Maine Developmental Disabilities Council

March 12, 2025

Dear Senator Ingwersen, Representative Meyer, and Members of the Joint Standing Committee on Health and Human Services: please accept this testimony in favor of LD 769, An Act Regarding Access to Behavioral Health Supports for Adults with Certain Disabilities. **MDDC strongly supports the discontinuation of planned restraint as a behavioral intervention.**

The Maine Developmental Disabilities Council (MDDC) works in partnership with people with disabilities, parents, advocates, and policy makers to promote independence, integration, and inclusion of all people with disabilities through advocacy, capacity building, and systems change throughout the state of Maine and on the national level.

Under the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000, MDDC is required to ensure that individuals with developmental disabilities of all ages and their families participate in the design of, and have access to, needed community services, individualized support, and other forms of assistance that promote self-determination, independence, productivity, integration, and inclusion in all facets of family and community life. **MDDC is committed to creating a Maine in which all people are valued and respected because we believe communities are stronger when everyone is included.**

General remarks regarding the portion of this legislation related to ***children****:*

Since the close of Pineland, children with DD have been a statutory afterthought. Section 24 was created as a temporary stopgap for people with DD until waivers were created for adults with IDD. Children with DD remained within Section 24 until early in the twenty-first century after CMS required Maine to update the rules directing care for children with DD. Section 28 then absorbed section 24 into slightly more targeted services to children with DD. 34-B, the section of rule directing services for adults with IDD is also where the archaic language for behavior management of children. **MDDC notes that this bill contains language addressing practices that are not current involving children with IDD.** MDDC believes that children with IDD need their own section in rule to describe how programs are to be executed. **Please consider a taskforce to develop an office for DD.**

General remarks regarding the portion of this legislation related to ***adults****:*

HCBS settings are intended to be different from institutional settings such as hospitals or jails. **For no other community dwelling adult population is it permissible to respond to undesirable behavior by restraining people as has long been the practice in adult developmental services. MDDC supports the Office of Aging and Disability Services in its**

commitment to eliminate the use of restraint in developmental services programming, in line with other Medicaid services, including other home community-based services.

Right now, the system puts people in impossible situations. People with IDD receive inadequate support: too few hours for people outside the residential system and a revolving door for staff for almost everyone. It's no wonder what people react poorly when the people providing critical, intimate, support don't know them or care for them. Many, many, people have experienced multiple traumas, many experienced outside the system that they are now in, have inadequately treated physical and mental health conditions, and have not learned skills that help them get what they want. In this culture, it is no surprise that the person acting out is generally blamed when something goes wrong, especially when it involves violence.
DSPs are inadequately compensated, often unskilled, and have unreasonable expectations placed upon them (supporting people they don't know, extreme hours, etc.), and lack in their own lives the "good things" that they are asked to help people with IDD get.

MDDC strongly supports the discontinuation of planned restraint as a behavioral intervention.

MDDC Would like to see the Dept ensure adequate resources to meet this goal. People with IDD need to be able to reliably access a robust and high-quality array of medical care, including mental health care, clinical supports, daily living supports, etc. At this time people struggle to access just some of what they need. MDDC notes that in recent years OADS has made significant efforts to improve access. However, the is longstanding and system wide. Without a robust plan, meaningful review and oversight and adequate resources to implement a system that does not utilize planned restraint, MDDC is concerned about the possibility of unintended consequences.

MDDC supports efforts to simplify access to safety devices.

The current process of reviewing rights restrictions centers around the Review Team, whose express role is to "ensure compliance with and raise concerns related to, the applicable statutes and regulations." This is certainly a necessary function, but insufficient.
The proposed process <u>may</u> include clinical review and does include the welcome perspective of an individual receiving services.
MDDC suggests that OADS consider how review processes can be structured to prioritize the protection of human rights, through a structure such as a human rights committee made up of community members with expertise in relevant areas. Such a process should require clinical review, preferably multidisciplinary review, as well as the perspective of individuals using the service system.

Specific remarks regarding the portion of this legislation related to ***adults****:*

Sec. 3. 34-B MRSA §5605, sub-§13-A is enacted to read: **<u>13-A. Behavioral health support, modification and management for adults…</u>**

Some of the language in this section is unclear.

- A "<u>positive behavioral health support plan</u>" is not referenced in in Chapter 5 (REGULATIONS GOVERNING BEHAVIORAL SUPPORT, MODIFICATION AND MANAGEMENT FOR PEOPLE WITH INTELLECTUAL DISABILITIES OR AUTISM IN MAINE.)
- A "<u>behavioral health support plan</u>" is not referenced in in Chapter 5

While this legislation goes on to provide definitions, I am concerned that introducing new verbiage may be confusing or unclear

- A “personal planning team” is not referenced in in Chapter 5
- A “positive support plan” as defined in the chapter 5 regs does not seem intended “to address dangerous or maladaptive behavior”

Some of the language is concerning:

- The plan must be reviewed and approved by a licensed clinical psychologist designated by the department. Having plans reviewed by a licensed clinical psychologist is an excellent practice. I am concerned about OADS’ long-term capacity to retain that person, especially given an historical lack of clinical capacity and that it seems to be not required across the board: The department shall convene a support and safety committee on a quarterly basis to review data regarding the number and type of plans implemented for adults under this subsection. The committee must include, but is not limited to, a self-advocate, a representative of the advocacy agency designated pursuant to Title 5, section 19502, a member of the Maine Developmental Services Oversight and Advisory Board established pursuant to Title 5, section 12004-J, subsection 15 and the licensed clinical psychologist, if any, designated by the department under paragraph C.

MDDC appreciates Maine’s commitment to systemic improvement and appreciate the Department and Senator Ingwerson introducing legislation on this important topic.

Rachel Dyer
Maine Developmental Disabilities Council