Testimony Neither For nor Against LD 279 An Act to Address the Shortage of Direct Care Workers for Children with Disabilities in Maine

Home Care & Hospice Alliance of Maine

March 24, 2025

Senator Ingwersen, Representative Meyer, and honorable members of the Joint Standing Committee on Health and Human Services,

My name is Sara Ratcliffe, and I serve as Executive Director of the Home Care and Hospice Alliance of Maine. The Alliance is submitting testimony neither for nor against LD 279, An Act to Address the Shortage of Direct Care Workers for Children with Disabilities in Maine. We support the intent of this legislation, but would recommend an amendment in order to ensure the bill can achieve its intended goal.

The Home Care and Hospice Alliance of Maine is a network of home care, hospice, and personal care providers across our State delivering in-home care to older adults and disabled individuals of all ages, including children with complex medical conditions, allowing them to stay in their homes and communities.

Alliance members serve children with complex medical needs through MaineCare Section 96, Private Duty Nursing and Personal Care Services. Unfortunately, due to workforce shortages and inadequate MaineCare reimbursement rates, our members have difficulty being adequately staffed to fully meet the needs of all children who qualify for Section 96 services. Many families are left providing care for their children to fill the gaps and ensure they can remain at home. This can be a huge hardship for families – parents may have to forego work opportunities and income in order to stay home to care for their child.

We appreciate Senator Baldacci's commitment to addressing this complex issue through LD 279. However, the current regulatory framework presents significant barriers as does the language passed in last year's budget directing the Department to implement a similar program in MaineCare Section 40. Private duty nursing and personal care agencies operating under Section 96 have the expertise necessary to support children with complex, chronic needs—but federal regulations prevent them from hiring parents as caregivers. Conversely, providers under Section 40 *can* hire parents, but their model is built for short-term, intermittent skilled care—not the long-term, continuous care these children require. As such, they are unlikely to establish a sustainable family caregiver program, even if permitted.

Over the past year, the Home Care & Hospice Alliance and our members have engaged in many conversations with DHHS as they work to develop this program. Unfortunately, the

path forward is far from simple. We all share the same goals: ensuring children can receive safe, high-quality care in their homes; enabling parents to provide that care; and ensuring they are paid a living wage. At the same time, we must work within the regulatory realities that govern these programs.

Furthermore, allowing a parent to register as a personal care agency is likely to create more challenges than it resolves. Who will be responsible for overseeing the care? Who will ensure the parent receives proper training? Who will ensure compliance with licensing requirements? While we fully understand and respect the intent behind this legislation, our members—who bring deep expertise in this area—cannot support it without first addressing these critical concerns. We urge a collaborative approach to work through the complexities and develop a solution that is both effective and sustainable.

Before further action is taken on a path that may ultimately prove unworkable, we strongly urge the committee to convene a formal stakeholder group to develop practical, effective recommendations that can truly meet the needs of these families.

Thank you,

Sara Ratcliffe Executive Director Home Care & Hospice Alliance of Maine

2023 Public Law Ch. 412

An Act Making Unified Appropriations and Allocations from the General Fund and Other Funds for the Expenditures of State Government and Changing Certain Provisions of the Law Necessary to the Proper Operations of State Government for the Fiscal Years Ending June 30, 2023, June 30, 2024 and June 30, 2025

PART GGG

Sec. GGG-1. 22 MRSA §2149-B is enacted to read:

§2149-B. Home health aide services to minors

Notwithstanding section 2147, subsection 2, a parent of a child who is eligible for home health aide services under the MaineCare program may receive reimbursement for providing those services to the child pursuant to this section and according to department rule. Rules adopted pursuant to this section are routine technical rules as defined in Title 5, chapter 375, subchapter 2-A.

Sec. GGG-2. State plan amendment. No later than July 1, 2024, the Department of Health and Human Services shall apply to the United States Department of Health and Human Services, Centers for Medicare and Medicaid Services for a state plan amendment to allow for qualifying parents of children and youth with in-home personal care needs who are eligible for the MaineCare program to be reimbursed for providing home health aide services under the Medicaid home health benefit.

Sec. GGG-3. Rulemaking. The Department of Health and Human Services shall amend its rule Chapter 101: MaineCare Benefits Manual, Section 40, Home Health Services, to implement the Maine Revised Statutes, Title 22, section 2149-B, no later than 12 months after receiving approval of the state plan amendment submitted pursuant to section 2. The department shall seek input from stakeholders including home health agencies when developing the rule.

Sec. GGG-4. Interim report. The Department of Health and Human Services shall submit a report to the Joint Standing Committee on Health and Human Services on its progress in implementing the provisions of this Part no later than February 1, 2024.

Sec. GGG-5. Contingent effective date. That section of this Part that enacts the Maine Revised Statutes, Title 22, section 2149-B takes effect only if the necessary approval pursuant to section 2 is received and rules are adopted pursuant to section 3. The Commissioner of Health and Human Services shall notify the Secretary of State, the Secretary of the Senate, the Clerk of the House of Representatives and the Revisor of Statutes when approval sought under section 2 is received and rules under section 3 are completed.