Center for Community Inclusion & Disability Studies
Maine's University Center for Excellence in Developmental Disabilities Education, Research and Service (UCEDD)

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Re: Testimony FOR LD 769 "An Act Regarding Access to Behavioral Health Supports for Adults with Certain Disabilities"

Chair Ingwersen, Chair Meyer, Distinguished Members of the Joint Standing Committee on Health and Human Services:

My name is Alan Cobo-Lewis. I live in Orono. I am director of the Center for Community Inclusion and Disability Studies (CCIDS) at the University of Maine. I am also the parent of two 24-year-olds, one of whom has autism and who receives Home and Community Based Services on the Section 21 waiver.

CCIDS is Maine's federally funded University Center for Excellence in Developmental Disabilities (UCEDD, pronounced "YOU-said"), authorized by the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 ("DD Act"). The purpose of the national network of UCEDDs is to provide leadership in advise federal state and community policy leaders about, and promote opportunities for individuals with developmental disabilities to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life. Part of the federal mandate of CCIDS is to educate and advise policymakers, including members of the state legislature. Consistent with CCIDS responsibilities under the DD Act and consistent with University of Maine Board of Trustees policies 212 and 214, I am submitting material pertaining to LD 769 for myself and for CCIDS, not for the University of Maine or the University of Maine System as a whole.

1 Alignment with federal and state findings and declarations

In the DD Act, Congress found that "The Federal Government and the States both have an obligation to ensure that public funds are provided only to [programs supporting individuals with developmental disabilities] that…**provide treatment, services, and habilitation that are appropriate to the needs of such individuals [and that] meet minimum standards relating to…prohibition of the use of physical restraint…unless absolutely necessary to ensure the immediate physical safety of the individual or others**, and prohibition of the use of such restraint…as a punishment or as a substitute for a habilitation program" 42 US Code 15009 ("Rights of individuals with developmental disabilities"). And under Maine law, "The Legislature declares that the system of services and supports through which the State provides services to and programs for persons with intellectual disabilities or autism must be designed to protect the integrity of the legal and human rights of [clients with intellectual disabilities or autism]" 34-B MRS section §5003-A(1). LD 769 clearly seeks to align with this Congressional finding and this Legislative declaration.

The goals of LD 769 include minimizing use of restraints and other restrictive practices in behavior management programs.

2 How to actually achieve the goals in federal and state law and LD 769

While I am testifying for the bill, I strongly suggest concomitant changes to MaineCare rule and amendments to LD 769 itself.

2.1 Adequate training and consultation in all waivers or in Medicaid state plan

To actually achieve LD 769's policy goals requires a system of services and supports that provides evidence-based behavioral support rooted in respect for human rights. This must include:

- Direct support professionals adequately trained in data collection, positive behavioral support, and positive alternatives to restrictive practices such as restraint,
- Adequate support from behavioral consultants trained in evidence-based practice and committed to respecting the rights of people with disabilities, and
- An adequate supply of both of the above, supported by adequate compensation and training pipeline.

These recommendations are also in the final report of a demonstration project that CCIDS conducted through an HCBS Innovation grant funded through last year by OADS.[1]

Maine's current system does not achieve this—behavioral consultation is too restricted in Section 21 (capped at 16.5 hours per year and compensated far below market rates) and is unavailable in the other HCBS sections, DSPs get inadequate training, and there are too few DSPs and behavioral consultants, aggravated by below-market compensation and inadequate training pipeline.

All of the above must be available to *anyone* potentially subject to a behavior plan. It must not be limited to the new lifespan waiver. For these supports to be available to the entire covered population, they should be adopted into ***all* the HCBS waivers (especially Section 21 and 29 but also Section 18, 19, and 20, as well as the planned lifespan waiver)** or adopted into Maine's **Medicaid state plan**.

2.2 Add consideration of titration to LD 769's review process

The bill should require that behavioral health support plans submitted for review include

- a functional behavioral assessment,
- a consideration of least restrictive alternatives,
- a plan for teaching skills to both the person receiving services and the person's direct support team,
- a plan for assessing effectiveness of the intervention, and
- a plan for potentially titrating the most intrusive aspects of the plan as behavior improves and risk recedes.

2.3 Add debriefing process to LD 769

The bill should require a debriefing process after a specific number of restraints in a defined period. For example, Maine Department of Education rule Chapter 33 ("Rule Governing Physical Restraint and Seclusion") requires that **every three incidents of physical restraint** experienced by a student with a disability within a school year, the student's **team must meet** within 10 school days to discuss the

[1] Cobo-Lewis, A. B., & Howorth, S. (2024, December 30). *Final report on HCBS innovation project on enhanced behavioral support.* Submitted to National Disability Institute and Office of Aging and Disability Services, Maine Department of Health and Human Services. Orono, ME: Center for Community Inclusion and Disability Studies, University of Maine.

incident and consider the need to conduct a functional behavioral assessment, develop a behavior plan, or amend an existing behavior plan (though schools are not required to hold more than one such meeting with a 30-day period). If the Committee moves forward with LD 769 then it should be **amended to include a similar review requirement**.

3 Safety device

I also endorse the codification of safety devices as distinct from positive behavioral health support plans not requiring the same level of review as positive behavioral health support plans.

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