

Janet Duncan
Maine Collaborative for Care of Children with Serious Illness
LD 346

I am Janet Duncan MSN, CPNP –a retired Pediatric Palliative Care Nurse Practitioner

This is a typical child patient that I helped care for.

The child has a rare disease diagnosed at age 4 that has caused her to lose function slowly. She has a g-tube for feeds and medications 4x/day.. She needs help with all of her activities of daily living- dressing, toileting, walking. She attends school when she is feeling well but does require assistance about 3 hours in the morning and 5 hours in the evening. Sometimes she sleeps through the night. Many nights she needs reassurance, a diaper change or an intervention to relieve discomfort. When she is sick or when a classmate has a potentially contagious virus, this child must stay at home to protect her or for increased medications or interventions like breathing treatments.

My main concern

Her mother worked as long as she could when she had a few reliable health care workers for her but then it became impossible. The shortage is real, there simply are not health care workers to hire. They also call out sick, or find a better job, or want a better schedule. Even when her daughter goes to school- there are professional days or a snow days or vacations. She worries that the family may lose their house never mind not being able to pay for a ramp to help with access for her daughter's wheelchair, or supplies like braces or equipment sometimes not covered by insurance or medication co-pays.

What we need

We need to find a way to reimburse parents who work around the clock as their child's nurse, case manager, therapist, aide, advocate, and 24/7 caregiver. Please support LD 346.