At the HHS hearing for LD 744, 35 providers and family members from Fort Kent to Saco shared their devastating reality. Some of the key points from the powerful testimony include:

- The provider agencies who testified are important members of their community and have been in business for up to 65 years and were founded by family members.
- 75 group homes have closed with 20 more projected to close within the next 6 months. Many of these homes were ADA compliant and completely accessible for those with physical disabilities and will never be replaced.
- Group home residents have been relocated great distances from their families or have moved in with their aging parents who may be one step away from needing
- direct care services themselves and now are finding themselves providing 24/7 direct care as a Shared Living Provider.
- Mainers with I/DD who are in crisis may be forced to live in emergency rooms because of no place for them to go.

- Providers have been forced to sell group homes to make up the losses that have been incurred from increased program costs and the insufficient reimbursement rate.
- 40 community support programs have disappeared leaving the I/DD people served with little opportunity for meaningful socialization.
- A favorite, 30 year old community support program was forced to abruptly close due to the the insufficient reimbursement rate and staffing ratio.
- DSPs are working 60 plus hour weeks in order for group homes to be sufficiently staffed to meet the minimum staffing level. One agency reported that there are 80 hours of overtime in each of their group homes every week.
- Providers have been paying 125% of minimum wage or more and are still experiencing a high shortage of DSPs.
- Experienced, trusted DSPs with 20 plus years of experience with the same provider are leaving for better paying jobs. This story was repeated often.
- A revised rate model based on a properly conducted rate study has not taken place in over a decade.

As a long-time board member of Independence Association and the agency that provides the high quality support services to Kate, this is personal. Out of necessity, I have become a week-end shared living provider because of the staffing shortages in my daughter's home. My daughter requires assistance with every aspect of her daily care. Our home is not ADA compliant or completely accessible. It is a stressful and physical job and I am approaching 71. Independence Association has consolidated programs and group homes, re-configured staffing models and sold prime real estate in an effort to offset the losses from the insufficient reimbursement rate, exorbitant overtime due to the DSP shortage, and increased program costs. The red ink that appears every month in the financial statements is frightening to see. IA started in the basement of a church by family members 56 years ago. Five parents and one self-advocate currently sit on our board of directors to help keep the mission going strong. "Independence Association celebrates the ability of all Mainers to live as valued, contributing members of the communities we all love."

It is imperative that the state of Maine make the disability community and those that have chosen to support this population a priority and not put this off for another legislative session. **Please help this mom help her daughter by voting to pass LD 744, LD 1037 and LD 1250.**

With gratitude for your service,

Debbie Dionne
Topsham

