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March 10, 2025

Re: LD 769

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

Unfortunately, I am not able to testify in person because of airport travel on the day and time of the hearing. I will not even be able to testify by Zoom. This matter is very important to me. I want to express my opinion.

I am urging you to vote “ought not to pass” on LD 769. I have been a representative designated by the Maine Developmental Services Oversight and Advisory Board (“MDSOAB”) on review teams established under 34-B MRS §5605(13)(B)(2) for about eight years. In that capacity I have reviewed approximately 400 Behavior Management/Modification Plans (“BMPs”) and about 800 proposals to use safety devices. I review an average of about five BMPs from DHHS Region 3 (Lewiston area) every month. In November 2024 I was appointed by Governor Mills to be a member of the MDSOAB.

You are busy. Time is short. I am going to reverse the usual order of things and state my conclusion at the beginning. I am asking that you vote “No” on LD 769. What I urge you to do instead is to say to the DHHS and all interested parties: “Draft a new version of 14 Code of Maine Regulations 197 Ch. 5, Regulations Governing Behavioral Support, Modification, and Management for People With Intellectual Disabilities or Autism in Maine. Please try to work out your differences and achieve as much consensus as possible. When you have finished that come back to us. We will hold the required hearing under the Maine Administrative Procedures Act for major substantive regulations so that all interested parties can comment on the draft regulation. If statutory changes are needed to implement the new regulation, submit a companion bill and we will consider that too.”

Behavior modification for persons with intellectual disabilities or autism has a long and somewhat sordid history. Indeed a significant cohort of people would retort “What do you mean, “somewhat”? There is no doubt that under the guise of “treatment” people were subjected to interventions that are now considered inhumane. I know from personal observation that untippable restraint chairs were not eliminated at Pineland until the early 1990’s. When they were the heads of several residential units complained that there was no way they could possibly operate without them. The word “restraint” carries with it the awful stench of institutional care. “Horrific” does not even scratch the surface of what Pineland was like prior to the implementation of the Pineland Consent Decree. Even though Pineland was closed almost 30 years ago, its specter still casts a dark shadow. Emotions run high in this area of the law.

I oppose LD 769 for three major reasons and two minor ones. All five apply to the adult portion that begins on page two of the bill.

Major Reason 1: <u>Overall law, practice, and policies</u>:

(a): Independent oversight and degree of oversight of BMPs: If passed, LD 769 will end any individualized independent oversight of BMPs. The law now requires a “case-by-case” review by a three- person team. (34-B §5605(13)(B)(2)) The MDSOAB representative is the only voting member of that team not connected to DHHS. LD 769 will relegate the oversight role of the MDSOAB to a nebulous “support and safety committee” that will meet only quarterly. The committee will include a licensed clinical psychologist chosen by DHHS “if available”. It will review only the “number and type of plans”. Under LD 769 the highest level of review will require approval only by “a licensed clinical psychologist designated by the department.” (LD 769 §13-A(C)) The reviews by the three person teams <u>always</u> hear from the person’s direct care staff and supervisors, the person’s case worker, sometimes the person’s guardian, occasionally the person her/himself, and not infrequently a clinical person responsible for overseeing the implementation of the plan. Prior to the meeting the team members study relevant records. They see the written BMP itself, the person’s person-centered plan, the monthly accounts by the psychologist (or other clinical person) responsible for supervising the implementation of the plan and the records pertaining to the number of times modification or management techniques were used, for whichever of each challenging behaviors the person has. Any review team member may ask questions about possible environmental modifications and possible less restrictive alternatives. The reviews are probing and highly individualized. There is dialogue about the quality of the person’s life with the people most responsible for deciding and delivering that care. Team members ask hard questions. LD 769 will terminate this independent review.

(b): <u>Unfiltered information for the MDSOAB to perform its oversight functions</u>: The MDOSAB is an Independent Advisory Board. (*See* 5 MRS §12004-J(15)) Members are appointed by the governor. It is a citizen oversight board. The MDSOAB has a part-time staff person, but its members are volunteers. The participation of the MDSOAB-designated person on the regional review teams is an important window through which the MDSOAB can obtain direct unfiltered information about the quality-of-care people receive. This source of information has led to the identification of systemic issues. The best example of this phenomenon pertains to dental services. Literally hundreds of Maine’s citizens with intellectual disabilities or autism are not receiving the prompt, appropriate dental care to which they are legally entitled. (*See* 34-B MRS §5605(8)) The MDSOAB never would have discovered this issue if not for the MDSAOB participants in the review process, who saw a repeated pattern of people with challenging behaviors for months on end that were masquerading as “behavior” when the actual cause is the lack of access to dental care. LD 769 would close this window.

