

From: Valerie Wood-Lewis
Sent: Wednesday, February 5, 2020 9:36 PM
To: Theresa Utton-Jerman; Rebecca Buck
Subject: Pay raises for in-home high tech nurses

Greetings,

I am writing to support pay raises for in home high tech nurses, as legislator's contemplate next year's budget.

We were in a position of NEVER having our high tech nurse horse filled for YEARS with our son, and moving heaven and earth to mostly provide his care ourselves, or, when lucky, relying on inappropriately lower-skilled levels of care, which increased medical issues, costs, and our burnout.

Below is something I wrote back in 2015, before my son passed away. From what I hear from other parents, little has changed.

DAIL appeal 4/30/15 Ben Wood-Lewis

Ben's current medical presentation

Severe, multi-faceted, dystonic, spastic, athetoid, quadriplegic cerebral palsy
Non-verbal, non-ambulatory, not able to assist with transfers
Full bowel care regimen
G tube fed with history of serious and chronic GI problems and surgeries, constipation
Auditory dysynchrony and vision impairment
At risk for pneumonia, aspiration, suffocation, contractures, bedsores, circulatory problems
Diagnosed sleep disorder
Takes several medications, including restricted

Ben's current care

Valerie – full time care, case management (20+ hours a week) – training, supervision, insurance, school, medical, implementing therapies, research, etc.-----
Michael – evening and weekend care, medical and educational appointments and trips
Howard Center – 6 overnights of care/week
PCAs – self managed; coverage evening, weekends, medical trips, camps, and vacations

Overnight overview

Ben needs to be safe, comfortable, get sleep, receive food and medications and therapies. Parents need sleep to care for Ben and supervise all care.

Recent bedsores, new equipment, risk of surgery, serious medication changes (e.g. Baclofen), med trials (e.g. clonazepam), difficulty with tone and sleep, increase in “foaming” through nose, etc. require skilled, trained, awake overnight care seven nights a week.

Doctor testimonials

Dr. Steve Contompasis: “Ben needs needs assessment overnight” and “overnight shift level of responsibility not reasonable for unskilled person”

Dr. Ann Goering – see attached

Dr. Harry Webster: “I am concerned that this child is not getting the amount of nursing care that is allowing us to fully do his program.”

We’ve been told that quality care has prevented more costly problems for Ben. During periods of less support, we have looked into Crotched Mountain for options.

Ben Wood-Lewis 4/30/15

Overnight care currently involves:

10 hour g tube feeding

2 sets of medications given during the night

~1 week/month Ben needs nebulizer treatments twice during the overnight

Ben requires wound assessment and care (tailbone and wrist) once per overnight

Ben requires repositioning approximately 3 times/night

Ben requires stretching a/o circulation massage at least once per overnight

Ben requires at least one diaper change per night

Hygiene and dental care part of overnight shift

Data is kept on med trials (re: sleep, tone, constipation) throughout the night

regularly. Ben is currently on a trial of dramatically increased Baclofen and requires close observation

Ben wakes between 2 and 7 times a night, for between 20 minutes and 3 hours each awakening, and requires attention and assessment of position and breathing and needs. At least one night a week (unpredictable) he gets less than 4 hours sleep total.

15 years ago, when Ben joined our family through adoption, I was thrown into a world previously unknown to me, the world of case management. Through 15 years of doctors at three hospitals, special ed with a team of 10, a USP at Howard, and self managed PCAs, we’ve maintained Ben’s health, our marital relationship, some paid work, and community involvement. (Show poster) Even with this experience and a Master’s degree, when we’ve been affected by various budget and service cuts, we’ve found work arounds. This is the first time in all these years that we’ve made an appeal.

That’s because 7 nights of overnight care for Ben is critical to Ben’s health and safety, and our ability to care for Ben at home. Since birth, it has been the medical professional consensus that this is needed, and yet we’ve been fighting since 2002 primarily to fill the

hours that were allocated. Over the years, despite a concern about forgoing more skilled care, we have worked with Howard to shift VNA hours over to Howard, not because nursing was not needed and preferred, but because VNA hours were rarely, and then never, filled.

Now that we have been officially taken off the hi-tech nursing rolls, those remaining hours (18?) just disappeared rather than being converted. Uncovered nights are covered by us, by using PCA funds meant for day shifts and doing those ourselves, by neighbors and friends occasionally for a break.

Ben requires 24/7 supervision, and I literally can not be “eyes off” him for 5 minutes at a time. Increasingly, two people are needed for physical maneuvering and some transfers. So we find ourselves being not only back up for help that is sick, on vacation, etc. but increasingly primary for unscheduled (unfunded and unfilled) shifts. (Show schedule.)

Ben’s overnight care involves the following priorities (overview) and specifics (list).

In conclusion, we respectfully request a reversal of the denial. For Ben’s health and safety, and for our ability to care for Ben at home, we request seven nights a week overnight coverage.

Please approve a Medicaid-funded Enhanced Pay Rate to raise the wage for these nurses so that they are comparable to hospital-based nurses.

Thank you,

Valerie Wood-Lewis