

Carolyn Anderson
Senate Medicaid Committee
Interested Party Testimony, HB33
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What if this was your son?



I wish to thank Chairperson Mark Romanchuk, Ranking Member Ingram and members of the Senate Medicaid Committee for the opportunity to provide testimony on HB33.

My name is Carolyn Anderson. My son, Kevin Anderson, is 39 and has been on an Ohio Medicaid Waiver since the age of eight. Kevin went into respiratory failure and I made the painful decision to have him trached, along with a ventilator (part-time) and gastrostomy button. I have never doubted my decision. We are very grateful Ohio has Waiver programs. It has literally made the difference between life and death for my son.

Kevin received a definitive diagnosis at the age of one of SMA – Spinal Muscular Atrophy. This is the No. 1 genetic killer of children under the age of two. As you can see, he has far exceeded any expectations of any doctor. This has only been with the help of nurses in our home. Nurses made it possible for him to attend school, even going on to Lakeland Community College and Lake Erie College where he eventually received a BA in Communications summa cum laude.

The advent of a tracheostomy tube meant life would never be the same. Though Kevin had physical and medical needs prior to this, they were manageable. Now, different resources would need to be put in place. That included additional equipment and nurses to help keep Kevin safely at home.

Like many people, COVID changed the game for all of us. The flight of nurses, including homecare, has left us with few options. Nurses started leaving for better paying opportunities even before COVID due to aging nurses retiring and increased demand for healthcare for aging, disabled and chronic disease population.

Families, like mine, are completely exhausted from filling in all the shifts that nurses are not available. At almost 72, that is not an easy task. Kevin currently only has one day shift covered. His night nurses, so I can sleep, range in age from 70-76. That is not a good long-term forecast. Without night nurses, I put cushions on the floor so I can hear him on the ventilator and turn him every 1.5-2 hours, suction him, and disconnect nutrition he receives through the night. I am a zombie and exhausted the next day especially when there is no nurse. I have no family or friends that would be able to take over for me. The only other option keeps me awake at night.

We have tried every avenue we have available. We have worked through agencies. One told us they posted but the respondents turned it down because of the low pay. Another agency sent someone out who also felt it was too much to learn for the pay. Someone told me they would only do it through private pay. We have

posted through independent provider FB pages. Going through our managed care company, CareSource, also proved fruitless. Lastly, we went through a new provider/client matchup through PCG which also came up with nothing. We are at a loss.

OHIO pays SUBSTANTIALLY LESS to both RN and LPN Medicaid providers and agencies than any of the surrounding states with the exception of Agency RN reimbursements in Kentucky. The differences can range from 21% more to 88 % more.

Kevin has been out of the hospital for six and a half years. For someone with his diagnosis, this is outstanding. He continues to amaze his doctors. This is certainly no coincidence. Hours of daily respiratory treatments, lung assessments, diligent skin care and a small, loyal group of compassionate, caring nurses have made this possible. However, without more nurses, I fear hospitalizations may be on the horizon. And when Kevin is hospitalized, he spends the entire time in the ICU unit, usually for a week. One does not have to be a math genius, to see how adequate homecare will save the state money.

The House's Substitute HB 33 Budget Bill Version included raising the reimbursement rate for direct service providers(DSP) in the Home and Community Based Services (HCBS) Medicaid Waivers by 32-40%. While we applaud these badly-needed increases for DSP's, nursing was completely overlooked. Nursing is a completely separate category from DSPs. Therefore, I ask that Nursing be given the same consideration as DSPs.

Whether your child is in utero, 6 months old, 16 or 40, he deserves to live life to it's fullest surrounded by those he loves. Isn't this what you would want for your child? Isn't that what pro-life really means?

If I can answer any questions, you may reach out to me at canderson51@sbcglobal.net.

Sincerely,

Carolyn Anderson