Major Reason 2: <u>The legal standards articulated in LD 769 are confused and are confusing</u>:

LD 769 would create two types of “behavioral health support plan”. A plan under §13-A(B) would “support” the person “to participate meaningfully” in the person’s community. It cannot waive rights. A plan under 13-A(C) would “modify or redirect” behavior. A “(C”) plan can waive rights. Under both sections the plan “outlines strategies to manage behavior concerns and may include both positive and negative interventions.” (lines 5 and 6 of page 2 of LD 769) There can also be a “positive behavioral health support plan” under 13-B(A) “to address dangerous and maladaptive behaviors”. A “positive behavioral health support plan” can only “emphasize” positive and proactive strategies “to address behaviors that negatively impact the health, safety and well-being of the person.” Then in 13-A(D) LD 769 reverts to the use of the terms “behavior modification or management plans”. One fundamental problem with this mishmash of language is that whether the plan is designed under A, B, or C, or the plan is a behavior modification or management plan under D, the fundamental goal of the plan is to “modify” some defined, specific challenging behavior. The only practical difference between the types is that the interventions for a positive behavioral health support plan must be “positive”. Read strictly, any “B” plan is a “C” plan and would qualify for that level of support.

A second problem is the failure to have legal definitions. What does it mean to “redirect”? Do the drafters intend to include physical redirection—any holding or touching of the person such that the person or any part of the person’s body is moved against the person’s will? Or do they intend to include only verbal redirection? If “redirection” means the former—moving the person or a body part of the person against the person’s will -- then redirection would qualify as a “restraint” as legally defined (*See* 34-B MRS §5601(6-A), “Restraint”). Under LD 769 a physical redirection could only be used “as an emergency short-term step to protect the adult from imminent injury to that adult or others”. (*See* §14-E of LD 769, lines 15 and 16) Note that BMPs each have their own legal definition under 34-B §§5601(1-B) and (1-C). Thus, the current system operates under legally defined terms.

Too often LD 769 uses words or phrases that are imprecise. They offer no real guidance and therefore create no enforceable legal standard. What does it mean to “emphasize” positive supports? What is meant by “participate meaningfully in community life?”, when it is used as LD 769 uses the phrase, to distinguish a “B” plan from any other type of plan that LD 769 envisions? What does it mean to “outline strategies” in B or C plan? Loose legal standards like this end up being harmful to the person they are trying to help.

Why is it that in 13-A(A)“an assessment by a medical practitioner… to rule out medical reasons for the behavior” applies only to a positive behavioral health support plan if the plan is to “address dangerous or maladaptive behavior?” Such a medical assessment ought to be required for B and C plans, as well as any behavior modification and management plans under D. Given the experience with dental issues that masquerade result in or masquerade as dangerous and maladaptive behaviors, why is a dental check also required, particularly if the behavior is self-injurious behaviors (“SIBs”) of repeated strikes to the jaw or face?

LD 769 does not pass the test of creating well-defined legally enforceable distinctions between categories.

Major Reason 3: <u>The outlawing of planned restraint except in emergencies</u>. This is the most controversial issue raised by LD 769. The legal definition of restraint has already been alluded to in Reason 2 above. A restraint is an "action that limits or controls all or any part of the person's body or maintains a person in an area against the person's will by another person's physical presence or coercion." (34-B MRS 5601(6-A)) Obviously that is very broad definition. It is so broad that technically, if a staff person blocks a blow aimed at his or her chin by the fist of an adult with intellectual disabilities or autism—an instinctive and, under the circumstances, a simple and totally understandable and appropriate reaction — the blocking action is a restraint. Also, the physical interposition of one's body between someone and somewhere s/he wants to go is a restraint. If a staff person places a hand between the hand of the person and the head of the person who is engaging in SIB, that too is a restraint. Under LD 769 all of these actions would be outlawed unless the "restraint is an emergency short-term step to protect the adult from imminent injury to that adult or others." (*See* LD 769 §14-E, lines 14 and 15 on page 4)

Person-centered planning teams ("PCPs") are legally required to include the person, the guardian if there is one, and the person's caseworker. (*See* 34-B MRS §5470-B(2)(D)) The PCP teams identify the "challenging behaviors" that BMPs are trying to address. There are times and situations that arise in which a restraint as legally defined is determined by the PCP team members to be in the best interests of the person.

