

24 March 2025

Testimony **Neither For Nor Against** Against of LD 791 An Act Regarding Children with Behavioral Health Awaiting Placement in Residential Care Facilities.

Senator Ingwersen, Representative Meyer and the distinguished members of the Committee on Health and Human Services:

My name is Nancy Cronin, and I am the Executive Director of the Maine Developmental Disabilities Council (MDDC).¹ Please accept this testimony **Neither For Nor Against** LD 791 An Act Regarding Children with Behavioral Health Awaiting Placement in Residential Care Facilities.

In receiving Medicaid dollars Maine has had to commit to being in compliance with the Early Periodic Screening Diagnosis and Treatment (EPSDT) obligation. The fact that children who have MaineCare are stuck in Emergency Rooms because of a lack of services is in direct violation of that obligation.

MDDC supports that hospitals need to get reimbursed when they find children with disabilities have no where else to go other than emergency rooms. We also support collecting and making transparent the scope of this problem. But this bill does not go far enough. We want you to remember 13-year-old Abby. Abby was a stuck kid in an emergency room for 303 days. Abby walked into the emergency room. But upon entry her life froze. She wasn't able to find a place to go that could meet her needs. And she sat in a small room not receiving any therapy or getting anything but her very basic needs met. I understand that Emergency Rooms are not made to provide non emergency services. But, none the less, she stayed in that room for over 300 days and lost ability. When a placement was finally found, Abby couldn't walk out. In fact, Abby wasn't able to transfer from a wheelchair to bed. Abby was so much worse when she left the hospital than when she checked in. She now resides in Maine in an ICF/IID institution.

EPSDT requires that:

"States are required to furnish all 1905(a) Medicaid coverable, appropriate, and medically necessary services needed to correct and ameliorate health conditions" https://www.medicaid.gov/sites/default/files/2019-12/epsdt_coverage_guide.pdf

"States are responsible for ensuring that EPSDT-eligible children or their families are informed about EPSDT requirements, have necessary assistance with transportation and scheduling appointments when needed, receive screening and diagnostic services at appropriate levels, and receive follow-up treatment as needed Section 1902(a)(43) and 1905(r) of the Act and 42 C.F.R. §§431.53, 441.56, and 441.62

¹Councils on Developmental Disabilities were created through the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) in 1970. Maine's DD Council has been advocating for individuals with developmental disabilities for over 50 years. The DD Council is a federally funded, independent organization with members from across the state, including persons with disabilities, family members, and representatives of public and private agencies which provide services and/or funding for services for individuals with developmental disabilities. As required in federal law, we are involved in advocacy, capacity building and systemic change activities, with the goal that individuals with developmental and other disabilities of all ages are fully included, integrated, and involved in their communities and the decisions impacting their lives.

"States are ultimately responsible for ensuring EPSDT-eligible children receive the coverage required by Medicaid statute and regulations." 42 C.F.R. §438.210(a)

"must ensure mechanisms exist to guarantee timely access to medically necessary services. 42 C.F.R. §438.206

Children should not be stuck in Emergency Rooms. They should get the services that they need so that emergency rooms are not necessary or as Medicaid has directed "Children's health problems should be addressed before they become advanced and treatment is more difficult and costly." (https://www.medicaid.gov/medicaid/benefits/downloads/epsdt-coverage-guide.pdf) But Maine has a very long way to go to come into compliance with EPSDT.

I agree, the emergency room is the worst place for a child to be stuck. But until our service system is robust enough for this last place scenario to be utilized then we implore this committee to ensure that stuck kids get the active care while in the emergency room so that they don't lose skills while waiting. Hospitals should get fully paid for all that. I do not understand why they are not.

Maine is failing in its EPSDT obligations. In addition to the legislative language, I urge this committee to implement the recommendation listed in the Blue Ribbon Commission to Study the Organization of and Service Delivery by the DHHS, specifically:

Recommendation #8 The Department should study, and report to the Health and Human Services Committee, how the Department is meeting its obligations under the Medicaid Early and Periodic Screening, Diagnostic and Treatment benefit, including identifying gaps in the services offered or the accessibility of services. As part of this study, the Department should engage stakeholders in the process of identifying gaps.

In addition once the report returns to this body the Committee should have authorization to submit new legislation.

Thank you for this opportunity to speak. I am available for questions and will try to be present for the work session.

Sincerely

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