

Senate Finance Committee
Interested Party Testimony, HB33
May 25, 2023

I wish to thank Chairperson Matt Dolan, Vice-Chairperson Jerry Cirino, Ranking Member Vernon Sykes and members of the Senate Finance Committee for the opportunity to provide testimony on HB33.

My name is Kevin Anderson and I reside in Lake County. I am 39 years old and have been on medical waivers since age 8. I am currently on The MyCare Ohio Waiver.

At one year of age, I was diagnosed with Spinal Muscular Atrophy (a form of muscular dystrophy). It is the number one genetic killer of children under the age of 2. It causes a general overall weakness in my muscles, especially the respiratory system.

After respiratory failure at age 8, it was determined I needed a tracheostomy tube, ventilator (for sleeping and illness) and g-button (gastroonomy button). It was then that I started receiving nurses through Medicaid funded homecare.

My disease has progressed as I have gotten older. Along with the nighttime ventilator, I can receive up to seven intensive respiratory treatments a day. This is in addition to personal care requiring total assistance in all areas. For example, my mornings include 4-4.5 hours of respiratory treatments, personal care and breakfast with virtually no downtime for me or my mother/nurse during this time. As you can see, daily life is not easy for me or my mother/nurses.

My life was already pretty stressful with adequate nursing. Then along came COVID 19 and everything changed for the worse. As of today, out of the 50 day hours/week I am allowed, only nine hours or one day is covered. This has put almost an unbearable strain on me and my mother.

Thinking about the present reality and the future only seems to induce a state of near panic. If this massive **nursing** shortage does not ease soon, what, I wonder, is my future? If I cannot find more nursing, am I destined to wind up, alone, in a long-term care facility unable to meet my complex needs (these facilities are not designed to care for individuals with complex needs), separated from friends and family just waiting to die? The thought, ever-present in my mind, is almost unbearable.

I do not believe it has to be this way. Though it will not be easy (and will not be an overnight fix), there are steps this body can take in H.B. 33 to address the crisis. First and foremost, homecare nurses must be given a SIGNIFICANT pay raise. I understand that this legislature wants to fund major pay raises to Direct Service Providers (DSPs). To be clear, **this does NOT include nurses**. DSPs only include home health aides.

This DSP pay raise is appropriate and well-deserved. That said, when I consider the level of care I receive from my nurses, I know they too are vastly underpaid. This must be remedied urgently. At a minimum, nurses MUST receive the same percentage pay raise as DSPs. Beyond that, additional incentives, like paying some, or all, of the costs of nursing school, should be quickly implemented as well.

Today serves as a “last chance” to work on this budget. For many of us who are in desperate need of more nursing, it might be our last chance to avert catastrophe. Inaction is simply not an option with this crisis. This truly has become a matter of life and death. I beg you, please do not let me (and other Ohioans in need) die!

Thank you, Mister Chairman and members of this committee, for giving me this “last chance” opportunity to address you on this crisis.

If you have any questions, please feel to contact me at kevinandy43@yahoo.com

Sincerely,

Kevin Anderson