

Richard A. Estabrook, Esq.

8 Sandhill Dr.
Brunswick, ME 04011
207-725-4228
estabrookrichard@gmail.com

March 20, 2021

Senator Ned Claxon
Representative Michele Meyer
HHS Committee
SHS # 100
Augusta, ME 04333

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”

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

I am testifying in favor of LD 716. I am a member of the board of directors of Independence Association in Brunswick and I serve as the Maine Developmental Services Oversight and Advisory Board (“MDSOAB”)-designated member of the three person committee that reviews behavior modification and safety plans for persons served by the Lewiston office of Disability Services. I am testifying as an individual. The MDSOAB has authorized me to speak for it as well.

Overview: Representative Dale Denno of Cumberland began working on this legislation in 2017. The genesis of LD 716 began with an investigation and report done by a team from the US Department of Health and Human Services Office of Inspector General (“OIG”) entitled “Maine Did Not Comply With Federal and State Requirements for Critical Incidents Involving Medicaid Beneficiaries With Developmental Disabilities” (August, 2017; A-01-16-00001). The OIG sent a draft of the report to the Maine DHHS in May of 2017. DHHS vigorously contested the OIG findings in a June 26, 2017 letter from Ricker Hamilton, then Acting Commissioner. (August ’17 report, pgs. 62-69) The OIG considered those comments but did not alter the report’s findings. OIG concluded: “...the State Agency did not comply with Federal waiver and State requirements for reporting and monitoring critical incidents involving Medicaid beneficiaries with developmental disabilities. Therefore, the State agency failed to demonstrate that it has a system to ensure the health, welfare, and safety of the 2,640 Medicaid beneficiaries with developmental disabilities covered by the HCBS waiver.” (Aug. ’17 report, p. 23) In January 2018 the OIG issued recommendations entitled “Ensuring Beneficiary Health and Safety in Group Homes Through State Implementation of Comprehensive Compliance Oversight”.

The purpose of LD 716 is to respond to the August ’17 OIG report, and implement the recommendations of the January ’18 report. LD 716 will establish independent oversight of Maine’s system of reporting, triaging, and investigating deaths and serious incidents occurring to Maine’s citizens with intellectual disabilities or autism who are receiving waiver-funded services. LD 716 will ensure transparency and accountability in the system.

The August 2017 OIG report, summarized: The OIG report is, in a word, devastating. It is thorough. It is sad. It describes a failed system. People suffered or were ignored. The report is long (70 pages). It depicts an adult protective system of reporting, investigation, and review that was piecemeal and

ineffective. The report used both case studies and statistical analysis to arrive at its conclusions. The case studies are particularly compelling. The following, which has been excerpted, is typical:

“A 32-year-old beneficiary died because of an unexplained death. Staff found the beneficiary in bed, unresponsive, and not breathing. Emergency services were called, and the beneficiary declared dead. Police also responded but did not open an investigation. A critical injury report from the prior day stated that the beneficiary suffered multiple seizures. The community-based provider contacted the beneficiary’s doctor who suggested using the person’s continuous positive pressure airway (CPAP) machine. The person had been diagnosed with sleep apnea a month and a half earlier and had been recommended to wear a CPAP at night. The doctor also requested that the person go for a blood test in the afternoon. The beneficiary’s death was not investigated by the State agency or reviewed by OCME.”(Office of Chief Medical Examiner) The Mortality Review Committee reviewed the report, but no corrective actions were taken because of lack of information reported to the State agency in the critical incident report and other EIS records.” (pages 58 & 59)

Statistical analysis in the report also established significant shortcomings in the system. Again, I have excerpted each of these: “Community-based providers did not report to the State agency all critical incidents involving beneficiaries with developmental disabilities. Specifically, we determined by matching Medicaid claims data with EIS entries that community based providers reported 1,474 (66%) of the 2,243 critical incidents involving emergency room treatment. However, community based providers did not report to the State agency the remaining 769 (34%) critical incidents. State agency officials did not provide an explanation of why the State agency did not ensure that community-based providers reported all critical incidents to the State agency.”(pages 5 & 6)

