



Maine Developmental Disabilities Council

April 14, 2025

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 1540, Resolve, to Direct the Department of Health and Human Services, Office of MaineCare Services to Create the Complex Care Assistant Training Program.

My name is Nancy Cronin and I am the Executive Director of the Maine Developmental Disabilities Council¹. The Council is interested and committed to children who are medically fragile getting their needs met. Our concern is this bill doesn't solve the problem. Creating a training program so that families can be paid caregivers won't allow families to get paid faster.

Two years ago the Maine Legislature passed a way to reimburse families of medically fragile children through Section 40. Today that stands and families who are Certified Nursing Assistance could technically get paid. The problem? There is only 1 Section 40 agency who provides services to the pediatric population. They aren't interested in expanding the service and have no incentives to manage family caregivers. Families have become CNAs and found that their effort did not help them get paid. Those families continue to keep their medically fragile children alive by providing the care that is necessary while struggling desperately with lack of income. They still have to weigh their child's life because they need 24/7 care but no professional able to care for them with having the income necessary to feed and house the family.

This bill seeks to create a training program under Section 96 with the hope that Section 96 Private Duty Nursing agencies will administer payment. Unfortunately there are not enough Section 96 Private Duty Nurses available to care for these children. Further, Section 96 agencies are dropping the number of pediatric clients that they will serve. If this bill is implemented there will still not be agencies willing to take on the work.

The issue related to the lack of Section 96 Private Duty Nurses is very serious. In addition to not having nurses for children who need them in order to live, let alone live in the community, many families cannot even access medical assessments for their children. Maine does not have a centralized waiting list so we do not know the extent of the problem. But we do know children who are medically fragile are waiting. We don't know the extent of the problem. In fact, there is no systemic structure that monitors children who are very medically fragile.

We recommend that this bill be amended to create a taskforce that will:

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.

- Determine how many children who need nursing care exists. How many of those children get the service for how hours of service vs hours of need. How many children are waiting for services? How many waitlists are the children on?
- If the above cannot be discovered then the taskforce should recommend a method in which the above data can be collected systemically.
- Identify the needs and develop recommendations to ensure that children who are medically fragile get their needs met including the best way to support families.
- Consider the best way to reimburse families whether it be Section 40, Section 96, a Children with Complex Medical Needs Waiver, a combination of strategies, or something else.
- Lastly, direct MaineCare to urgently remedy the MaineCare system to ensure that the EPSDT obligation is fulfilled so that medially fragile children receive medically necessary assessments and treatments.

Thank you for your time and attention to this critical issue. I am more than happy to work with anyone to amend this bill. Thank you

Sincerely,

A handwritten signature in black ink, appearing to read 'Nancy Cronin', written in a cursive style.

Nancy Cronin
Maine Developmental Disabilities Council.