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February 21, 2023

Re: LD 258, An Act Making Unified Appropriations and Allocations for the Expenditures of State Government, General Fund and Other Funds, and Changing Certain Provisions of the Law Necessary to the Proper Operations of State Government for the Fiscal Years Ending June 30, 2023, June 30, 2024 and June 30, 2025

Senator Rotundo, Representative Sachs, Senator Baldacci, Representative Meyer, and members of the Joint Standing Committee on Appropriations and Financial Affairs and the Joint Select Committee on Health and Human Services, my name is Cullen Ryan, and I am the Executive Director of Community Housing of Maine or CHOM. I am also the parent of a 26-year-old son with Intellectual/Developmental Disabilities (ID/DD). 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. I also serve as chair the Maine Developmental Services Oversight and Advisory Board (MDSOAB).

I am testifying in strong support of the Biennial Budget. Specifically, I urge you to support the \$84 million funding request pertaining to Disability Services. This funding request includes:

- \$34M to add 900 individuals to Section 29 by 2025 (50 per month). This aims to eliminate the Section 29 waitlist in its entirety by 2025.
- \$3M to continue reserve capacity in Section 21.
- \$42M for future cost-of-living rate increases in Section 18, 20, 21, 29, Intermediate Care Facilities (Section 50), and PNMI-Fs (Section 97).
- \$5M to launch the Lifespan project and enroll 540 individuals in the Lifespan waiver in 2025 (in the last six months of the Biennium).

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 addressing the growing Section 29 waitlist. This is huge and should be applauded. However, more work remains.

As of September 20, 2022, there were 2,028 people on the Section 21 waitlist, and 218 people on the Section 29 waitlist – with some waiting years for services. This means there are more than 2,000 people waiting for services lacking adequate support and care. Appropriating funding to for the Section 21 and Section 29 waitlists, as well as investing in the Department's Lifespan project would greatly assist in remedying this. 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 the proposed COLA increases in the biennial budget that I also strongly support.

The biennial budget would also provide an opportunity to actualize the Developmental Services Lifelong Continuum of Care (which was created by the Maine Coalition for Housing and Quality Services in partnership with DHHS), by funding the Department's Lifespan Project. This would ensure HCBS truly address people's changing needs and desires throughout the entire lifespan, so that each person is met where they are at, providing the amount and type of services needed.

In late 2009 and throughout 2010 the Coalition initiated a parent-led project to redesign, from the ground up, a system of care for persons with developmental or intellectual disabilities. This work culminated in a White Paper outlining a Lifelong Continuum of Care in September 2011. In 2012, the Maine Legislature created the LD 1816 Developmental Services Workgroup which was charged with studying ways to create a more efficient and effective service delivery system. This Legislatively appointed workgroup soon decided that the Coalition's White Paper proposed a service delivery model that addressed nearly all of the concerns the Workgroup was tasked to solve. On February 1, 2013, the Developmental Services Workgroup adopted the interim report, the Developmental Service Lifelong Continuum of Care, to be sent to the Legislature through the DHHS Commissioner.

The Developmental Services Lifelong Continuum of Care model prizes the concept of "No one-size-fits-all". It takes into account that formal support, such as that required for unique or complicated behavioral or medical conditions, must be flexible and designed to meet each person where they are. And, support must ebb and flow over the lifespan as the individual's needs change. Included within the model is quality flexible wraparound support, which means varying services as needed (from minimal to maximum) to promote personal development, safety, stability, and inclusion. At its heart, it is designed to provide an individual with the exact amount of support the person needs, no more and no less. Everyone, including leadership at DHHS, believed that this would be a superior model, one which would maximize efficiency of resources, and maximize the success of every individual as part of the community.

The Department's Lifespan Project is critical to accomplishing the goals set forth in the Developmental Services Lifelong Continuum of Care and would ensure that the full spectrum of needs of people with ID/DD in Maine are met effectively.

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 hope that you will invest in helping people with intellectual/development disabilities have access to and receive the services they need by supporting the disability services funding request in the biennial budget.

Thank you for the opportunity to comment.