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

March 23, 2021

Senator Claxton, Representative Meyer and Members of the Health and Human Services

Committee,

My name is Jennifer Putnam and I am the Executive Director of Waban Projects, Inc. Today, I offer testimony as a member of the Maine Developmental Services Oversight & Advisory Board. When I was appointed to the Board many years ago, I felt deeply honored. I also felt, and still feel, a keen sense of responsibility. All of the members of the Board are tasked with a simple yet profound obligation: to make certain that people with intellectual disabilities and autism are receiving the care and services they need and to recommend improvements to the system when they are receiving inadequate care or services.

LD 716 provides a mechanism to ensure that any deaths or serious injuries that occur among people receiving services with intellectual disabilities or autism in Maine are thoughtfully and independently reviewed. This bill is not a novel approach nor is it an outlier among states. It is modeled after Maine's child death and serious injury review panel as well as the State of Connecticut's mortality review panel. Missouri, Hawaii, Louisiana, New York and more: All have developmental disabilities mortality review panels. In Georgia, part of the consent decree required an independent contract to conduct mortality reviews.

When the US GAO (Government Accounting Office) reviewed states' handling of deaths among the developmentally disabled, they identified four components that supported the most accountability and transparency: state-level interdisciplinary review panels, involvement of external stakeholders, statewide action to address problems identified, and public reporting. LD 716 incorporates three of these components. The fourth, statewide action to address identified problems, could perhaps be fostered in rulemaking.

Many of us were distressed when the Office of Inspector General's (OIG's) August 2017 report regarding Maine's noncompliance with federal and state critical incident reporting was issued. The report states that Maine did not "ensure that all beneficiary deaths were appropriately reported, analyzed, investigated, and reported to law enforcement or the Office of the Chief Medical Examiner". Further, "The State agency must review deaths to determine the number and percentage of unexplained, suspicious, and untimely deaths for which investigations resulted in the identification of preventable causes (HCBS waiver, Appendix G) The OIG report goes on:

The State agency maintained that its Mortality Review Committee reviewed 54 of the 133 total beneficiary deaths. However, the State agency was only able to provide us with a spreadsheet containing those 54 beneficiary names and some general information regarding each death. This spreadsheet did not contain the details of the State agency's review. It did not specify any

trends the State agency identified, what its reviews entailed, or the outcomes of the reviews, including potential corrective actions. Furthermore, the State agency did not investigate any deaths of beneficiaries with developmental disabilities involving allegations of abuse, neglect, or exploitation and did not immediately report these beneficiary deaths to the appropriate district attorney's office or OCME (Medical Examiner).

Last, the OIG report noted that the State agency was unable to provide any documentation regarding the Mortality Review Committee's frequency of meetings or minutes of meetings during the audit period and despite the OIG's requests, the State agency's Mortality Review Committee did not provide us details of the review process in effect from January 1, 2013, through August 13, 2014.

The Death and Serious Injury Review Panel proposed in LD 716 provides the Department with a clear path to compliance with the OIG report and creates a transparent process for reviews to occur. The OIG subsequently issued a joint report with the US Department of Health and Human Services and other federal entities based on investigations in Maine, Massachusetts and Connecticut. The report recommended all states implement an effective mortality review process. The report offers model practices that include intended outcomes, essential participants and activities and a mortality review database. The model practices mirror the proposed components of this bill.

To my knowledge, there has not ever been a report of the 133 individuals' deaths ever having been reviewed.

With the current Administration's support, we can work together, all of us, to ensure that deaths and serious injuries of people with intellectual disabilities are reviewed independently, thoughtfully and thoroughly in the years ahead.

Respectfully Submitted,

Jennifer Putnam, Executive Director
Waban Projects, Inc.
5 Dunaway Drive
Sanford, ME 04073
jputnam@waban.org