



Complex Child E-Magazine

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Working Together for Change: Addressing Nursing Reimbursement

by Michelle Detwiler

As an infant, our daughter had been so ill that she spent more time in the hospital than she did at home. Emily was born at 29 weeks gestation, while normal gestation is 40 weeks. Arthrogryposis, an orthopedic medical condition, twisted her legs up around her head and curved her body into a backward "C." This curve in her back, along with the issues of prematurity, caused her breathing and lung function to become severely compromised. By the time most children are walking comfortably and feeding themselves, our daughter could do little more than breathe and look around. At age two she continued to need suctioning and airway support, and was now labeled as medically fragile.

Those of you who have children with medical challenges understand the magnitude of support required to care for your child. Emily was so fragile that I needed to provide care 24/7 as I had no help. In the years that followed, Emily's caregiving needs increased with the addition of a seizure disorder. Our doctor suggested that we apply for in-home nursing care support. Living in Washington State, we applied for in-home nursing care hours through the Division of Developmental Disabilities, Medical Intensive Program.

Emily qualified for the Medical Intensive Program because:

1. She needed breathing support
2. She needed deep suctioning
3. Her respiratory infections were near constant
4. All of the above required constant care which I couldn't continually provide

So, with a doctor's referral and qualification through the Medical Intensive Program, Emily received a monthly allotment of in-home nursing care hours to be used at times that we required.

Finding Nurses

The Medical Intensive program in our state does not hire nurses for in-home nursing care but makes available a list of Medicaid-approved nursing agencies. The client is responsible for finding a nurse through an approved agency.

I chose an agency to work with and we were interviewed. Once a nurse was matched with our daughter and began working with us, I thought that was the end of my quest. Not so. As soon as our nurse decided to change jobs the agency needed to find another nurse. In the last two years we've had more than our share of nurses.

Soon, the agency couldn't find a nurse for us. What was going on? Aren't agencies supposed to fulfill the nursing needs of the client? When I would call and talk to the agency I was told that there was a shortage of nurses. The agency was offering an incentive to anyone who could find a nurse to hire on and stay for six months.

I thought maybe I would be able to find a nurse myself, so I advertised by word of mouth and in the newspaper. Through my efforts there were several nurses who applied to the agency. But they didn't follow through with orientation, or just plain decided not to work with the agency. What was going on here? I just couldn't figure it out.

In the last few months we've had several part-time nurses. As I talked to them about the shortage in nursing care I found out that when they worked for us the rate of pay was only half to two-thirds what they would make working for a patient who has private health insurance. There was the problem. Medicaid wasn't paying comparable rates to private insurance. If a nurse made \$20 an hour working for us, she could make \$30 an hour or more working for a client with private insurance. Now the real issue is how to get Medicaid to increase private duty nursing wages.

Learning to Advocate

A friend of mine asked if I wanted to take a leadership class. I didn't even know what a leadership class was! The training involved a once-a-month class about advocating for people who have special needs, and was filled mostly with parents of children who had special needs. The only way their children have received and will receive needed services is because other people have advocated for them in the past.

I am not and have never been very politically-minded. I always vote, but I don't usually hold signs and I don't march on the capitol. That just isn't me. But I do write. And now with needing nursing care and not being able to find it because Medicaid doesn't pay enough, I knew I needed to do something. So I took the class hoping that I could learn to write letters to my state representatives at the capitol.

One of the first things I learned in my class was how a bill becomes a law. A bill needs to be sponsored by a state representative. It is written up and then sent to a House committee for debate. It is re-written and debated again. The committee then looks for public comment on the bill and it is debated some more. Once the House decides the bill is in good order, and is approved by a passing vote, the bill then goes to the Senate and the same thing happens. When the bill passes the Senate it then goes to the Governor who can sign it into law or veto it.

The key to getting a bill noticed and passed is to find out who my representatives are at the state capitol and let them know what we need. My class actually visited the state capitol and we had a day of learning about speaking to the legislature. We practiced giving testimony to a pretend committee during the public comment time. We also learned that our senators and representatives are available and eager to hear from us, their constituents.

After I returned home, I made an appointment to visit with my representatives the following month. I also got on my computer and went to the Internet site for our state capitol. On the legislation home page I found an area to sign up for legislation news from specific committees. Each Friday I get an e-mail telling me what bills my favorite committee will be discussing during the week and into the next week. This keeps me apprised of things I'm interested in.

In preparing to visit with my legislators, I contacted our nursing agency so I could get more information about nursing wages. When I spoke with the agency supervisor I found out that a group of nursing agencies in our state had just gotten together and was already on the road to advocating for higher Medicaid nursing wages. The nursing agencies asked for Washington State House Bill 1503, a bill that would regulate home health care rates, to be introduced. It was thrilling to the nursing agency supervisor to know that we wouldn't have to work alone to effect change!

Effecting Change

Homework from my class was to explain how I will effect change. My thoughts evolved into a tangible poster and bookmark that I can give to my legislators at our appointments when I visit them at the capitol. I also have a group of people to work with now, the nursing agencies, and together we will make a difference.

Below I've listed some things you can do to effect change, along with how I applied these concepts to my particular cause, nursing reimbursement.

1. **Identify your need.** We need an increase in the Medicaid Private Duty Nursing wages.
2. **Find training.** I signed up for a class on advocating for people with special needs.
3. **Begin plan of action.** I made an appointment to meet my representatives. I also made a poster and bookmark to give to my representatives so they could better understand the need for increased Medicaid private duty nursing wages.
4. **Find others to work with.** I am working with my nursing agency.
5. **Work with your representatives.** I have e-mailed and called my representatives about this matter and am willing to testify in front of a committee and give support in this area.

I don't know how long it will take. It would be nice to think this legislation would pass during this session, but realistically it may take a year, maybe more. Change doesn't happen overnight. And even if we don't see better nursing Medicaid wages and better coverage right now, families in the future will benefit because I got involved.



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