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Vickey Rand Advocacy & Communications Manager Brenda Sylvester Development Officer

Bree LaCasse Development Officer

Brian Kilgallen Development Officer March 23, 2021

Re: LD 716, An Act To Enhance and Improve the Maine Developmental Services Oversight and Advisory Board and To Establish the Aging and Disability Mortality Review Panel.

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 housing provider for homeless populations in Maine. Our staff of 11 works collaboratively with 48 different service provider organizations to effectively and efficiently house well 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 716, An Act To Enhance and Improve the Maine Developmental Services Oversight and Advisory Board and To Establish the Aging and Disability Mortality Review Panel. This bill establishes the Aging and Disability Mortality Review Panel to review deaths of and serious injuries to all adults receiving home-based and community-based services under a waiver approved by the United States Department of Health and Human Services, Centers for Medicare and Medicaid Services.

The bill also makes changes to the laws governing the Maine Developmental Services Oversight and Advisory Board, moving the budget of the Board from the Department of Health and Human Services to the Department of Administrative and Financial Services, and requiring disclosure of final reports of investigations pursuant to the Adult Protective Services Act to the Board. It also clarifies the appointment process for members of the Board.

I fully support establishing an independent review panel to review deaths of and serious injuries to people with ID/DD and am glad that this bill includes specific language regarding this information being provided to not only the Department but also the MDSOAB. This is consistent with the State's response to the OIG (Office of Inspector General) Report and assists the State in fulfilling its duties as laid out in the Adult Protective Services (APS) Act and the APS Rules, which states the Department shall prevent and protect people from abuse, neglect, and exploitation. The OIG Report findings stated that the Department had been inattentive in reviewing, investigating, and reporting on the deaths of people with intellectual disabilities or autism who were receiving MaineCare services provided under Chapters 21 and 29 waiver services. The report documented 130 deaths over the course of two years, for which the Department could only provide information on 54 individuals, of which at least nine necessitated further examination per the Report. Establishing this review panel and providing detailed information to the MDSOAB for further oversight, is one way in which Maine can ensure the thorough review of deaths of and serious injuries to people with ID/DD, and work towards a system which prevents them altogether.



I enthusiastically support the MDSOAB having timely and unfettered access to the information it needs in order to fulfill its statutory obligation to provide oversight to the Department and developmental services in Maine. The MDSOAB has enjoyed the recent rejuvenated efforts by the Department to be participatory in the Board – I want to thank the Department for its commitment to working with the MDSOAB, this is a welcome change! However, this legislation would build upon what is already codified in State statute, ensuring that this information sharing and transparency continues uninterrupted for the benefit of people in Maine with ID/DD, whom the Department is charged with serving. Without access to information from the Department, the MDSOAB is unable to fulfill its statutory obligation to provide oversight to the Department and developmental services in Maine – this bill will help ensure that it is always able to fulfill its duties.

Additionally, I think it makes great sense to move administration of the MDSOAB from DHHS to the Division of Administrative and Financial Services. This would alleviate any real or perceived conflict of interest that could arise from the Board being administered by the Department it is statutorily obligated to oversee. This is a common sense solution, which I fully support.

Thank you for the opportunity to comment.