

March 23, 2021 Senator Ned Claxton, Chair Representative Michele Meyer, Chair Joint Standing Committee on Health and Human Services Cross Office Building, Room 209 Augusta, Maine 04333

## Re: Testimony 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

Dear Senator Claxton, Representative Meyer, and members of the Joint Standing Committee on Health and Human Services:

My name is Monique Stairs and I am the Executive Director of Speaking Up For Us (SUFU). SUFU has been the self-advocacy network in Maine since 1993 and we are an established 501(c)3 non-profit. Self-Advocacy is part of the civil rights movement for people living with Intellectual and Developmental Disabilities (I/DD) to advocate and voice their opinions on issues that are important to them. Our Board of Directors is made up 100% of adults living with I/DD, which makes us a unique organization.

I am submitting this written testimony in favor 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. In 2017, Tucker Conley (Board Chair at that time) wrote an editorial concerning the news that DHHS had failed to investigate abuse, neglect and deaths of people receiving services in Maine. Self-advocates were extremely concerned about these findings and at the time called for further oversight and investigation. The editorial can be read here: Disability does not make one 'less than' - CentralMaine.com

This bill will develop a panel to review deaths and serious injuries and provide the oversight that self-advocates believe is important to keep people living with developmental disabilities in Maine safe. Self-advocates are in favor of how the panel will be made up of law enforcement, medical, advocacy, service providers, and DHHS representatives.

However, it is obvious to self-advocates that the panel is lacking the voice of the people receiving services. All too often decisions and oversight is provided by "experts" and the viewpoint of the person is left out. One of the great self-advocacy mottos is "Nothing about us without us." We would ask the committee to consider amending the language of this bill to include representation of a person living with a developmental disability.

Thank you for your time and consideration to share with you the viewpoints of self-advocates. If you have further questions, please contact me.

Sincerely,

Marigne Stair

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