

Chair Carruthers and members of the committee. Thank you for the opportunity to speak to you today regarding the proposed budget.

My name is Sarah, I am the mother of 5 outstanding humans, my oldest daughter, Evangeline, is disabled and qualifies for services through the Ohio Department of Developmental Disabilities.

Evangeline was born with Down syndrome. At 4 months old she developed infantile spasms (a destructive form of epilepsy), at 14 months old, she had a gtube placed due to being unable to swallow food without aspirating. At the age of 3, she received a vagus-nerve stimulator (it is like a pacemaker for your brain), at the age of 5 she became ill and would spend the next 10 months living in the Pediatric Intensive Care Unit. This resulted in a tracheostomy being placed and the use of a ventilator, oxygen, and frequent deep suctioning. Since she is a first born and overachiever, she also lives as a fragile diabetic, requires assistance in all areas of daily care, and uses a wheelchair for mobility.

Evangeline is 9 years old (10 soon!) and loves pretty clothes, having her hair done, and Harry Styles. While Evie does not communicate via words, she is fluent in eye rolls and heavy sighs and knows how to get her point across.

When Evangeline was born, I already had been working in the DD field for some time. I did not feel panic or fear, because I knew that Ohio had an amazing system in place to help her succeed in life, and I knew, that I would do everything in my power to make sure she had every chance to live to her fullest potential.

What I've come to see over the years, working as the CEO of a provider agency, working for a county board, and working in collaboration with DODD, is that while we have the structure and a whole lot of heart, we lack the funding.

Direct Support Professionals are the frontline of the work we do. Currently, they are not making competitive wages in the state of Ohio. I am a single parent household, when Evie does not have a DSP, it makes things difficult. She requires almost constant 1:1 care. The longer that Evie goes without proper support, the more her ability to thrive is in danger. Not only, her, but this impacts her siblings as well. I want more for my children than just to survive, I want them to thrive. I want them to see that we care for family and our community. I want them to know the value of all humans and to embrace differences.

I am told that in order to get people to understand the magnitude of what we face, I need to share the hardest, darkest moments of caring for a child with disabilities and complex medical needs. There are plenty of dark moments, I have watched my child turn blue, I have rushed her to the ER, running in yelling for help, I have talked my other children through (step by step) why all the first responders were in our house late at night, and I have listened as medical professionals told me I was a mother who, "just couldn't let go."

But all of that is secondary. People with disabilities are not burdens. Evangeline is not a burden. She is my child, and my family is more than a statistic. Our experiences may be different, but every moment is worth it.

As a parent, it is my job to fight for the future of my children. I do this, unapologetically and fiercely. I recognize that this is a very small portion of the bigger picture. If just my story is not enough to move you, allow me to go larger.

By failing to support people with disabilities, the DSP's who support them, and the system, the outcome would be catastrophic. Other systems (hospitals, prisons, long term care facilities) would suffer the fall out. Ohio citizens (taxpayers, voters) would lose the ability to maintain jobs, and Ohio businesses would be impacted. The solution to this is to support the payment of Direct Support Professionals to earn a competitive wage.

My child is deserving of a life as a meaningful member of her community and her family. People with disabilities are contributing and valuable members of our state. The stakes are high and we as a state have the opportunity to show the nation our commitment to all of its citizens.

Thank you for your time and attention.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7899057/#CR14>

https://www.researchgate.net/publication/49831208_The_health_of_disabled_people_and_the_social_determinants_of_health

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3182460/>



