



April 13, 2023

RE: 131st Maine Legislature LD 208-An Act Concerning Home Care Services

My name is Laurie Bourgoin, and I am the Chief Clinical Officer at Home Hope & Healing. Home Hope & Healing provides services to 63 clients across the state of Maine, covering all districts (except Aroostook County) The clients we serve are primarily children and young adults requiring Private Duty Nursing services in order to remain in the home/community setting. Our clients require the skills of a licensed nurse to care for severe respiratory conditions (requiring tracheostomy and home ventilator treatment), severe seizure disorders requiring the skills of a nurse for immediate intervention, and neuromuscular conditions, to name a few.

I am writing today in support of “An Act Concerning Home Care Services” because the pediatric “private duty” services are very difficult to navigate, as a provider and for the parents. Currently Home Hope and Healing has 42 children on an inquiry “wait” list within the agency. These children all appear to qualify for skilled nursing services, from 20-168 hours/week. Conservatively speaking, these children ‘waiting’ would qualify collectively for the services of 47 full time RNs/LPNs.

Inquiries from families, Targeted Case Managers, Hospitals, physicians, and schools are fielded by our team, and, when there are not nurses available to fill the needs, we offer to put the child on this list and to increase our advertising with awareness of this child’s needs. During the conversations we have a loose idea of what the child might qualify for, but the assessment (the MedKids Assessment) is not done at the time of the referral but when a nurse who is a good match for the needs of the child is found. (MedKids assessment is only to be done with a plan of care to take care of the child’s needs). This can take many months to achieve.

There are several problems with this situation:

- **MaineCare is completely unaware of these medically fragile children “out there” with serious needs for home care services, because the trigger to involve MaineCare is only at the time of the MedKids assessment.**
- Families, physicians, and hospitals are desperate to procure help for these children, and resort to calling multiple agencies to see if they can get on lists with each, to increase chances of help being found.
- Agencies do not know which children are on each list, and how many are duplicated.
- An agency might find a nurse in a particular geographic area where the agency itself has no client in need, and no one on the agency’s list. Only to learn that another agency has a potential client in need in that area.
- In today’s shortage of nurses, providing care to these medically fragile children often involves collaboration between multiple home health agencies.
- **Families relate feeling invisible and frustrated.** They wonder if there will ever be help for them. They wonder if their child will even qualify.

I urge you to support the creation of a meaningful waiting list for children in need of private duty nursing/Personal support services that would be available for all agencies providing the services. **In order to be meaningful, the list would need to include information about skilled needs and actual or potential number of hours the child would require.** This would necessitate some sort of intake/referral system that is centralized, and an assessment with minimum data to better understand and document the needs.

The families of medically fragile children and children with disabilities are looking to us to do this better. Please support LD 208.

Respectfully,

Laurie J. Bourgoïn

Laurie J. Bourgoïn, RN, BSN, MBA