

Maria A. Matzik
House Finance Committee
Interested Party Testimony, HB 33

March 30, 2023

Chairperson Edwards, Ranking Member Sweeney, and members of the House Finance Committee, thank you for the opportunity to provide testimony on HB 33.

My name is Maria Matzik, and I am a consumer of the Ohio Home Care Waiver program through the MyCare Ohio program. I have Spinal Muscular Atrophy Type II. I use the assistance of a ventilator and I have a tracheostomy. I use a reclining motorized wheelchair for mobility.

I am submitting this testimony to advocate not only for myself but for thousands of people with disabilities who will be forced into institutions and nursing homes because we will not have direct care staff to assist us with our activities of daily living and skilled care needs. For individuals who rely on home health services, it is a terrifying time. This issue is still not being addressed by the state or federal government.

I want to specifically bring to your attention a population that is always overlooked, individuals with disabilities who are age 21 to 64 and, in most cases do not have any family or spousal support. This is the population that I work diligently to ensure have equal opportunity to live a full and productive life. Many times, these individuals have no other supports except for the Waiver service providers. These in home caregivers become family, advocates, and friends. People with disabilities should not be at risk of institutionalization when they have a life in the community with opportunities and independence.

People get confused when we start using the word “independence”. Independence does not mean being able to do everything for yourself, it means being in control of how and when things are done and who provides the service.

I chose the option of receiving care in “my” home instead of the state’s segregated, abusive, and expensive entitlement to institutionalization. I have been my own advocate, as well as an advocate for my peers with disabilities across the nation, my entire life. It is crucial that you understand the importance of the programs that the Ohio Department of Medicaid, the Ohio Department of Aging, and the Ohio Department of Developmental Disabilities administers. If these programs were not in place individuals with disabilities would be forced into institutions with no chance of ever leading a fulfilling life. Unfortunately, we are at a place where programs for individuals to remain safe and independent in the community are just not enough.

I was asked by Representative Liston, during testimony to the Finance Subcommittee, if there are other issue that prevent individuals from getting the care that they need in the community. I stated that this is a systemic issue with many faucets.

It is the lack of:

- benefits
- PTO
- respect by the state in recognizing direct home caregivers as professionals
- support in making this a career with potential advancements and pay raises
- navigation assistance for provider enrollment
- timely reimbursement so caregivers do not go without pay for weeks or even months
- And the list goes on!

But for thousands of Ohioans with Disabilities who are currently in crisis the reason is clear. We cannot find, hire, and keep in-home direct care workers to assist with daily living needs and/or skilled nursing tasks. These tasks are necessary for us to remain in our homes and not be forced into institutions. This crisis impacts people who receive Home and Community Based Services through waivers from the departments that I stated above. It is important to note that home care workers include both skilled workers who offer nursing care and the direct care workers and personal care aides who help with activities of daily living.

Home care providers are a lifeline to those of us who rely on their services. Home care providers are dedicated to assisting individuals with quality care. In addition, they offer individuals the opportunity to have independence, control over their lives and the freedom to live their lives in the community and environment that they choose.

Without an immediate action plan to resolve the caregiver crisis in Ohio, we will lose more home care providers. The loss in coverage would mean consumers going into nursing homes or other long-term care facilities. Going into any facility or institution, would bring loss to each of us. Loss of dignity, loss of voice, and the loss of ability to make our own choices, losing our jobs, homes, pets, independence. For some, a forced incarceration would mean a death sentence. I know that's true for me.

I was a HOME Choice Transition Coordinator where I transitioned individuals from long-term care facilities and assisted them in returning to community settings. I assisted individuals who had been physically and sexually abused by facility aids, and other residents. I saw individuals neglected in facilities by staff who would not answer call lights for hours. I worked with the Ombudsman's office regarding individuals who were not being bathed, fed, or receiving treatments for pressure sores that were caused by the facility's negligence. At one point I witnessed an individual lose their ability of their bodily functions because the facility would not assist them to use the bathroom and instead kept them in diapers, which were only changed twice a day.

I had a close friend who had an experience in facility that should have shut the facility down. She had to be rushed to the hospital twice to have her feeding tube replaced in a 5-day span, due to lack of care and knowledge at the facility. She again was rushed to the hospital for an overdose that was later covered up by the facility's administrator. Her sister had come in to visit and saw a nurse administering a medication. Her sister could not wake her up and questioned what was given to her and why. The nursing home staff would not answer. The EMTs insisted to see medication logs and were given blank logs. When she arrived at the ER, she stopped breathing. They revived her and about that time the nursing home administrator arrived. He extended no apology or support. He only came by to notify the family that when she was discharged from the hospital that she would only be permitted to have one visitor for two hours per day. He informed her mother that his staff said they were a distraction to the staff, that they cussed at the staff, and that they tried to look at logbooks. The family was horrified by the accusations and took her home and managed without caregivers until she passed away. I ask you, should facilities be an alternative to the lack of in-home care providers? If so, would you want to exist in these so called long-term "care" facilities or place your loved ones in one? I say exist because there certainly is no quality to life in most of them.

Home care providers have been the unseen warriors before, but even more apparent, during the COVID pandemic. Their dedication has not been valued and their work has been underpaid. The general public, and our policy makers, have not recognized home care providers as first responders or as essential workers.

Home care providers are seldom offered health care benefits, insurance, and are not compensated for any leave of absences (PTO). Many providers are on Medicaid themselves due to their low pay which is near poverty level of income.

It is time that Ohio recognizes our in-home Direct Care Workforce as the professionals that they are and compensate them appropriately for the vital work that they do. Our society places more value on athletes,

lawyers, and politicians. This profession continues to be undervalued and unrecognized for the life sustaining work that they do. This is the profession that will care for your parents, your children and even you some day. Shouldn't we invest in the future of in-home caregivers for the future of all Ohioans?

I was asked by a Senator recently, "If we raise wages for the Direct Care Workforce, what should we cut?" My response was that you should not cut anything. By investing in this profession, you are investing in a sustainable future for all individuals who rely on skilled and community living services. You are creating a future for your family and ours where we have freedom of choice in the community that we choose to live in. By doing this Ohio will save money because individuals will have the supports that they need to gain and maintain their health, work, and pay taxes, participate in their local community, and grow the economy, and age in place with family and loved ones. The need for ER visits and hospitalizations will decrease. And long-term care facility placements, solely for the purpose of receiving sub-adequate personal care, will be uncommon. Now, I am not a businessperson, but I believe that this is an investment that Ohioans would get behind.

In closing, I am asking you to support the wage increase for all in-home Direct Care Workers in Ohio. Remember: The Disability Culture is the only culture that anyone can enter at any time!

Respectfully Submitted March 30, 2023

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