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LD 769, ***An Act Regarding Access to Behavioral Health Supports for Adults with Certain Disabilities***

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

My name is J. Richardson Collins. The narrative of this testimony largely is a statement of my relevant background with respect to the matters associated with LD 769 along with comments concerning a couple of key considerations for your attention. This is followed by specific comments and recommendations concerning the language of the bill. In your deliberations concerning the bill, I respectfully ask that you consider the context of my experience as well as the specific matters addressed.

I am a resident of Augusta, a Section 29 Waiver recipient with autism as well as physical and behavioral health disabilities, and the Community Outreach Liaison for the Autism Society of Maine (ASM). I'm submitting testimony on he half of my own personal experience and the Board of Directors. I also am a former special educator with experience working with students with language-based learning disabilities and autism, and a social worker with previous experience providing both HIV/AIDS and adult clinical case management. For purposes of full disclosure, other professional experience includes terms on ASM Board, being a former appointed member of the Maine Developmental Services Oversight and Advisory Board (OAB), and a current unappointed non-voting member of the OAB.

The Autism Society of Maine (ASM) has been serving Maine families for 49 years with a mission to create connections, empowering everyone in the Autism community with the resources needed to live fully; envisioning a world where everyone in the Autism community is connected to the support they need, when they need it. This includes being a source of information through various services and programs of ASM as well as addressing legislative and policy developments in the interest of laws, policies, procedures, and funding practices that align with the stated mission and vision.

As the community Outreach Liaison, I am responsible for reviewing, tracking, and disseminating information concerning legislative and policy initiatives to support the work of ASM's Legislative Committee as well as to keep our membership and other interested parties both informed and able to participate in the legislative process. I am providing testimony regarding LD 769 on behalf of ASM as informed by my lived experience both personally and professionally.

My training as an educator and as a social worker – both in my degree programs and in additional post-graduate work – has been grounded in person-centered, strengths-based approaches including functional application of behavior analysis and approaches to person- and family-centered planning. I have worked with individuals across age ranges and across settings including schools, community programs, workforce initiatives, mental health agencies, hospitals, and death and bereavement support. This background combined with my personal experience, while often not positive and which I will reference in a moment, makes me particularly able to speak to the matters relevant to LD 769.

First, let me thank the DHHS, specifically the Office of Aging and Disability Services (OADS), for its investment in advancing a person-centered intent and respect for human dignity. I support the move toward planning behavior supports as fully as possible within the context of person-centered planning teams and the explicit requirement that possible medical reasons be ruled out before use of a positive behavioral health support plan. I also appreciate the intent to include clinical oversight of implementation of any plan that involves the waiver of rights as well as the explicit distinction of safety planning/use of safety devices as outside of any behavior plan/approval process. As such my comments reflect general support of the intent of the bill, but with significant points of comment and strongly urged recommendations for amendments to the language of the bill.

As an autistic person, I initially did not use speech to communicate; even once I could speak. Even when I began to use speech more regularly, I did not have any sense of when and how to communicate (my needs) to others. This still is a struggle for me, and the connection between words and internal/sensory processing (including interpersonal responses, emotions, and bodily sensations) is missing or, at best, not a direct alignment between what I am experiencing and the words to name it. I may be able to provide the facts of the moment, but I will be unable to express my experience or respond to the interaction itself. To this day, I still may lose the ability to speak as a complete disconnect between what I am experiencing and my ability to process. However, as someone who is expected to use speech and who also has a history of childhood sexual abuse as well as sexual manipulation, physical assault, and chemical and physical restraint as an adult (now documented as used for the convenience of others and not my own safety), I am concerned that LD 769 as stated does not leave room for written plans that outline in advance when and how to use physical contact to intervene as a means of de-escalation.

For some, touch is part of communication and also may be necessary in the process of being a regulation support partner. For me, there are times when deep pressure (which may require hands on) is regulating but I am not always able to provide that for myself. While such contact by another person may be redirecting by shifting the use of one’s body, it is not a restraint – it serves as regulation assistance. A straightforward way of addressing these aspects within LD 769 would be to define restraint so that it is clear certain forms of touch/deep pressure and blocking not only are not necessarily restraint but may be part of pro-active plans to avoid restraint. Simply substituting a buffering object for the human contact is not a solution for someone needing the human contact for communication and/or regulation assistance. At present, as defined elsewhere, any hands-on contact or blocking is considered restraint and not allowed except in cases of emergency/to prevent physical injury. This fails to recognize the harm done to the person when communication frustration and/or dysregulation is allowed to escalate to the point of imminent crisis/injury.

I am not ignoring the importance of developing support plans to reduce, if not eliminate, such times of escalation. I am stating that any known information about when and how to intervene during times of escalation needs to be documented as the go-to plan as needed – even in never needed. A keyway to support this would be an explicit statement added to the LD regarding the individual being able to provide (with or without support) advance instructions about behavioral supports, including use of hands-on support and identification of the point at which restraint or other physical contact will prevent escalation to the point of imminent harm. Equally as important is the capacity to indicate in advance indicators concerning when not to touch that otherwise might be associated with impending harm and lead to unnecessary restraint. I, for example, may not experience escalation to the extent or frequency as in the past and it remains true that I generally should remain untouched at such times. Nonetheless, with respect to supporting me when I physically am manifesting agitation, it is essential to know that I likely will look the most calm right before I am going to bang my head. If that were part of an advance statement also outlining what to do at that point (or better yet beforehand) even if it includes hands-on support, it is not permission to restrain me – and should not be deemed a plan to use restraint. If such an advance statement needs to be tracked and reviewed as a behavioral health support plan with a waiver of rights – even if never executed – there seems to be a process for that. All combined a definition of restraint as noted above, the recognition of some hands-on support as a necessary part of communication and/or regulation support, and the option to outline the parameters in advance could be both clarifying and instructive – to those reading the LD and those drafting policies and procedures.

