

Kevin Anderson
House Finance Subcommittee on Health and Human Services
Interested Party Testimony, HB33
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I wish to thank Chairperson Carruthers 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 (gastronomy 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 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, separated from friends and family? 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. When I consider the level of care I receive from my nurses, I know they are vastly underpaid. This must be remedied urgently. Beyond that, additional incentives, like paying some, or all, of the costs of nursing school, should be quickly implemented as well.

Inaction is simply not an option with this crisis. For many of us who need nursing care, it is a matter of life and death.

Thank you, Madam Chairwoman and members of this committee, for giving me this opportunity to address you.

You may contact me at: kevinandy43@yahoo.com