Maine Developmental Disabilities Council

January 6, 2026

Dear Senator Ingwersen, Representative Meyer, and Members of the Joint Standing Committee on Health and Human Services: please accept this testimony Neither For Nor Against of LD 555, An Act to Create a Separate Department of Child and Family Services.
My name is Nancy Cronin, and I am the Executive Director of the Maine Developmental Disabilities Council (MDDC)[1]. I appreciate the opportunity to testify today.

I chose to testify *Neither For Nor Against* this bill rather than simply *In Favor* because, as is often the case, the devil is in the details. Approximately one year ago, I sat in this room as a member of the Blue Ribbon Commission to Study the Organization of and Service Delivery by the Department of Health and Human Services when it presented its findings to this body. At that time, I did not believe that separating children's responsibilities into a distinct department was necessary. Today, I am no longer certain that it is true.

I would like to share several facts that have led me to this conclusion.

MaineCare

A comparison of the 1994 and 2024 *Kids Count* data shows that Maine has made meaningful progress in ensuring that children have health insurance coverage. In 1994, 8.7% of Maine children lacked health insurance. By 2024, that figure had been reduced to 4.3%. This progress did not occur by chance; it reflects deliberate policy decisions, including expanded eligibility for MaineCare.

In 1994, only 27.5% of Maine children were covered by MaineCare. Today, that figure has nearly doubled to 53%, underscoring the essential role public programs play in ensuring access to health care for children.

Federal law is explicit: children are entitled to Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services so that conditions are identified, evaluated, and treated early—so they are ameliorated or mitigated. States that accept Medicaid dollars must ensure EPSDT that they meet this obligation. Despite this

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[1] [1] Councils 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 with and 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.

obligation and the fact that over half of its children rely on MaineCare, Maine lacks a thoughtful, coherent, coordinated approach to ensuring appropriate care for its children.

In fact, children's health policy within MaineCare has become increasingly fragmented. The only staff position dedicated to children's policy—the EPSDT coordinator—was removed from policy and reassigned to prior authorization. I personally don't understand that at all. The only other dedicated children's MaineCare position who is responsible for coordinating policy and communication across education, community, and health systems was similarly removed from policy and placed in provider relations.

Despite the fact that more than half of Maine's children now rely on MaineCare, there is no position within MaineCare policy dedicated exclusively to children's health. I believe there should be an entire team. **As a result, there is no systematic analysis of whether children's needs are being met, or whether services are delivered in a health-effective or cost-effective manner.** Some children receive appropriate care; others are effectively invisible—attempting to navigate a system not designed around their developmental, behavioral, or family-based needs. **The absence of focused policy oversight increases the risk that children's needs go unmet and that public resources are used inefficiently.**

Early Childhood

Universal developmental screening is critically important, as not only is it educating parents it is catching developmental problems early so, we hope, those problems can be addressed. However, Maine currently has more than four programs that screen young children and provide parenting education, while vital evaluation and treatment resources for young children have steadily disappeared. Without diagnosis and treatment what good is investing only in screening?

Last summer, the Edmund Ervin Pediatric Center—the last multidisciplinary pediatric diagnostic center north of Boston—closed. Today, families seeking a same-day, multidisciplinary diagnostic evaluation with coordinated collateral contact must travel to Boston. While families may still obtain multidisciplinary diagnoses in Maine, they must now manage multiple appointments with multiple providers, many of whom are located only in Southern Maine.

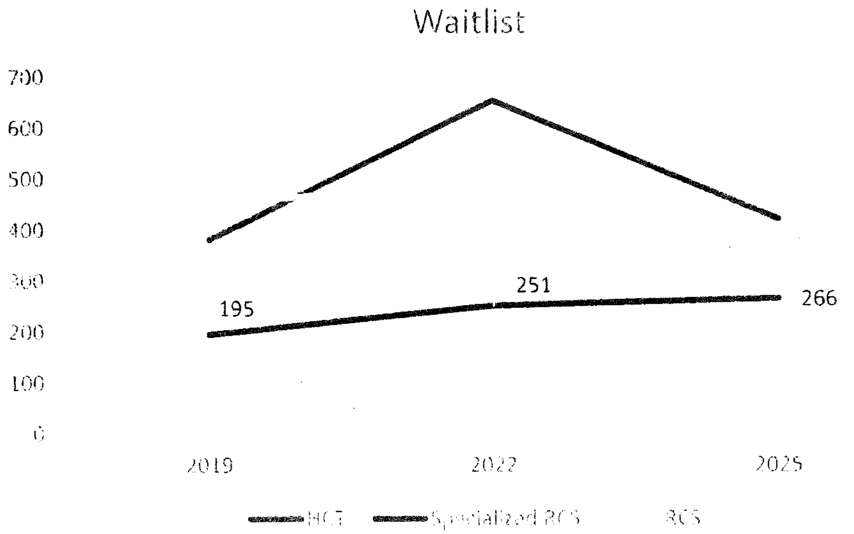
For families living two or more hours from Portland—which includes most of the state—this creates an enormous burden of coordination, travel, and time off work. As a result, children with developmental concerns beyond typical variation face unacceptably long waits for accurate diagnosis and appropriate treatment recommendations.

