CHOM
Community Housing of Maine

April 21, 2021

Re: LD 1360, An Act To Provide Services to Maine's Most Vulnerable Citizens by Eliminating the Waiting Lists for Certain MaineCare Services; and LD 962, An Act To Appropriate Funds To Eliminate Waiting Lists for Home and Community-based Services for Adults with Intellectual Disabilities, Autism, Brain Injury and Other Related Conditions

Senator Claxton, Representative Meyer, and members of the Joint Standing Committee on Health and Human Services, my name is Cullen Ryan, and I am the Executive Director of Community Housing of Maine or CHOM, the largest supportive housing provider for homeless populations in Maine. Our staff of 11 works collaboratively with more than 50 different service provider organizations to effectively and efficiently house some 1100 of Maine's most vulnerable people, including more than 100 people with intellectual/developmental disabilities (ID/DD). I am also a parent of a 24-year-old son with ID/DD. In addition to being a parent, I serve as Chair of the Maine Coalition for Housing and Quality Services, a coalition of some 4000 people, consisting primarily of parents, that focuses on housing and quality services for people with ID/DD. Ultimately, the goal of the Coalition is to create a system of quality housing and personal supports that is person and family centered, with choice, dignity, and efficiency being at the forefront of efforts. I also serve as chair the Maine Developmental Services Oversight and Advisory Board (MDSOAB) Board.

I am testifying today in support of LD 1360 and LD 1360. Both bills address the waitlists for home and community-based services for adults with intellectual/developmental disabilities, autism, brain injuries, and other related conditions. LD 1360 would provide funding to clear the MaineCare Section 29 waiting list through the end of FY 21, and provides funding to reduce waiting lists for MaineCare Section 21 services by providing services to those individuals who are designated as Priority 2 and are receiving no other MaineCare home and community-based or support services. LD 962 would provide funding to eliminate the Section 18, 20, 21, and 29 waitlists in their entirety. I urge the Committee to support any bill which would address the waitlists for HCBS. LD 1360 is good – and LD 962 is better.

I can tell you that the biggest concern parents have, including myself, is what happens when we die.

We know that we are going to die before our children who, by the very nature of their disabilities, will still require support to allow them to flourish in the community, and to keep them from danger. Children without special needs can launch into independence and success. But what will happen to our loved ones who in many ways can't care for themselves? Who will take care of them?

As a society, we long ago decided: Care for this vulnerable population should be a state obligation. As citizens, we empowered and entrusted DHHS to step in and ensure that our most vulnerable citizens received proper care and support for success in their lives.

I would like to thank the Department, specifically leadership and staff within the Office of Aging and Disability Service (OADS). OADS has been working diligently to improve and streamline the ID/DD service system, seeking stakeholder feedback on how best to do so, and incorporating this feedback into its short- and long-term planning efforts. And, 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 January 1, 2021, there were 2,111 people on the Section 18, 20, 21, and 29 waitlists – with 1864 of those people waiting for Section 21, some waiting years for services. This means there are more than 2,000 people waiting for services lacking adequate support and care. Enacting LD 962 would remedy this in its entirety, so long as agencies have adequate staffing capacity, the crux of which is having the ability to pay direct support staff suitable wages – something addressed by bills in today's public hearing schedule that I also strongly support.

Society cannot afford to fail these people.

Here is why. We have learned that when we do this right, when someone has the supports and services needed – no more, no less – we see a human being launch and achieve his or her greatest potential. We see people like my son shine. We see them participate and make a meaningful difference in the community, making all of us better. And we know that doing it right is optimal; and if it is optimal, it will cost the absolute least it possibly can.

When a person is successful in the community, and when a person is successful in a job – they need the least amount of support from DHHS.

And when sons and daughters launch, their parents, who are often at the pinnacle of their careers, are able to work and contribute fully to the economy.

Without support for their sons and daughters, parents are often forced to quit their jobs and careers and play the role of care givers, something not good for parents or their adult children who often revert to increased neediness and see their hard-earned independent skill capabilities atrophy.

If we don't do it right, we will see our sons and daughters languish, and launch into crisis. We will see our loved ones lose skills they worked hard to develop, growing up with special education where they learned exactly how to be part of a community with the right amount of support. We will see them falter, and we see them fail. And their small needs then become very large needs, and we all will pay for that.

I believe helping everyone reach their full potential is the way to go. I hope that you will invest in helping people with intellectual/development disabilities, brain injuries, and other-related conditions receive the services they need, so that they can be included as part of the community.

Thank you for the opportunity to comment.