



May 2, 2022

To Whom it May Concern:

I am a licensed clinical social worker with over 30 years' experience in medical social work at a pediatric hospital. I am writing today to ask for increased Medi-Cal reimbursement rates for shift nursing. In my role as medical social worker in various services (HIV/AIDS, Neurology, and now Gastroenterology), I have worked with hundreds of families of very medically complex children. For the purpose of this letter, I have also consulted my social work colleagues in other services including Pulmonology, Nephrology, Neurology, Rehabilitation, and the Neonatal Intensive Care Nursery in order to include perspectives and case examples from their subspecialties.

Many of our patients qualify for private duty nursing based on their medical complexity. Their skilled nursing needs (e.g., feeding tubes -gastrostomy or jejunostomy, central lines for venous access, ventilator dependence) make them eligible for varying amounts of shift nursing: from 32 hours/ week to 126 hours/ week or more. We refer these patients for private duty nursing but the home health agencies are unable to find nurses for these families. The reason, as I understand it, is the low Medi-Cal reimbursement rates which make it extremely difficult to hire and retain nurses due inadequate pay, creating a kind of nursing shortage.

This "nursing shortage" (a lack of pediatric-trained nurses willing and able to work for inadequate pay) has tremendous adverse impacts on the patients and families we serve. I will outline below some cases (without identifying information) to illustrate the situation.

**From Gastroenterology:**

- 10 year-old with intestinal failure, short gut syndrome, chronic diarrhea, anemia, central line (broviac catheter) for IV access, dependence on IV nutrition (total parenteral nutrition). Due to pregnancy and new baby, Mom was wanting nursing (since other parent works full time outside of home). Family has been waiting for nurse for past 7 months
- 9 year-old with Autism Spectrum Disorder, feeding difficulties, muscle disorder, self-injurious behavior, and feeding tube (gastrostomy) dependence. Due to extreme behavioral dysregulation, child requires 2 caregivers for feeds (one to distract/ hold child while the other does the feed). Since death of one caregiver, the remaining one is now a single parent. A live-in grandparent used to assist but needed to leave for home country. No nurse available since initial nursing referral 17 months ago.
- 2 year-old with rare genetic disorder, congestive heart failure, aspiration into airway, gastrostomy tube dependence, self-injurious behavior. Child needs 24/ 7 constant care. Single parent who is unable to place child in a day care setting because of the medical complexity. Parent worn out by constant caregiving; sometimes misses child's medical appointment due to exhaustion. Family could desperately use a nurse.



- 12 year old who was severely injured in a motor vehicle accident in 2017 resulting in spastic quadriplegic cerebral palsy, scoliosis, developmental disability (non-verbal), feeding difficulties, and g tube dependence. Sadly, one parent (the primary caregiver) was killed in the accident. The surviving parent, in whose care the child was placed, struggles to manage the complex care needs: tube feeds, ordering supplies, getting needed equipment (e.g. wheel chair, braces, lift, bath chair), attending medical appointments with multiple subspecialists (Pedi Rehab, Neurology, Neurosurgery, GI, Orthopedics), and coordinating with special education staff at the school. This child would greatly benefit from a private duty nurse, but none are available.

#### **From Neurology**

- 18 month-old with complex life-threatening medical issues: brain malformation, intractable seizures, ineffective airway clearance/ aspiration into airway, chronic respiratory failure with hypoxia on home oxygen, obstructive sleep apnea with BiPAP dependence, gastrojejunostomy feeding tube. Family unable to get nursing.
- 7 year- old child with Down Syndrome, intractable epilepsy, chronic lung disease, recurrent pneumonias and urinary tract infections, kidney disease requiring urinary catheterization every 3 hours, and feeding tube (gastrostomy). Primary caregiver works afternoons/evenings. Family unable to enroll child in after school care due to medical complexity. Without a nurse, primary caregiver ends up either bringing the child along to the workplace, or missing work. As a result, the child risks being under-supervised and /or the family suffers economically. The family used to have a private duty nurse (who left job due to pregnancy) and has now been waiting 7 months for new nurse.

#### **From the Neonatal Intensive Care Nursery (NICU):**

- NICU baby with history of prematurity, tracheostomy and ventilator dependence. In the past (before current nursing shortage), this child would never have been discharged home NICU without home nursing already in place. The child qualifies for 18 hours/ day private duty nursing due to the complexity of medical needs. The child needs someone to be awake and watching them 24/7. Now, due to lack of available nursing, child will be discharged without nursing.
- NICU baby with short gut syndrome, intestinal malrotation, history of prematurity, gastrostomy dependence, dependence on IV nutrition (TPN or total parenteral nutrition). Complicated psychosocial situation impacting caregiver availability. This child will also need to be discharged without home nursing.

#### **From Nephrology**

- 15-year-old with cerebral palsy, developmental delay, epilepsy, gastrostomy tube dependence, and urologic problems for which child needs catheterization every 3-4 hours. The child used to have shift nursing until the nursing agency stopped accepting Medi-Cal (due to low reimbursement rates). Family has been waiting 6 months for a new nurse



**From Pulmonary-** All of these children (below) have been referred for nursing. None of them have it. All families have been informed that their child needs to have a caregiver at their side, awake 24- 7. Many parents can't work because they don't have anyone to watch the child. Some parents work full time and come home to watch the child so the other parent can sleep. Many parents are experiencing exhaustion and depression. The children are at risk for adverse outcome without sufficient support.

- Child with Spastic quadriplegic cerebral palsy, epilepsy, restricted lung disease, tracheostomy, g-tube dependence, global developmental delay, contractures. Medical team has advised parent that child needs to be monitored 24/7. Family has very limited social support system.
- Child with brain malformations, cerebral palsy, chronic respiratory failure, autism, aspiration risk, dysphagia, g-tube dependent. Requires 24/7 supervision. Limited support. One caregiver providing the majority of care and is exhausted and depressed.
- Child with multiple congenital anomalies, brain malformations, epilepsy, status post tracheostomy, ventilator dependence, feeding tube dependence. This child has very complicated care, is followed by home hospice program due to complexity and guarded prognosis (but hospice services do not include shift nursing).
- Child with retinopathy of prematurity, tracheostomy /ventilator dependence, global developmental delay, g-tube dependence. Very limited social support. Living in transitional housing. Mom is sole caregiver. Recent fall resulting in severe head injury.
- Toddler age child with history of prematurity (26 weeks gestation), history of brain bleed, chronic lung disease, severe bronchopulmonary dysplasia, trach dependence, ventilator dependence, g-tube dependence, developmental delay. Parents are separated. Very limited income. Limited social support. Primary caregiver can't hold a job because of child's care.

I hope the above case illustrations serve to convey even a glimpse of the severe caregiving burden experienced by many of the families we serve. I hope too that the cases explain why, on behalf of my patients and colleagues, I am earnestly requesting that urgent action be taken to increase Medi-Cal reimbursement rates for shift nursing.

Finally, I hope the cases raise for you this question with which I find myself struggling: if we value our youngest and most fragile, how is that we are knowingly putting their lives in the hands of adults who are not permitted to sleep?

Thank you for taking the time to read my letter and consider my request.

Kind regards,

Peggy Macy, L.C.S.W