Senate Finance Committee Testimony on Substitute House Bill 166

Gretchen Jolliff

May 28,2019

Thank you for the opportunity to address you today. My name is Gretchen Jolliff and my son Cayden is a consumer on the Ohio Medicaid Waiver program.

In November 2014, we went for our 20 week anatomy scan and found out our son had CDH, a congenital diaphragmatic hernia with less than a five percent chance of survival. Once he was born, he was immediately rushed to Nationwide Children's Hospital where we spent 838 days. When it was finally time to discharge Cayden, we met with a respiratory therapist from Central Ohio Specialty Company that gave us training on the equipment we would need when we finally were able to take our son home. The amount of equipment was quite extensive and they were very thorough in the process. Everything was ready for him to be transported 839 days after his birth. When we finally got him home, the therapist met us there and was there if we had any questions. I cannot begin to tell you the amount of nerves we had bringing him home. Here was a child that had spent over two years of his life in the hospital. At the hospital we had doctors, nurses, RT's, OTs, and PTs to guide us through each and every day and now my husband and I had to become each profession. At that point, we had no nursing and it was just us. It was scary but knowing we had a DME there for any questions or concerns twenty four hours a day helped relieve a little bit of that nervousness. We had no idea where to begin, what to order for supplies, or even how to go about training our future nurses on the equipment. Once we chose COSC as our DME, this was all taken care of for us. It was extremely important to Kevin and I, to be involved with each choice and decision that was being made for our child.

Our DME has been with us from the time we were able to come home. We have had the pleasure of always having the same respiratory therapist from COSC for over two years. She knows our family, our nurses (training each of them on the operations of his equipment), and most importantly everything Cayden needs to survive. Survive may seem like a dramatic word to use, survive, but it is of the upmost truth. He needs a ventilator for his lungs, oxygen to breathe, a suction machine to make sure he doesn't get a plug in his trach, a pulse oximeter to monitor his oxygen saturations and heartrate, formula for his nutrition (he is only fed through his GJ tube), and a massive amount of other medical supplies for his day to day routines. All of this is supplied through our DME, making sure that all his needs are met.

There are times, as with anything dealing with technology or machines, that malfunctions occur. COSC is on call twenty-four hours a day and we have had to call them several times. They will either troubleshoot my error over the phone or will come out and fix the problem no matter the time or day of the week. This type of service also ensures that my son does not require a hospital admission due to him being given inadequate supplies or products. This is quality customer service that I would be scared to lose if I wasn't able to choose my DME.

Cayden is thriving at home and living the best life we could expect. He is making an extreme amount of progress in his development and because of this his equipment settings and supplies we are constantly changing. Our DME handles all calls to our doctors and prior authorizations for much of the extra supplies that we have been required to have for Cayden's care. A huge stress lifted off the backs of parents that already have so many worries and anxiety from raising a medically complex child. This is just one more fantastic service we receive from our DME.

It truly worries me to know that any time, my son's health and life, could be jeopardized by a company that does not know him or his condition because ODM and MCO don't give their consumers the choice to choose their DME. Large companies that have a monopoly on equipment are not going to come out with a phone call from a stressed and scared mom because she messed something up on her son's ventilator. They are not going to be able to be reached at two A.M. in the morning when my son has a plug in his trach or why our nurse can't figure out why the suction machine doesn't have enough pressure. Again, his equipment is life saving and not being able to have the choice to find a company that displays compassion and excellent customer service is terrifying. We depend on these people. Cayden is not just a number or a name to Central Ohio Specialty Care. He is a four-year-old boy that has gone through so much and fought to be home with his family. He will continue to fight and live the best life he can. There will be a time, we hope and pray, that we will not need the waiver program or a DME, but that time is not now and right now, our DME provider is our lifeline.

Respectfully Submitted,

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