

Senator Baldacci Representative Meyer Members of the Committee of Health and Human Services

RE LD 779 An Act to Create a Separate Department of Child and Family Services

Senator Baldacci, Representative Meyer and members of the Health and Human Services Committee. My name is Carrie Woodcock I am the parent of two children with special needs and the Executive Director for Maine Parent Federation (MPF), the federally funded Parent Training and Information Center (PTI), Family to Family Health Information Center (F2F) and Statewide Family Network. We assist families of children with different abilities and special healthcare needs to navigate all systems of care. I am submitting this testimony neither for nor against LD 779 An Act to Create a Separate Department of Child and Family Services.

As both a parent and a professional I have navigated the various systems of care for my family and many families in Maine with children who have different abilities and special healthcare needs. To receive services and interventions which are crucial to their children's development a family must be fluent in what services are available, what department they are available through, the various application processes and assessments they will need to qualify, and their rights to appeal a decision if they do not qualify. If a family is lucky enough to gain access to all the services, they then need to be efficient at coordinating all the services. This in and of itself is a full-time job.

In addition to the well documented issues within our Child Protective Services these are services "available" to our children and the Departments in which they reside. I put available in quotes because while these services exist, they all have various waitlists which means our children while going through all the work of qualifying are not actually receiving the service.

Part C – Early Intervention Services for birth through the age 2 – Child Developmental Services (CDS)

- Currently our state has one of the strictest eligibility criteria therefore making it extremely difficult to qualify for the services.
- Only offering on average 1 1.5 hours every 2 weeks to identified parents/caregivers of eligible children. Some children are not receiving direct intervention at all.

Part B 619 – Early Intervention Services for ages 3 – 5 – Child Developmental Services

• Currently our state is out of federal compliance as there are many waitlists for services and therefore, we have large unmet need.

Just looking at Part C and Part B 619 our state is failing children with different abilities at an age when all the evidence shows intervention can make the biggest positive impact on the rest of their lives.

Section 28 & 65 – In Home and Community Based Supports – Office of Children and Family Services

• In home and community-based supports to assist with daily living skills, behavioral challenges, mental health challenges and community integration.

- We are currently being investigated by the Federal Department of Justice for long waitlists which again is putting us out of federal compliance.
- It was mentioned at the public hearing that in the Lewiston area individuals are waiting 6-9 months for services. In our experience at Maine Parent Federation 6-9 months is a relatively short period of time to wait in our state. We are working with families that have been waiting for over a year and some even years. If you have a child with increased challenges or live in a more rural part of the state, you may never be taken off the waitlist. The average wait time is closer to a year or more.

Targeted Case Management

 Children's case management in our state is episodic. Meaning it opens and closes based on need in our state. This forces families to re-qualify for assistance (which means lengthy paperwork) every time a need arises. By the time paperwork is processed and approved the need may have already reached a crisis level. In addition, most Case Managers are only well-versed in the state services which they represent. Therefore, they are only able to provide a very narrow area of support.

Respite Care – Contracted by the DHHS through NAMI ME

- Service to provide families/caregivers of individuals with different abilities a planned intentional to break. Most parents use this to run every day errands that most people take for granted.
- Due to the waitlists making the service mostly inaccessible (unless a family has their own provider) it is very difficult to obtain.

Office of Children with Special HealthCare Needs – Housed within the CDC but does fall under the supervision of OCFS.

- Offers 1 Coordinator to work with assisting families to refer to direct services. There is no way 1 Coordinator can meet the need in the state.
- Provide the state contract through the Maternal and Child Health Block grant to Maine Parent Federation to offer their peer-to-peer Family Support Navigator program.
  - This program provides the only true model of Care Coordination in the state (assisting families in navigating every single system of care they encounter; this is the number one need of families). There are no waitlists for the services but due to such high need in our state last year we overspent our contract by \$12,000. While we had the funding this year to be able to sustain that overspending it is not a sustainable model to be able to continue to meet the very high needs.

As you can see for our children with different abilities our state is failing them in every system of care, we say we provide. Why is the relevant? If you look at the children encountering our child protective services a good majority most likely have a diagnosis. When our state is failing these children and their families in providing services it puts extraordinary pressure on the parents/caregivers. When children are in a single parent household (75% of marriages who have a child with a different ability end in divorce) that pressure rises significantly. Putting all these circumstances together mean more children are encountering child protective services.

It is a virtual spider web of services that even if navigated successfully usually ends in a waitlist. All these systems are under the oversight of the Department of Health and Human Services through various branches. Unfortunately, it is quite evident that the Department has gotten too big to understand what each branch has to offer, how to navigate and become eligible through that branch, and the status of the services through that branch. As a results when families are attempting to receive services, they are sent from one person to the next without ever getting an answer and in the end without services.

My hopes are a stand-alone Department which is all things children would provide a more streamlined structure. One which leadership would be working together to understand and meet the needs of children across all services. Resulting in no wrong door to all children's services through this Department. The system which I outlined to you above is fragmented at best and not meeting children and family's needs and have landed our state in crisis.

Thank you for your consideration.

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