Think, for instance, of a person in the preceding paragraph who engages in SIB. Suppose the SIB is a hit to the person's right eye. This hit puts some pressure on the eyeball, but it does not leave bruises. The person's eye still appears to transmit visual messages to the person's brain just like it did before. Just one hit does not rise to the level of an "emergency" or qualifies as an "imminent injury." Assume that the person's PCP team has a reasonable expectation that this form of SIB will continue. Under LD §13-A(D)(4) "planned use of restraints" is not allowed. The PCP team wants to plan proactively to allow staff to use restraint to stop the behavior, even if the restraint amounts to nothing more than the staff person gently putting her/his hand in the space between the person's hand and the person's eye. Now multiply that one hit by some number: say, 50. Or, as sometimes happens, a number in the hundreds over the course of a week or a month. People in this situation have blinded themselves. At some point the danger becomes "imminent" but the exact time it became imminent is undiscernible. LD 569 would outlaw the interception of all but the last strike before the person blinds his/her right eye.

Assume that the challenging behavior happens to be one in which the person likes to enter parked cars. Staff may learn to anticipate this and stand in the way of the person, preventing the person from opening the door of a stranger's car. Such a blocking move would be illegal if LD 769 is enacted, but there is no emergency, no "imminent" danger to self or others.

Maybe the same person is too quick, and the person actually does enter the parked car. There is no imminent danger. There is no "emergency" as that word is commonly understood. The person is doing nothing more than sitting in a car. Of course it *could* become an emergency. The owner of the car appears. The owner demands that the staff get the person out of the car. The staff explains that there is no emergency, no imminent danger so the staff cannot use any physical force to move the person, however gently that touching might be applied. The staff can only use verbal intervention or such other positive supports that might be tried. That might be in the form of a reward of some kind: "Come on, we will go get an ice cream cone". The problem with such "positive" interventions is that they then reward the challenging behavior and the person learns that if s/he wants the reward all s/he has to do is engage in the behavior.

What happens if verbal interaction and positive support fail to convince the person to leave the car? There is a risk that the owner, who knows nothing of any medical condition that the person might have, will proceed to remove the person from the car.

This issue of "When does the emergency start? When does the likelihood of injury become imminent?" becomes crucial to the operation of the law. In any particular situation there are likely to be multiple possible answers to those questions. The reason PCP teams like to be able to use "planned use of restraint" is that they want to be able to train staff. Certainly part of any planned use of a restraint has to be to try less restrictive alternatives. All of the plans reviewed in Region 3 have restraint as a last resort. If restraint was not the last resort the plan would not be approved. I believe that is the same for all of the other review teams. If positive interventions do not produce decrease the danger or make the person safe, it is far better for both the person and the staff to have a plan in place, even if it does involve restraint.

We cannot talk about positive supports or, as they are sometimes known, "differential reinforcement of incompatible behavior" without acknowledging that Maine's system of care is under the stress of not having enough essential care workers. A system of care that is able truly to fill all of the hours of a person's day with activities that the person loves to do would undoubtedly see a marked decrease in challenging behaviors. In fact, the review teams do sometimes see such a decrease even now. There are BMPs that are discontinued because the person no longer engages in the challenging behavior, or at least no longer engages in the challenging behavior to the extent that a BMP is necessary, mainly because the person receives attention, or staff understands the person better, or for some unknown reason the person is happier than they were six months ago. But the idea that we as a society are now capable of relying exclusively or primarily positive supports alone to systemically address dangerous or maladaptive behavior is to dream the impossible dream. We never want to give up the aspiration of positive supports being the answer, but the law has to deal in the reality of everyday life. As well intentioned as LD 769 may be in its goal to eliminate planned restraints, such a goal is both unrealistic and not in the best interests of a significant number of people the system of care serves.

Minor objection 1: LD 769 repeals 5605(12)(E). See lines 1 and 2 of LD 769. Section 12E of the rights law is a provision that allows a provider to establish house rules in a residential unit operated by the provider. Residents are entitled under the law to participate in the formation of any house rules. Section 12E has nothing to do with behavior modification, behavior management or safety plans. The law has never come up once in the time I have been reviewing BMPs and safety plans. The Legislature has found that people are best protected under a system of care that operates according to the principles of normalization. (*See* the first two lines of 34-B MRS §5604 "Protection") 34-B MRS §5601(5) defines the "normalization principle" means "assisting the person to obtain an existence as close as possible and making available to that person patterns and conditions of everyday life that are as close as possible to the norms and patterns of the mainstream society." Condo associations impose rules on residents. College dorms are known to devise their own house rules. Adults with intellectual disabilities or autism often find themselves living in group homes with people who for all practical purposes are strangers to each other. Why can't adults with intellectual disabilities or autism living in a residence together set some expectations within the residence in which they live? If someone has an objection to this law, they should come to the legislature with a separate bill and explain why it needs to be repealed. It should not be repealed by appending it to a bill having to do with restraints and safety plans.