“Community-based providers did not always conduct administrative reviews that attempted to identify the cause of critical incidents and recommend preventive or corrective action as necessary and submit the report findings to the State agency within 30 days. Community-based providers reported through EIS to the State agency 8,678 critical incidents involving serious injuries, dangerous situations, and suicidal acts for 1,781 beneficiaries during our audit period. These reports documented critical incidents that potentially jeopardized the health, safety, and rights of the beneficiaries and included injuries of unknown origin, emergency room visits for serious incidents, and lack of beneficiary supervision that resulted in repeated elopements “. (pages 8 & 9, excerpted)

“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. 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 abuse, neglect, or exploitation and did not immediately report these beneficiary deaths to the appropriate district attorney’s office or the OCME.” (pages 19 & 20, excerpted)

The quotes above are representative samples taken from the August 2017 report. They are intended to capture the tone and substance of the OIG report. Obviously the full report is far more comprehensive. There can be no doubt that the OIG revealed extremely serious deficits in Maine’s adult protective system for its citizens with intellectual disabilities or autism.

How did it occur that Maine’s system of investigation for such a vulnerable population failed to the degree that it did? There are probably several answers to that question, including the failure to train and sufficiently supervise front line staff, both within the Department and in the provider community. DHHS admitted as much in its response letter. (See August ’17 report, p. 68) But principal reason the APS system degenerated into the state it was in when the OIG review was done was that after the federal

court found Maine in compliance with the Community Consent Decree in 2010, there was erosion and evasion of any independent oversight of the adult protective system. A key part of the state's overall compliance with the Community Consent Decree was the state's ability to investigate and address adult protective allegations. Clarence Sundram, the Special Master in the Community Consent Decree litigation, was and remains a recognized national expert in adult protective matters pertaining to vulnerable people. The investigation and resolution of adult protective situations was a very high priority for him. In 2007 under his guidance the parties agreed upon, and DHHS promulgated, a comprehensive regulation that established detailed reporting, investigation, and response mechanisms in the adult protective system for people with intellectual disabilities or autism. That regulation was in effect from July 2007 until May, 2018. An electronic copy of that regulation as it existed in 2016 is attached.

Even before the regulation was promulgated in 2007, the Consumer Advisory Board, the predecessor to the MDSOAB, reviewed all adult protective reports pertaining to persons with intellectual disability or autism. The 2007 regulation memorialized that arrangement, giving the CAB, or its successor, legal authority to review those reports. Between 2007 and 2010 the CAB or its designees met monthly with the APS component of the DHHS. The CAB could question APS on any issue that was raised in any of the reports. True oversight took place. The 2007 regulation was cited in the OIG report as one of the sources of the legal standards by which the OIG judged Maine's adult protective system for its citizens with intellectual disability or autism. (August 2017 OIG report, p. 44). Had DHHS continued to adhere to the 2007 regulation, the disaster revealed by the OIG review never would have occurred.

Obviously the state was in compliance with the regulation in 2010. Otherwise the court would not have released the state from the Decree. Unfortunately after Mr. Sundram was discharged as special master in 2010, the plaintiff class had no legal standing. The class could no longer enforce the promises made by the state in the Community Consent Decree. Through one pretext or another, in the years 2013 to 2017, DHHS successfully evaded any independent oversight of the APS system. The culmination of this process was in May 2018, when DHHS repealed and replaced the 2007 regulation that had been negotiated by Mr. Sundram. What remains in the regulation essentially describes the reportable events system that had been devised in 2007. An electronic copy of the current regulation is attached. There is no provision in the regulation for independent oversight of the APS system for people with intellectual disability or autism. The state successfully reneged on one of the most important promises made to the plaintiff class in the course of the Community Consent Decree litigation.