In short, DHHS funds too many programs that identify concerns and refer families, while investing too few resources in the evaluation and treatment services those referrals require. This makes no sense.

Behavioral Health

Children's Behavioral Health Services (CBHS) serves some children—specifically those with a mental health diagnosis, autism, or an intellectual disability. Maine has been found inadequate in meeting these children's behavioral health needs, as evidenced by the recent Department of Justice settlement.

We know that children are waiting for services. We know that Maine is increasingly sending children out of state for behavioral health care because their needs cannot be met here. While efforts are underway to address some of these failures, significant gaps remain.



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Meaningful evaluation of CBHS is currently limited, as the public dashboard has not been updated since January 2025. Reviewing waitlist data from January 2019 to January 2025 shows some improvements. Children with behavioral health needs are accessing Home and Community Treatment (HCT) services more quickly as evidenced by wait times having decreased. Similar improvements are evident for children and youth with developmental disabilities who require **basic** rehabilitative and community supports.

However, for children with developmental disabilities who need more specialized and intensive services, the data show little to no progress. The same is true for out-of-state residential placements. These are the children and youth that tend to have more complicated challenges.

Office of Child and Family Services

Maine continues to face serious challenges within the child protective system. While MDDC does not primarily focus on child protection, it is important to note that many of these children also have developmental disabilities and significant health care needs.

As Maine works to improve the child welfare system, we remain concerned that these children are served in fragmented silos. **Challenges related to health, disability, education, and family stability are addressed separately rather than holistically—exacerbating risk for some of the most vulnerable children in the state.**

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[2] https://www.maine.gov/dhhs/sites/maine.gov.dhhs/files/inline-files/CBHS%20FAQ%20Sheet_1.pdf

Children and Youth with Special Health Care Needs

Despite multiple national frameworks outlining best practices for serving children and youth with special health care needs (CYSHCN), research consistently documents service gaps and persistent health disparities. According to the 2022 National Survey of Children's Health[3], only 17.1% of Maine's CYSHCN receive care within a well-functioning system—a figure that drops to just 9% for youth ages 12 to 17. More than one in four Maine children—approximately 66,239—have a special health care need, ranking Maine third nationally. Seven percent experience conditions that consistently affect daily functioning, and 41% are moderately affected at some point. Fewer than one in four receive services that adequately support their development, and approximately 40% lack effective care coordination—an essential component of a high-functioning system. Despite clear and compelling data demonstrating need, Maine DHHS maintains only a small, under-resourced CYSHCN program that lacks organizational authority and leadership standing. Although federal guidance requires that 30% of Maternal and Child Health Block Grant funds be directed to this population, funding and statutory requirements are not being fully implemented—resulting in harm to children and youth with special health care needs.[4]

Children with Medical Complexities

Maine has no office specifically responsible for overseeing services for children who are medically fragile. While the CYSHN program provides limited care coordination through a single staff position, it lacks the funding and authority necessary to meet need.

There is no coordinated, clearly defined system to address the medical, social, and developmental needs of medically fragile children and their families. What we do not know is deeply concerning: we do not know how many children are waiting for nursing care, how many are unable to attend school due to lack of nursing support, or how many technology-dependent children are unable to access durable medical equipment essential for survival.

We do know that families repeatedly come before this Legislature asking to be reimbursed for providing life-sustaining care when no nurse is available—because they cannot work while keeping their child alive. Despite multiple legislative efforts, Maine has not created a viable solution. The true scope of this crisis remains unknown because it has never been systematically measured. What we do hear—consistently and troublingly—are stories of preventable hospitalizations, financial devastation, and harm caused not by medical complexity, but by the absence of coordinated care.

Restructuring

Does MDDC believe Maine needs a separate department focused on children? It would be encouraging if **someone** clearly focused on Maine's children. At a minimum, Maine needs a comprehensive, coordinated

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[3] https://www.childhealthdata.org/learn-about-the-nsch/NSCH

[4] The DHHS rule Bureau of Health Division of Maternal and Child Health Chapter 272 (https://www.maine.gov/sos/cec/rules/10/144/144c272.doc) authorizes the Children and Youth with Special Healthcare Needs program. This is an extremely out-of-date rule. The Council does not believe that laws and rules should be just left on the books unheeded.

strategic children's plan developed that includes *all* children. Without that plan a separate department could just be new letterhead.

Without a cohesive structure, accountability is weakened and children's health policy cannot be effectively developed, monitored, or improved. The current system manages access rather than assessing need, outcomes, or performance—and those at greatest risk, including the most disabled and medically fragile children, are the least well served.

What is the purpose of government if those with the greatest needs are left without support?

Maine must do something.

Thank you for the opportunity to testify. MDDC is available as a resource for systems change, and I will make myself available for the work session.

Respectfully submitted,

Nancy Cronin
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Maine Developmental Disabilities Council