Minor objection 2: Safety plans are an area of the law that is very detailed and nuanced. LD 769 essentially takes the existing Section 5 regulation, lists the many possible safety devices, and puts that list into statute. Then it removes the review teams from approving or disapproving safety devices. The review of these devices by the review teams is a paper review. The scrutiny of safety devices is "case by case" but does not involve dialogue with the PCP team or caseworker or anyone else. There is no Zoom calls in safety plan reviews. From a policy perspective safety plans are reviewed in order to make sure that restraint or some sort of behavior modification is not being occurring under the guise of the use of a safety device. There is no reason to put safety devices in law, other than what statutory language already exists. If in the future some new safety devices come into use, it is much easier to amend a regulation than a law. I would urge the committee to keep the safety device law as it is and let state regulation handle issues that arise with safety devices.

You will hear that there has been a group of people, usually referred to as "the Section 5 group", who have been engaging under the auspices of DHHS in monthly meetings (more or less) by Zoom. I am a member of that group. My understanding of the purpose of the Section 5 group was to consider possible changes to the Section 5 <u>regulations</u> that govern BMPs and safety plans. I am open to such changes. One of my recommendations would be to consider changing the definition of "restraint" so that a blocking motion by a staff member of a blow to his head is not a restraint. Also, the use of some safety devices may be related more to bodily aging than anything else. For that reason, possibly less oversight of some of the safety devices ought to be required. However, helmets have always been somewhat controversial and the use of them has been abused in the past. They deserve a higher level of scrutiny than just the approval of a doctor, the guardian if there is one, and the PCP team.

Changes like these are best done from below, by and with people who have experience with the law and how the law is applied. The issue of scope of independent review generally, the issue of the composition of any review team, or the dissolution of the review teams entirely, and the issue of the MDSOAB having the right to appoint someone to each regional review team, was neither raised nor discussed by the Section 5 group. There was never any discussion of allowing all safety plans to go into effect without any independent oversight. There was never any mention at all of repealing the law pertaining to house rules. At our last meeting there was a discussion of the limitation of restraint to emergency use only, but there was no consensus reached on that issue. At no time was any draft of legislation shared with the Section 5 group. At no time was any draft of proposed changes to existing Section 5 language circulated.

LD 769 is a trojan horse. It is trying to enact provisions into law for which there is no consensus and about which there has been either no or inadequate discussion. The section of the existing rights law, §13(B)(2), giving the MDSOSAB the right to appoint a representative to the review teams that do case-by case reviews, was originally enacted in 2007. The law was entitled "An Act to Clarify and Affirm the Scope of Services Available to Persons with Mental Retardation or Autism". It went into effect in 2010 after Maine achieved compliance with the Community Consent Decree. Each and every provision of the mechanisms of future compliance law (SP0707, item 1, 123rd Maine State Legislature) was negotiated with Special Master Clarence Sundram and the parties to the Community Consent Decree. It was enacted because there had been backsliding in compliance by the state of Maine in complying with the Pineland Consent Decree. The plaintiff class in the Community Consent Decree—the same people who were the plaintiffs in the Pineland lawsuit-- specifically insisted that there be state laws and regulations in place that would guarantee that there would be no backsliding in compliance with the Community Consent Degree. This time things would be different. In oral arguments on February 26th, 2010 Janet Mills, as the state's Attorney General, averred to Judge George Z. Singal that mechanisms were in place to guarantee ongoing compliance. This was a major element of the oral argument. Now the state of Maine is attempting repeal one of those mechanisms of future compliance.

LD 769 is being presented to you at this time in the hope that you will accept it. You are now, at this time toward the end of the legislative session, being asked to try to understand and then repeal and replace some very nuanced and important laws, some parts of which because of Maine's institutional history are emotionally charged. That is unfair to you and unfair to the people who are served by Maine's system of care for its citizens with intellectual disabilities or autism. You, and they, deserve better.

Sincerely,

Richard Estabrook