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April 3, 2017

Re: LD 323 – An Act to Fully Fund the Waiting List for the Home and Community Benefits for Members with Intellectual Disabilities or Autistic Disorder Waiver; and LD 967 – An Act to Ensure Access to Community Services for Individuals with Intellectual Disabilities or Autism.

Senator Brakey, Representative Hymanson, and members of the Joint Standing Committee on Health and Human Services, my name is Cullen Ryan and I serve as the Executive Director of Community Housing of Maine or CHOM. I am the parent of a 20-year-old with developmental disabilities.

I am also the Chair of the Maine Coalition for Housing and Quality Services which includes 4000 people who are mostly parents, but also self-advocates, relatives, concerned friends, and caregivers, for people with developmental/intellectual disabilities in Maine.

My testimony is in support of both LD 323, which would provide full funding for the Section 21 waiting list, and LD 967, which would increase the Section 21 and Section 29 rates to the inflation-adjusted 2007 rates established by the Legislature and the Department.

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.

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 the end of December 2016, there were 1399 people on the Section 21 waiting list, some of whom have been waiting *years* for services. This means 1399 are waiting for services who already lack adequate support and care. Enacting LD 323 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 – as LD 967 proposes.

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 our sons and daughters 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.

Because when a person is successful in the community, and when a person is successful in a job – they don't need much support from DHHS. The rest of the kind people in Maine will offer a natural hand, and we see a better world for it.

This may not sound like a very big deal. But let me tell you about my son. He is a very easygoing young man, who is easy to work with, and eager to please. People enjoy working with him. He is a joy. I may be biased, but I've repeatedly heard this from a lot of people.

In fact, in his short 20 years, he has now had some 38 different direct service workers. People who enjoyed working with him, and wished they could have continued, but had to leave for other jobs because they paid 15 cents more an hour.

Thirty-eight people have come and gone in my son's life. They have been there long enough for him to get to know them, and then they have abandoned him. And each time it has left a gap because it was then hard to fill the position. And my son languished without support over and over again. Imagine if my son had one or two professionals over his formative years who could have afforded to stay with him long enough to take what they learned and really help him launch. Today he would be more independent, more self-confident, more ready for employment, and better prepared for everything.

Direct service providers, the people who work with my son and others with intellectual disabilities – these people are the very nexus of where the system of care meets my son. Direct service providers need to be paid enough to stay. They need to be paid enough to want to work in the field. They need to be paid commensurate with the work they're asked to perform daily. Direct support staff are professionals who cannot be paid minimum wage, the same wage they could make for work requiring far less effort and skills in the service industry. But all over the state they are right now.

LD 967 would increase the rates for Sections 21 and 29, while ensuring that the increase goes directly to Direct Support Professionals (DSPs), helping to alleviate the current DSP workforce crisis – including high vacancy and staff turnover rates which has led to my son, and many others, having numerous workers come in and out of his life. If agencies can't hire anyone, if agencies can't retain anyone, people like my son won't receive services. And, if the Legislature enacts LD 323 and fully funds the Section 21 waitlist, agencies won't have the staffing capacity to actually provide services if wages aren't increased. If enacted, LD 967 would assist in this, allowing providers to pay DSPs professional wages, commensurate with the level of work required of the position.

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 receive the services they need, delivered by people who are paid an adequate wage, so that they can be included as part of the community.

Thank you for your time and careful consideration.