

Carolyn Anderson  
House Finance Subcommittee on Health and Human Services  
Interested Party Testimony, HB33  
March 15, 2023

I wish to thank Chairperson Carruthers for the opportunity to provide testimony on HB33.

My name is **Carolyn Anderson** and I am the proud mother of Kevin Anderson. Kevin is 39 and has been on Medicaid Home and Community Based Waivers since the age of eight.

We welcomed our second son, Kevin, into the world on June 24, 1983. Two healthy boys! Did we luck out! Unfortunately, our luck was to be short lived. We would learn he had a genetic disease, spinal muscular atrophy (a form of muscular dystrophy), that would not only affect him, but the whole family as well.

Life took another plummet, when at age eight, his condition necessitated a tracheostomy tube and a ventilator for nights and periods of illness. Life would never be the same for any of us. The idea of caring for my son with such complex medical needs now was, to say the least, overwhelming. Though I loved Kevin unconditionally, I hated my life. I was a nurse, respiratory therapist, physical therapist, aide and mom(barely). It was only with the introduction of nurses through waiver that I had time to once again be a mom, not only to Kevin, but to his brother as well.

Fast forward 31 years. We are in a place I never thought we would be. Initially, when Kevin first got on the waiver for people with complex medical needs, there were few cases and plenty of nurses. Now there are many cases and few nurses. We have never experienced a shortage like this. Sadly, without intervention, I do not see a light at the end of the tunnel.

Nurses have provided Kevin with the care he needed to stay at home. This includes daily assessments of all body systems, tracheal suctioning and trach care, monitoring of ventilator, administering up to seven respiratory treatments a day, not to mention total assistance with all his personal care. One homecare nurse is responsible for all these duties, while many different people perform the same tasks in a hospital. Kevin's room has more equipment than an ICU room. Kevin was instrumental in assuring at least one piece of equipment, a cough assist, would be included in necessary respiratory equipment in the hospital.

At 72, I am in a place, I hoped I would never be. All three of our night nurses are 70-75 and will retire shortly. Without night nurses, I cannot sleep. Kevin is only covered for one day shift even though he is approved for six. This has been the way for the last three years. I have postponed needed procedures, such as a colonoscopy. It became so difficult that we considered a nursing home with a vent unit. After one visit, I knew I could never send my son there. I am convinced, given his level of care, he would be dead within two weeks. It was then I decided we would do

whatever was needed to keep him at home. What is needed, is more nursing, specifically, in homecare.

Don't get me wrong, Medicaid Waivers are a godsend and I am extremely thankful for them. The whole purpose of these programs is to keep individuals at home, where they will thrive and do their best and stay out of the hospital or/and institution. Without adequate nursing, it is doomed to failure.

So, my recommendations include addressing the **homecare** nursing crisis directly in the budget for HB33. To be competitive with other areas of nursing, the rate needs to be raised – and considerably for both nursing agencies and independent providers. In addition, there should be an incentive program, possibly paying for schooling/training for LPNs and RNs or offering a bonus after one year. If ever there was a time for change, it is now.

Recently, I viewed a post on a FB portal in which a mother was pleading for nursing for her child on a ventilator. She was beyond exhausted. She typed, “we shouldn't have to live like this.” I agree.

Thank you for your time.

Carolyn Anderson

Please feel free to contact me at: [canderson51@sbcglobal.net](mailto:canderson51@sbcglobal.net)