



Maine Developmental Disabilities Council

April 21, 2021

Testimony Support of LD 1490 “An Act To Improve Home and Community-based Services for Adults with Intellectual Disabilities, Autism, Brain Injury and Other Related Conditions”

Senator Claxton, Representative Meyer and the distinguished members of the Joint Committee on Health and Human Services. My name is Nancy Cronin and I am the Executive Director of the Maine Developmental Disabilities Council (MDDC)¹.

MDDC is clear that providing flexible services and supports to individuals with Developmental Disabilities (DD) so that they can contribute and be active members of the community should be Maine’s primary goal. MDDC is also clear that we are not there yet. We have hopes that innovative, flexible, suitable structures of services and supports like self-directed services for all waivers will be adopted in the upcoming years. We also have hopes that all people with DD who need services and supports will be able to access them.

We support everything in this bill. Instead of going through each point we will instead highlight a few items. This bill would require the Department to post regular information about waitlists. We believe that policy doesn’t change quickly. It changes even slower when information is not transparent and available. It is critical that waitlist data be regularly, transparently published.

¹ Councils on Developmental Disabilities were created through the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) in 1970. Maine’s DD Council has been advocating for individuals with Developmental Disabilities (DD) for over 40 years. The DD Council is a federally-funded, independent organization with members from across the state, including persons with disabilities, family members, and representatives of public and private agencies which provide services and/or funding for services for individuals with developmental disabilities.

As required in federal law¹, our purpose is to promote systems change to ensure that all individuals with developmental disabilities are able to live and fully participate in their communities of choice. Working in partnership with people with disabilities, parents, advocates, and policy makers, Maine’s DD Council works to promote the independence, integration, and inclusion of all people with disabilities through advocacy, capacity building, and systems change activities throughout the state of Maine and on the national level. The DD Council’s mission is **to create a Maine in which all people are valued and respected because we believe communities are stronger when everyone is included**. The Maine DD Council employs four full-time staff who are responsible for all of the internal projects, external grants, and business of the Council.

In addition to the metrics described in the bill we would suggest an addition, under Sec 6, please consider adding shortest and longest wait time in addition to the proposed median. This will give the Committee a sense of how long waits actually are for a particular waiver. For example, consider if the shortest wait time is 1 day and the longest wait time is 2000 days. If the median wait time, in this example, is 34 days you know there are some outliers and can assume a relatively short wait time for most. However, if the median wait time is 1500 days you can deduce that people are really having to wait a very long time. We think those two additional data points as anchors are critical to be able to interpret the information.

This bill also amends the current required biannual plan to broaden the term “stakeholder” to include people who would be eligible to receive services, namely people with DD, and the people who care for them, namely direct care providers. This change is long overdue. MDDC firmly believes in people with DD having meaningful input in the policies that affect them.

The biannual plan would also be required to include a proactive analysis of how providing services in the least restrictive environment early might reduce costs as opposed to when an individual’s need increases to such an extent that more restrictive placements are warranted. MDDC believes that this type of introspection about Maine’s services is critical to healthy systems change and will ultimately provide the quality that is necessary.

Lastly, this bill gives flexibility to this body to introduce legislation in each session to act upon the data that you review. This makes sense as having one’s hands tied to fix a problem identified is painful at best.

I hope you will all support this bill. Thank you for hearing my testimony and I would be happy to take any questions.