LD 716 restores significant independent oversight for the APS system. A Panel coordinator with medical expertise will have the authority to review all deaths and serious injuries of people receiving waiver services. The Panel coordinator would have sufficient access to records so as to be able to perform a thorough review of any particular case. A Panel with wide-ranging expertise will have the authority to review deaths and serious injuries. The MDSOAB will have access to aggregate data regarding investigations. Already with proper authorization from a guardian, the person, or the person's personal representative in the case of death, the MDSOAB may examine confidential information. (See 34-B MRS §1223(10(D))

The OIG's January 2018 report "Comprehensive Compliance Oversight" (mentioned in the "Overview" section above) is a sixty-four page document that comprehensively sets out best practices for oversight of a state's adult protective investigation system. The report establishes a benchmark of 86% score for the Centers of Medicare and Medicaid Services (CMS) to judge whether a state has sufficiently complied with the suggested oversight and review requirements. The January '18 report states: "States should develop and implement plans of correction for all performance measures of less

than 86% before CMS’s approval of new or renewal waiver application.” “Failure to implement appropriate corrective actions for substandard compliance scores may result in CMS sanctions, including but not limited to adverse decisions on new or renewal waiver applications.” At its discretion, CMS may impose immediate sanctions against States....” (January ’18 Report, p. B-viii). A goal of oversight is to “ensure public transparency”. (January Report, p. C-i) Obviously in order to ensure future waiver funding it is imperative that Maine maintain an effective APS system for its recipients of waiver services. LD 716 will ensure that Maine has met the federal oversight expectations.

Section 6 of LD 716 requires an annual report to the Legislature. This is an important feature, because the annual report will act as an ongoing independent barometer for the Legislature and the general public of adult protective services for persons with intellectual disabilities or autism. A draft of the annual report must be offered to anyone who granted permission for death or serious injury review. (LD 716(C), p. 5) Thus there will be a feedback loop that will help guarantee that the annual report is accurate and comprehensive.

It should be noted that, much to the credit of the current administration, there has been a substantial improvement in the relationship of the Department and the MDSOAB. The previous administration did whatever it could to minimize any meaningful oversight by the MDSOAB. For at least the last four years of the previous administration the MDSOAB was ignored. The new administration has made an effort to participate in MDSOAB monthly meetings. It appears to try, with limited success, to be responsive to the MDSOAB information requests the MDSOAB needs to perform its statutory responsibilities under 34-B MRS §1223. This may be a more function the Department’s outdated electronic data systems than a willful abnegation of the MDSOAB’s role. Significant improvement still needs to occur in the transmission to the MDSOAB of aggregate data about the system of care, but the improvement in the overall relationship between the MDSOAB and DHHS is commendable.

The MDSOAB realizes that the current administration is acutely aware of the August 2017 OIG report. The MDSOAB believes that DHHS is making good faith efforts to rectify the deficiencies stated in the OIG report. Nonetheless, the MDSOAB is convinced that the enactment of LD 716 is crucial to maintaining a viable and effective adult protective system for Maine’s citizens with intellectual disabilities or autism. Internal review alone, in and of itself, is too conflicted, too susceptible to the political or fiscal pressures of the moment, to address systemic failure and protect this uniquely vulnerable population. It is absolutely imperative for the overall quality of life of persons served by the system of care that the state has an efficient, effective, and responsive APS system. The previous administration’s repeal and replacement of the regulation negotiated in the Community Consent Decree litigation robbed the system of independent oversight. For the good of everyone—the State, the provider community, parents, guardians, and most particularly the recipients of services, that independent oversight must be restored. Without such oversight, sooner or later, even assuming the best of intentions on the part of the state, the risk is too great that the APS system for Maine’s citizens with intellectual disabilities or autism will again degenerate into the chaotic condition in which it was found in 2017. As a society we must do what we can to avoid that outcome.

For all of the above reasons, I ask, and the MDSOAB asks, that LD 716 be reported out of committee favorably.

Sincerely,

Richard A. Estabrook, Esq.