Another key aspect that seems missing is greater clarity regarding oversight. Per 13-A. C., the reviewing clinician for a behavioral support plan that involves a waiver of rights would be designated by the Department so would not represent a third party. Moreover, the designation of a "support and safety committee" outlines the membership by indicating that the "licensed clinical psychologist, if any [emphasis added]" be a designee of the Department so may not be part of the committee and, regardless, is not a third party. Similarly, the designation of said committee stipulates, reasonably so, the inclusion of a self-advocate, but fails to include a requirement that advocate be a person with I/DD-Autism who is engaging in person-centered planning as part of service delivery and has lived experience of being restrained. Additionally, there is no indication of the purpose of the data review; what is to be recorded and reported upon review; how, to whom, and at what frequency any report is to be made; or what will be done with and in response to the reports. Especially given the apparent plan to replace the three-person committee review process, the duties and responsibilities as well as the response by the Department to the support and safety committee's review needs to be stipulated.

In addition to the two overarching matters outlined above, I have noted the following aspects of the LD that require attention for both clarity of the bill itself and with respect to subsequent development of policies and procedures.

1) Separation of the child and adult content would better serve understanding and purpose. At a minimum, organization of the content to avoid switching back-and-forth between the two would help.
2) For improved clarity, it would be very helpful for terms to be defined in a "For purposes of this subsection list" at the beginning of 13-A.
3) In 13-A. A. the term "maladaptive" should be replaced with language more consistent with the rest of the text. For example, "behaviors that cause self-harm or otherwise interfere with meaningful engagement and/or self-care" might replace "dangerous or maladaptive."
4) 13-A. A. refers to the person-centered support team and 13-A. B. and C. refer to the personal planning team. Each should reference the person-centered support team since that by definition includes the person with or without support and regardless of whether the person attends planning meetings.

5) In addition to the clarification regarding person-centered support team, an explicit statement concerning the person's agreement may be warranted since not all individuals attend the team meetings.
6) Since the bill includes definitions that distinguish between a "positive behavioral health support plan" and a "behavioral health support plan," why does only 13-A. A. which is with respect to a "positive behavioral health support plan" designate the requirement "to rule out medical reasons for the behavior?" It seems this should proceed any plan, especially one that allows for a "waiver of rights" (per 13. A. C.) and/or "negative interventions" (per the definition of a "behavioral health support plan").
7) Given 13-A. B., how does the need for what is addressed in 13-A. C. impact community involvement? It seems to allow (whether intended or not) that someone with a behavior plan as outlined in 13-A. C. would not be in the community. A wording revision seems needed in 13-A. B. and/or 13-A. C.
8) The conditions for a behavioral health support plan should require a functional assessment ideally, regardless of whether a positive behavioral health support plan or a behavioral health support plan; and minimally, for a behavioral health support plan (i.e. one with a waiver of rights and/or may include so-called "negative interventions"). The requirement should include the approved provider type(s) and/or recognized credentials for provision of such assessments.

(Note: An advance statement as discussed in my narrative above seemingly would preclude need for such an assessment since the support needs and protocols already are known unless additional support planning is required.)

9) The minimum standards of training and experience with respect to I/DD-Autism should be stipulated with respect to the licensed clinical psychologist as referenced in 13-A. C. and with respect to the support and safety committee.
10) A requirement for the Department to address expectations, training/credentialing, and capacity for a positive behavior supports culture within the service delivery context – including, but not just with respect to individual support plans – is essential so that it be an expectation of any subsequent policies and procedures.
11) With respect to definitions:
    a. Restraint, as noted above, needs to be defined including the aspect of chemical restraint.
    b. Positive reinforcement needs to be defined.

(Positive reinforcement when misused as a behavioral approach – earning something for "right" behavior versus true reinforcing experience(s) that increase one's capacity – can be another form of coercion.)

    c. Negative interventions needs to be defined, and a clarification needs to be made between the practices restricted from a positive behavioral health support plan and what would be allowable negative interventions in a behavioral health support plan. Is it really meant to allow that painful stimuli, for example, only is excluded with respect to a positive behavioral health support plan (but otherwise acceptable as negative intervention/waiver of rights as part of a behavioral health support plan)?

12) It seems wise that the statement (as noted in the LD summary) "Also, to conform with current practice, the bill repeals a provision of law regarding the authority of providers of residential services to establish house rules in residential units owned or operated by the provider" be rewritten or clarified to affirm the allowance for house rules to be developed and implemented through the engagement of the house residents.

I appreciate your consideration of my comments and may be contacted through ASM regarding any questions.

Respectfully,

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Community Outreach Liaison
Autistic Self-Advocate/Waiver Recipient