



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

RE: LD 346 An Act to Clarify the Requirements for Family Caregivers &
LD 874 An Act to Address the Shortage of Direct Care Workers for Children with Disabilities in Maine

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 disabilities and special healthcare needs to navigate all systems of care. I am submitting this testimony in support of LD 346 An Act to Clarify the Requirements for Family Caregivers & LD 874 An Act to Address the Shortage of Direct Care Workers for Children with Disabilities in Maine.

My daughter Sami was born on April 12, 2007 and at the time of her birth we learned that not only did she have Down Syndrome but she also had a severe heart defect. It was not long after bringing Sami home that I realized there was no way for me to take care of her needs and work at all. My full-time job was now to keep my daughter alive. Despite the financial implications for my family the decision was not hard to make. Our family is extraordinarily lucky that Sami's heart condition was able to be resolved with surgery. That said Sami's needs due to her Down Syndrome remain very high. Our family knows the balancing act of meeting her needs while we sit on waitlists, being present for our son, and trying to maintain two financially necessary full-time jobs.

LD 346 and LD 874 looks to address multiple needs in our state while at the same increasing positive outcomes for these children and their families.

Waitlists for services such as nursing care and residential and community-based support are long. In fact, in a letter from the Department of Justice on June 22, 2022 Maine was put on notice that due to the lack of availability of these services we are currently in violation of the ADA. LD 874 would instruct the Department of Health and Human Services to apply for a federal waiver which would enable the state to qualify family members to provide and be paid for the services they are currently sitting on waitlists to receive. In doing so the State would be addressing part of the workforce shortage that is creating the waitlists, a problem we have seen arise in many bills this legislative session. The State would then be able to remove these children from the waitlists effectively decreasing the numbers which are currently putting our state out of federal compliance.

We acknowledge that applying for federal waivers can be a very lengthy process and while that process proceeds there would continue to be unmet need. LD 346 would put into place a pilot program which

could start addressing the need. As with any new programming there are always unforeseen hurdles which arise and often, we fly the plane before it is built. I believe LD 346 would not only give the Department time to apply for the federal waiver it would also provide us with invaluable data on the possible hurdles. Having the knowledge of these hurdles would allow us to write legislation that is proactive. My ask for LD 346 is that it would also include a stakeholder group to be able to identify and address hurdles and assist in the creation of future legislation if a waiver is granted.

Finally, and perhaps most importantly both bills would allow for families to address the need while being provided financial compensation. The research shows that when parents can provide their children with Special HealthCare Needs and Disabilities the full intervention, they require then positive outcomes for everybody involved increase. You heard from many families and professionals during the public hearings who did an amazing job telling you all just how much of a positive difference this would make in their family's lives. Knowing that their children can receive proper care without putting their families into a dire financial situation is invaluable.

For these reasons I urge the committee to please support both LD 346 and LD 874.

Thank you for your consideration.

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